



UNIVERSITÀ PER STRANIERI DI SIENA

Corso di Dottorato in Linguistica Storica, Educativa e Italianistica

**DIGITAL NARRATIVE MEDICINE IN ENDOMETRIOSIS
TREATMENT: THE ENDONAR PROJECT**

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List of abbreviations

AouS = Siena local hospital and University, Azienda Ospedaliero-Universitaria Senese

CCMS = Comprehensive Clinical Model of Suffering

DA = Discourse Analysis

DNM = Digital Narrative Medicine

G1 = G1 surgeon, and professor at AouS University, male

G2 = gynaecologist, junior, male

G3 = gynaecologist, senior, female and professor at AouS University

GP = general practitioner

HH = Health Humanities

NM = Narrative Medicine

MH = Medical Humanities

NRS = NRS: Numerical Rating Scale

PCC = Patient-centred Care

TA = Thematic Analysis

WHO = World Health Organization

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Digital Narrative Medicine in Endometriosis Treatment:

The Endonar Project

My PhD project is part of the wider research programme “Tuscany Health Ecosystem” (THE). This aims to improve and innovate the regional healthcare system in Tuscany.

According to the requirements of this programme, I identified the geographic context of my research in the city of Siena, Tuscany, and explored the possible application of technologies to my study area, as specified in the name of the research spoke I relate to: “Advanced Technologies, Methods and Materials for Human Health and Well-being”.

According to a recent survey on the perception of healthcare quality in Tuscany, critical areas for improvement in the regional medical system are the management of doctors’ and nurses’ fear and anxiety, alongside the active engagement of patients, families and caregivers in medical encounters (ARS Toscana, 2022). In this context, I started investigating the theme of communication in Medicine and identified the core field of my research in Narrative Medicine (NM). Looking for a possible connection of my project with technological applications I found out about the Society for Digital Narrative Medicine (DNM), with which I started an interesting and enriching collaboration.

The research path I outline in this thesis requires a deeper investigation into the idea of medicine prevailing in the second half of the last century.

In Chapter 1, I outline the theoretical framework in which Medical Humanities (MH) developed, focusing particularly on the shift from the biomedical to the biopsychosocial model, and on the relationship between art, science, and medicine.

The analysis of the entangled connections between Medicine and the Humanities introduces the theme of uncertainty and interpretation, which unfolds throughout my research.

The thesis chapters all revolve around the concept of uncertainty, an intrinsically human condition which pertains also to medical sciences, hence to patients’ and doctors’ experiences.

Talking about uncertainty in Medicine questions the expectations and assumptions of and about both patients, a role that most of us somehow have experienced in life, and of doctors: the relationship between patients, disease, care and science is complex, and the scientific name of a disease or a therapy sometimes accounts just for *one* of the many sides of the illness experience (and of the healing *process*, when this is possible), lived by each one of the many patients affected by that disease and responding to that specific therapy. This lack of *exhaustive* explications about human health, this partial loss of meaning, is not to be ascribed only to the limits of human knowledge, although for many diseases there is no cure unfortunately, like for endometriosis, my case study developed in Chapter 5. In the thesis, I stress how uncertainty relates to the act of searching for causes, triggers, solutions, sense, while staying open to the outcome of the research, tolerating an unavoidable degree of ambiguity, knowing that meaning making requires and carries in turn subjectivity.

Lastly, in Chapter 1, I also investigate the factors that make healthcare human from a philosophical and sociological perspective.

In Chapter 2, I examine the reasons for medical uncertainty in the light of the *complex* idea of pain and suffering, leading to the concept of *pain-related* suffering (Noe-Steinmüller et al., 2024), which is more representative of the diverse life dimensions affected by the illness experience. I also review the linguistic processes that can cause ambiguity but also lead to reciprocal enrichment and negotiation of epistemic and power roles in the medical encounter. I also offer a critical perspective on the attitude to illness and vulnerability in Western contemporary societies, which in turn is reflected in and reinforced by social and linguistic dynamics.

Especially in the first two chapters, the research contributions analysed do not always follow a chronological order, but rather a thematic one. I tried to connect concepts and chapters to the theme of uncertainty in this research project, but, as it happens in narratives with flashbacks and anticipations, also in this thesis, things often follow a cyclical and back-and-forth-pattern, so

frequent references to previous and following parts of the work occur throughout sections and subsections, to offer a more organic and comprehensive overview of my research.

In Chapter 3, I consider the inherently narrative structure of medical practice and knowledge, uncovering the common features of stories and medicine with a special focus on their shared retrospective and interpretive search for meaning.

Finally, I foreground NM. I introduce Rita Charon's work (2001, 2006) along with other researchers on the same topic, although she is considered the founder of NM at Columbia University (Marinelli, 2022).

My choice does not mean that Charon's research has been undervalued, but it is simply based on the assumption that, according to Charon herself (2001), Columbia's approach is "not so much a new *specialty* as a new *frame* for clinical work" (p. 1898, emphasis added).

Moreover, Charon's placement in this thesis reflects the view of NM that I developed throughout my PhD research in the last three years.

The course I attended at ISTUD in 2023 laid the foundation for my general knowledge of NM, offering diverse and valuable viewpoints from clinicians, medical educators, writers actively engaged in the field, who practically showed how this approach worked in their experience. Not by chance was the course called "Master in Medicina Narrativa *Applicata*" (Master's Degree in Applied Narrative Medicine), where "applicata" (applied) implies *to clinical practice*. During this course, I received various insights and was offered more perspectives on NM, among which Charon (2006), of course, plays a crucial role in highlighting the method of "close reading" (p. 113), and for *systematically* introducing the "parallel chart" (p. 165) as a method in medical education.

During my research semester at Southern Denmark University, I received important bibliographical suggestions that profoundly influenced my view of NM. I had the chance to learn about Kathryn Montgomery's idea (2005) of narrative as a process working *from inside* medicine and medical education (from the general practitioners' anamnesis to the residents' training in clinical cases presentation). I could also learn about the connection between narrativity and

uncertainty: this reshaped the position of Charon's work in my NM research, notwithstanding her major contribution to the definition of the principles of this approach.

Throughout this PhD pathway, I realised how intertextuality underlies the different contributions to NM research, as if these anticipated or confirmed each other's findings, and yet kept their different approaches focusing on particular features of the same topic. Patient-centred care, for instance, was addressed by Balint (1969), Charon (2006), Launer, (2018), and Pilnick (2023), but it features so many facets and drawbacks in terms of communication and authority, that every author, while agreeing on identifying the patient as a whole being, adds a different piece to the overall picture.

In Chapter 3, I highlight that NM is a *method*, as specified both in the English and the Italian definition: it consists essentially of close-listening/reading patients' stories, processing them through self-reflection, and verbally co-retelling or co-rewriting those stories to co-create a meaning for the illness experience in which both doctors and patients are engaged at a professional and human level. This is the method I try to apply in the EndoNar project, as developed in Chapter 5: based on scientific literature on endometriosis, I first carry out narrative research, focusing particularly on all the dimensions of the illness experience that could affect the project participants: unpredictability, changes in daily routine as well as in the inner life, medical ignorance of causes, lack of cure, social preconceptions and medical mistrust.

While I was reading one of the foundational books of NM, *Narrative Medicine: Honoring the Stories of Illness*, by Rita Charon (2006), I was surprised by the verb "honor" mentioned in the book title, which in Italian, as much as in English, occurs in a relatively limited set of contexts, is stylistically marked, and linked with a formal register and solemn occasions. It occurs in religious, commemorative and legal texts and means: to do something that shows great respect for somebody/something; to do what you have agreed or promised to do; to give public praise, an award or a title to somebody for something they have done (Online Oxford Learner's Dictionary, n. d.). At the beginning of my reading I wondered what an action like honour might have in common

with medicine. As I expand in the Chapter 3, in the endometriosis case, the connection between these two concepts became clear to me: the experiences shared by women participating in the project show that in most of the cases their illness stories had not been honoured by their doctors, not even by their caregivers and families, nor the ethical engagement in the care for the patient had been fulfilled. Honouring someone's story means listening attentively to them, with *care*, and recognise their value.

The data collection was carried out within a participative process: first and foremost, the choice of a digital diary allowed the patients to add free notes on whatever feature of their illness experience they found worth writing about, to leave room to their spontaneous narrative flow and thoughts on what matters to them as unique individuals, transcending their role as patients. This had a twofold effect: it granted a relative degree of independence from the clinical research priorities (e.g. quantitative, scalable data) that can surreptitiously limit the real and comprehensive representation of endometriosis, as explained by Denny (2009) in Chapter 4. Besides, although the patients/authors were informed that clinicians could read their writings, the diary narrative form, recalling the private experience of sharing one's thoughts with oneself in a temporal dimension that is detached from the medical interview, is expected to set women free from the societal constraints of doctor-patient interactions.

At the same time, the diary notes are guided by some prompts collectively co-decided by: me as a PhD student with a background in language studies; an expert in NM and anthropologist from the DNM society; the gynaecologists from the hospital of Siena (AouS). These three actors represent multiple epistemic perspectives on the research topic. In the representation phase, the outcomes of the analysis of patients' stories were shared with doctors and discussed together to find new insights in the approach to medical encounters. The doctors' reflections on the patients' accounts were also collected and analysed. The results of the analysis of narratives represented the

bricks upon which to build new communication strategies, for example, adopting an alternative and more representative method of pain description and assessment¹.

¹ According to the APA7 guidelines, chapters should not be numbered because they are recognisable by heading levels. However, since I suggest links between the themes of the various chapters throughout the thesis, for the sake of readability, I numbered the chapters.

Chapter 1

The Role of the Human Factor in Medicine

The match of “Medical” and “Humanities” in the term “Medical Humanities” (MH), used for the first time by the historian of science George Sarton (1948, p. 127), carries a mix of meanings and is related to two areas of knowledge that are broad and layered. The aim of this chapter is to present a theoretical framework to better understand how and why these fields interact in today’s healthcare. I review selected information and references to bring clarity and avoid confusion. Three main topics are discussed in this chapter in the following order: the shift to the biopsychosocial model of medicine, the role of the humanities in medicine, and the pathway towards the humanisation of care.

Hence, the following chapter begins by commenting on an essay by the psychiatrist George L. Engel, which proves representative of many of the issues addressed by the Medical Humanities even without ever mentioning them. This is because it dates back to the 1970s, when MH awareness was just starting to rise. At the same time, the changes that Engel claimed were good for the healthcare setting of his time are very similar to those pursued more than fifty years later in the present day. Although research and information sources have increased and improved in the meantime, the challenges remain the same. This accounts for the choice of Engel’s representative title as a starting point of this research. There are several analogies within the current context that bring us full circle. This chapter contains short and critical references to the historical evolution of MH, and contains some reflections, on a semantic level, that demonstrate the connection between linguistic research and medical sciences.

The biopsychosocial model of medicine

As already mentioned, most of the discussion in this section is based on a diversity of papers that were presented at international medical conferences and lectures by the psychiatrist George L. Engel and then collected and adapted in the article *The Need for a New Medical Model: A Challenge for Biomedicine* (2012).

The choice of this source, which is also a classical reading in medical literature, is due to several reasons. Firstly, Engel's paper covers topics such as the view of sickness and care in the academic environment, research and scholarship, and in the folk, popular perception, as well as the dominant views of the human body, health and medicine in Western culture.

In this thesis, for the meaning of the word "culture", I adopt and refer to two definitions: one by Napier et al. (2014), according to which culture is "a set of practices and behaviours defined by customs, habits, language, and geography that groups of individuals share" (p. 1609); the other, by Kleinman (1988), is literally that of "cultural orientations", described as "the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of these worlds" (p. 2).

Within the conceptual framework of this thesis, the word "Western" relates to the countries of North America and Western Europe. These countries' views of MH and Narrative Medicine (NM) are explored in this work. This basic understanding of "Western" also conjures up specific views of a society's sets of beliefs, values and expectations about life, death, health, illness and healthcare that, with different nuances (it suffices to think about private vs public healthcare), are assumed to be shared by people living in the geographic area mentioned. Anthropological approaches to conceptions of pain, wellbeing and other health-related issues are referred to in the following chapters, but are not the core of my discussion.

Secondly, Engel's work offers an overview of the theoretical and professional background behind the increasing need for interactions between different disciplines (mainly sociology, and psychology) as for a new attitude towards patients, two core features of MH. Thirdly, I look at the different relationships between Engel's insights and the themes that emerged from analysing the stories of illness investigated in the following chapters.

Engel (2012) debates the crisis of psychiatry within the medical model of the latter part of the 20th century, a model that he describes as firmly rooted in biological sciences, supported by

technology, and successfully focused on “elucidating mechanisms of disease and devising new treatments” (p. 377).

In comparison to this idea of medicine, psychiatry seemed to be undergoing a crisis, having no proper self-discipline and struggling to fit into the same “neat and tidy” (Engel, 2012, p. 377) medical model. Engel strongly refused this view, arguing that the crisis concerned the whole medicine itself.

Although it cannot be ignored that Engel is influenced by his personal interest in psychiatry, an argument which is beyond the scope of this piece of research, his point of view is still meaningful. A psychiatrist like Engel that questioned the very idea of disease and the dominant medical attitude toward it in the 70s, psychiatry included, regardless of the medical area concerned, was adding important nuances to the debate.

Engel (2012) starts from the following observation: “[...] since ‘disease’ is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues, which lie outside medicine’s responsibility and authority” (p. 378).

Indeed, according to the model that Engels (2012) calls *biomedical*, disease is regarded as a set of deviations from the norm of biological/somatic variables. This leads to the assumption that, on the one hand, disease can be treated without considering social, psychological, and behavioural dimensions, on the other hand, social, psychological, and behavioural deviations can be accounted for by somatic/biological disorders. Engels states two consequences that result from this view.

The former is reductionism, which claims that primarily, basic principles and, in this specific case, *biological* principles can fully explain complex phenomena. This assumption may have significant consequences on a linguistic, and broadly speaking, communicative level: the expressive means used in care processes are expected to be strictly linked with biology, or as Engels himself puts it in metaphorical terms: “the language of chemistry and physics will ultimately suffice to explain biological phenomena” (Engel, 2012, p. 379). So, the language used in medical settings does reflect this reductionist view and at the same time conveys and supports it. As highlighted in

the chapter on the endometriosis case-study, also the descriptions and assessments of pain align with this objective, data-based and factual view of health and disease. Even the reliability of patients' self-reported symptoms depends on their statistical significance: if they are not statistically significant, they cannot be taken as an evidence of disease.

This may have crucial implications for the diagnosis and treatment of rare diseases, where symptoms are necessarily not statistically remarkable although they do appear and persist, or of diseases whose aetiology (cause) is still unknown and whose symptoms are unpredictable, like in endometriosis. In this respect, if a given form of pain and distress is not explicable in terms of biomedical standards, the words to convey it, to code and decode it through language are not available or adequate, and laypeople, already striving for clearness in the professionals' jargon, must double their effort to make themselves understood and trustworthy. In extreme cases, as I show in the endometriosis case-study, not only the words but also the existence of the symptom itself are questioned. This introduces us to the concept of discourse, which I discuss more in depth in Chapter 2, but it is worth mentioning here because of the interaction between (bio)medical approaches and issues of communication and language as elements that determine and reinforce each other.

The latter effect is *dualism*, which considers body and mind as two separate entities. This mind set and its effects on the patient-professional relationship and communication is further investigated in the specific case study on endometriosis (Chapter 5). This is a systemic disease, in that it does not affect just a specific part of the body, but the whole quality of life and mental wellbeing. This calls into question the idea of body and mind being separate as assumed in the biomedical model and calls for some reflections on whether or how it mirrors the real overall illness experience.

It was pointed out how, in Engels's view, the biomedical model responds to the need to explain disease as deviation from standard biological parameters in scientific terms, in that it is a model devised by healthcare professionals to promote scientific advance and research. The social

and cultural perception of disease as an undesirable and harmful condition, surrounded by uncertainties, gives rise for the need of explanatory models and corrective measures: the so-called popular, “folk” model. As Engel argues (2012), in Western society of the 1970s the scientific and popular model merged:

biomedicine not only has provided a basis for the scientific study of disease, it has also become our own culturally specific perspective about disease, that is, our folk model. The biomedical model has thus become *a cultural imperative*, its limitations easily overlooked. In brief, it has now acquired the status of *dogma*. In science, a *model* is revised or abandoned when it fails to account adequately for all the data. A *dogma*, on the other hand, requires that discrepant data be forced to fit the model or be excluded. (p. 380).

The effect of the turn from a scientific model into a cultural dogma is, says Engel, *exclusionism*, whereby whatever cannot be explained through the biomedical model “must be excluded from the category of disease” (Engel, 2012, p. 381). In the following chapters, this effect is also discussed in relation to the case of endometriosis, with women being told that their pain is *all in their head*, so their alleged disease would not exist, just because their symptoms do not fit into specific biomedical categories. Besides, the *all-in-your-head* theme implies a separation between body and mind as two autonomously, hence often opposed, working entities, of which just one seems to deserve medical attention.

It is noteworthy here also to give a more detailed look at the special link between the upsurge of the biomedical model and its rootedness in each geographic area with its own specific cultural tradition. These reflections are also consistent with the overview of NM developments throughout different countries and cultural backgrounds which are presented in Chapter 3.

According to Rasmussen’ (as cited in Engel, 2012), the reasons for the development of the reductionistic, dualistic and exclusionist biomedical model in the West would lie in the Church’s permission to study human bodies through dissection as long as this did not affect the study of the human mind, supposed to remain the domain of religion as care for the soul.

On the other hand, Engel notices the philosophical trends in Western society represented by Galileo, Newton and Descartes, which supported the idea of the whole as the sum of smaller parts, of the human body as a machine, whose breaking causes disease and whose parts can be fixed by doctors to restore its functioning. Both the religion-driven division between body and soul and the view of the body as a machine account for the essentially anatomical, analytical and mechanistic attitude on which the modern Western medical system is based.

This separation between body and mind is explored further with reference to the endometriosis illness stories, where patients often report that the lack of control over their illness results in a disconnection from their own body, perceived as something external (in Chapter 5).

Against the conception of medicine as a corrective, repairing measure for phenomena not fitting into predefined categories (the biomedical view), Engel calls for a new model that he defines as biopsychosocial, as this does not rely primarily or even solely on biomedical data, such as laboratory tests, but also on the social, behavioural and psychological factors that may underlie one's decision to seek medical help. The word *biopsychosocial* conveys both continuity and novelty compared with the word *biomedical*, as it allows physicians to rethink the balance between clinical evidence and standard procedures on one hand and the patient's verbal account on the other: what the patient tells provides data related to behavioural and psychosocial features that are usually downplayed or bypassed in the biomedical model.

In this respect, Engel (2012) questions the absolute accountability of laboratory results and clinical manifestations, as they cannot account alone for "how these [clinical manifestations] are experienced and how they are reported by any one individual, and how they affect him, all require consideration of psychological, social, and cultural factors" (p. 384). Thus, he actually anticipates Kleinman's (1981) distinction between *disease* as a set of symptoms complying with certain core medical patterns and *illness* as the individual's unpredictable experience of those patterns. Besides, adds Engel,

a biopsychosocial model would make it possible to explain why some individuals experience as “illness” conditions which others regard merely as ‘problems of living,’ be they emotional reactions to life circumstances or somatic symptoms. Indeed, some people deny the unwelcome reality of illness by dismissing as ‘a problem of living’ symptoms which may in actuality be indicative of a serious organic process. It is the doctor’s, not the patient’s, responsibility to establish the nature of the problem and to decide whether or not it is best handled in a medical framework. (1977, p. 133)

This statement is particularly important to our analysis: recognizing the role of the physician in setting the boundary between conditions from “organic processes” and conditions from “problems of living” (Engel, 2012, p. 379) is objectively based on professional reasoning and expertise. But if this is not supported by a comprehensive biopsychosocial attitude this role can also prove tricky and harmful: in the specific case of endometriosis, which is addressed in Chapter 5, the relationship between *illness* and *problems of living* is somehow turned upside down: patients claim that something is wrong, that their pain is too much, but the symptoms they report to their physicians are not recognized (or as mentioned before, are excluded from medical patterns, so regarded as fake) and are often defined as an exaggeration, a form of *problems of living* (all in their *head*, as mentioned before). This has a massive impact on timely paths of care, especially if considering the long diagnostic delay recorded for this disease.

Last, but even more relevant to the scope of this work are Engel’s reflections on the fact that a biopsychosocial model should rely on the content *and* the form of what patients report. The focus on content and form is of paramount importance at a linguistic level as it considers the ambiguity of patients’ (and human) language, especially when it comes to talking about symptoms, as effectively explained here (Engel, 2012, p. 385):

[...] many verbal expressions derive from bodily experiences early in life, resulting in a significant degree of ambiguity in the language patients use to report symptoms. Hence the same words may serve to express primary psychological as well as bodily disturbances, both

of which may coexist and overlap in complex ways. [...] The most essential skills of the physician involve the ability to elicit accurately and then analyse correctly the patient's verbal account of his illness experience.

Three main ideas can be inferred from these statements: 1) both levels, bodily and psychological, are intertwined in a *complex* way; 2) the assumed division between body and mind finds little evidence or confirmation in the way patients would spontaneously convey information about their illness experience: vice versa the language they would be prone to use is representative of both dimensions, physical and psychological; 3) in medical-patient interactions physicians should pay attention not only to *what* but also to *how* patients report on the same dimensions, physical and psychological. This final aspect is among the highlights of the fifth Chapter: symbolic and figurative language in patients' illness accounts.

I would like to conclude this section with a short comment on the relation between the biomedical model Engels suggests challenging and Kleinman's idea of disease, which I have only briefly hinted at so far.

According to Kleinman, (1988) the word "disease" defines a clinical specific condition diagnosed by a physician, normally characterized by known biomedical causes, treatments and cures. From the biomedical point of view questioned by Engel, it is a set of alterations "in biological structure or functioning" (Kleinman, 1988, p. 3), a deviation from given standards. Doctors interpret health problems in terms of nomenclature and taxonomies that create and objectify "a new diagnostic entity: "it" -the disease" (Kleinman, 1988, p. 3). In the biomedical model, the patient's fear, the family worries, the financial crisis and the private relationships are unaddressed and undiagnosed as part of the "disease". In contrast, says Kleinman (1988), referring specifically to Engels' claims, in the broader biopsychosocial model, disease "is construed as the embodiment of the symbolic network linking body, self, and society" (p. 3). Medical Humanities try to capture this very network, as I show in the following section.

Towards Medical Humanities

Medicine, Art and Science. It has been argued that Engel focuses on the interaction of different factors determining the wellbeing of a person. These factors are related to culture, education, sociology, and psychology, and the humanities area.

A review of the definitions of humanities provided in scholars' works, encyclopaedias and dictionaries can help clarify what humanities are at a basic level as well as in more specialised academic research. Then I explore the connections between Humanities and Medicine. The choice of these sources aims to represent both the academic viewpoint of scholars and professionals engaged in the subject and the perception of humanities conveyed in everyday language and life, based on the assumption that language shapes reality and thought and vice versa.

According to the online Cambridge and Oxford Dictionaries (n. d.), humanities are respectively "literature, language, history, philosophy, and *other subjects that are not a science*, or the *study* of these subjects", and "the subjects of study that are about *the way people think and behave*, for example literature, language, history and philosophy". For the online Merriam-Webster dictionary (n. d.) humanities are "the branches of learning (such as philosophy, arts, or languages) that investigate *human constructs and concerns as opposed to natural processes (as in physics or chemistry) and social relations (as in anthropology or economics)*". The online Britannica Encyclopaedia (n. d.) reports for the item "humanities":

those branches of knowledge that concern themselves *with human beings and their culture* or with analytic and critical methods of inquiry derived from *an appreciation of human values and of the unique ability of the human spirit to express itself*. As a group of educational disciplines, the humanities are *distinguished in content and method from the physical and biological sciences and, somewhat less decisively, from the social sciences*. The humanities *include the study of all languages and literatures, the arts, history, and philosophy* [emphasis added].

These definitions share different features: a partial agreement on the range of disciplines concerned, (they may or not include social sciences, for instance), the stress on the educational level

more than on the activity or a practice (the word *study* often occurs in the definitions reported) and finally the opposition to natural sciences.

At a linguistic level, this dialectic relation between humanities and sciences depicted in these definitions is curiously reshaped and partially lost in German, where the idea of humanities is conveyed by *Geisteswissenschaften* and includes both the concept of spirit, mind (Geist) and that of science (Wissenschaft).

In the light of this short semantic dissertation, the discussion can now focus on when, why and how humanities are called into question in medical sciences. A new link to Engel's just discussed biopsychosocial model can be helpful.

Engel's claim for a dynamic and complex approach to health issues represented a critique and a challenge to the prevailing biomedical model that prioritised causality and linearity. Yet, as pointed out by Kirklin and Richardson (2001):

it is only in relatively recent times that the professional and public perception of medicine has shifted to a biomedical model: the dominant impression that the practice of medicine is governed by scientific truths subject, at least in theory, to experimental verification. (p. 1)

Indeed, the humanities that Engel tried to include in a new medical approach did not feature prominently in medical sciences back in the 70s but has been an important part of medical training in the recent past.

Although an in-depth investigation into the history of medicine is not among the aims of this work, a quick look at the path that leads to what nowadays is called Medical Humanities can offer a better understanding of the relationship between medicine and humanities.

This connection dates back to very ancient times (460-377 BCE), when Hippocrates, traditionally considered the Father of Modern Medicine, classified medicine as *art*: art was meant as a craft enabling us to make things, distinguished from science, more concerned with knowing and demonstrating truths (Pellegrino, 1979b). On this note, I find a speech held by Trotter (1932) even

more clarifying. He speaks about the similarity between the medical students' transition from university to hospital and that from science to a *practical* art.

Trotter (1932) points out that, unlike art, the object of medicine is not the production of beauty, and that, more importantly in terms of doctor-patient relationship, "medicine uses material that "is not inert and disposable but an active factor in the art process" (p. 93). So, the lack of aesthetic purposes, and the participative role of the patient as a whole, made up of biological and existential, body and mind, would distinguish medicine from art. Yet, Trotter qualifies medicine as a *practical art*, as opposed to an *applied science*. In applied sciences, such as engineering, ascertained principles are applied to particular cases leaving little room for unpredictable or subjective factors, so that potential failures depend mostly on the ignorance of those principles. In a practical art, knowledge is not simply applied but requires interpretation, judgement, intuition, or personal skill. Trotter (1932) also notes that "the general process of culture seems towards the ultimate conversion of practical arts into applied sciences" (p. 96), but the hallmark of a doctor's profession lies in the blurred boundary between art and science, and this degree of vagueness should be held as an added value by doctors. In sciences, human faculties are removed as much as possible to grant for accuracy, but, as Trotter maintains, as long as medicine is an art, its main and characteristic tool *must* be human faculty.

In an article by Pellegrino (1979b), meaningfully titled "Medicine, science, art: An old controversy revisited" this dichotomy between the *scientific* and *artistic* side of medicine is overcome. Pellegrino (1979b) recognises that "verifiable, quantifiable, and predictive knowledge" (p. 47) is necessary to medicine, but needs to be adapted in the interest of the specific patient through a decision-making process, since the goal of medicine lies in making decisions and taking actions in the interest of the sick. This requires questions of values and relational dynamics that cannot be based on scientific considerations alone and relate more to liberal arts, such as:

rhetoric, the artful use of persuasion which, while avoiding any manipulation of the patient to accord with the doctor's own value system, yet leads him toward that which is in his best

interest; and the skills of ethical discourse, a discipline too little understood by physicians as a rational and systematic inquiry (Pellegrino, 1979b, p. 51).

So, concludes Pellegrino (1979b), the controversy about whether medicine is science or art is pointless, since it cannot transcend either science or art.

This view was reflected in the standards of a proper medical education in Early Modern Europe, which included the study of Greek, Latin, Philosophy, Grammar and Rhetoric², in addition to anatomy and medical theory. Attention to linguistic subjects like the ones just mentioned seemed to mirror the importance that Engel ascribed to the way (and not only what) patients report about their health issues to doctors and are a crucial preliminary step to the understanding of NM as argued in the following chapters. It should be emphasised that humanities meant as non-medical disciplines have been part of medical training for a long time, and that it is no coincidence that these subjects have such an ancient history, just as the art of storytelling is also ancient.

Yet major cultural trends and historical events slowly lead to a different scenario.

A more detailed knowledge of the human body, in the 16th century, allowed medical students to accurately locate physical processes in tissues, organs, and cells, starting a trend to study medicine by more limited and specific areas. In the 19th century Positivism focussed on experimenting, measuring, quantifying and predicting phenomena according to a cause and effect relationship, shifting the research focus on the quantitative dimension, though with “no power to reveal context [...], and no power to reveal novelty [...]” (Thomas, 2006, p. 451). Within the larger context of the social division of labour in the industrial era, the necessity to introduce a more structured and layered system to manage healthcare delivery emerged while societies became increasingly complex at a demographic and social level (Weisz, 2003).

If the processes outlined here account for the growing scientific interest in particular medical branches and the development of specialism in medicine throughout the last two centuries, the Flexner report in the USA 1910 marks a further step in this path. Inspired by the success of

² In Chapter 5 I illustrated how figurative language is largely deployed to express pain.

German medical education, this report defined the biomedical model as the gold standard and the advancement in scientific knowledge as the main goal of any physician. Yet, as stated by Duffy, (2011) “the profession’s infatuation with the hyper-rational world of German medicine created an excellence in science that was not balanced by a comparable excellence in clinical caring” (p. 275).

There were certainly other voices of dissent, among which Balint et al. (1969) argued that in addition to “‘illness-orientated medicine’ [whose prime aim is] to “find a localizable *fault*, diagnose it as an illness and then treat it”, another possible way of medical thinking is “patient-centred medicine”, in which “the patient, in fact, has to be understood as a unique human-being.”, [...] and “a whole person in order to form what we call an ‘overall diagnosis’” (p. 269). In the latter part of the 20th century an emerging need to narrow the distance between medicine and humanities followed crucial and shocking events such as World War II and other conflicts (such as in Vietnam). This drew public attention to violence, and to the extent to which experimentation and technology, especially in war, could be allowed, rising some questions on the *human* and *humane* dimension in science advances and their relation to humanities.

Medical Humanities and Medicine: convergences and oppositions. Medical Humanities are alternatively called *Health* Humanities, but both essentially refer to the same idea. Yet the former expression is lexically more selective as it refers mostly to physicians. Conversely, the latter encompasses a wider range of professionals and non-professional stakeholders participating in care pathways, including clinicians, such as nurses, as well as paramedics, pharmacists, and people working in complementary and alternative healthcare. As Jones et al. (2017) noted, the shift from Medical to Health Humanities may also refer to a focus shift from the specific field of medicine to the broader idea of health. In this respect, the definition of health by the World Health Organisation, (WHO) is insightful: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1946, p. 1).

The title of Evans’ research contribution, “Medical humanities: stranger at the gate, or long-lost friend?” (2007), which I discuss in this subsection, seems to hint at the historical overview of

the previous section. The fact that the relationship between medicine and the humanities has been controversial over time and has ancient, namely classical, origins, is particularly important. Yet, Evans reminds his readers that the term “Medical Humanities” is originally American, and was later assimilated, in its form and meaning, into the British academic sphere. This reference to the Western English-speaking world as the specific context in which the term “Medical Humanities” has been coined is not purely geographical. It draws attention to specific culture-bound understandings of and expectations about health, illness, cure and care that underlie MH. This implies a certain degree of awareness of the cultural limitations of the use of verbal language, whether spoken or written, and of storytelling in MH, a topic that is explored in greater depth in the chapter on narrative medicine.

In Montgomery et al.’s view (1995), MH refers specifically to bringing the study of humanities topics, especially literary studies, to the teaching of medicine: once again, the link between MH and education emerges as a key feature. This literature-based understanding is broadened by Evans (2002a), who considers MH an integrated, interdisciplinary, approach to recording and *interpreting* human experiences of illness. Evans (2007) includes in the MH “literature studies, history, philosophy, fine art, drama, critical theory, historiography, theology and religious studies, linguistics, music, law and so forth” (p. 367) and, in an elective view, also social sciences and psychology. Kirklin and Richardson include in the list “the invaluable insights of the patients” (2001, p. 3), a mention that is linked to my research on NM.

Evans (2007) also contends that MH disciplines share two concerns: one for the human experience, “as it is humanly encountered” (p. 368), as it is lived and perceived by human beings rather than as observed by natural sciences; two, easily deducible from the previous one, is the concern for subjectivity, namely the acknowledgment that observations of a given individual or situation are as interesting and determining for future decisions and actions as are the replicable and generalizable findings of the natural sciences. As detailed in Chapter 3, these two peculiarities of MH are strictly linked with Narrative-Based Medicine and its relationship with the evidence-based

approach, as expressed in this passage: “Logicoscientific knowledge attempts to illuminate the universally true by transcending the particular; narrative knowledge attempts to illuminate the universally true by revealing the particular” (Charon, 2001, p. 1898).

Kirklin and Richardson (2001) once again address MH within the broader framework of academic education. They illustrate the essential requirements for the training of “humanistic physicians” as follows: “Medicine is a *caring* profession, requiring *sensitivity and imagination*. However sound their medical knowledge, doctors who do not have these attributes make no good clinicians” (p. xiv).

An increasing focus on sensitivity and emotional factors as well as for tolerance and open-mindedness when faced with ambiguity emerges also in Hurwitz and Dakin (2009), who argue that MH can help:

to attune the technological capacities of modern healthcare to the needs and *sensitivities* of individuals [and] the formation of *emotionally and culturally competent scientific practitioners* whose primary skills include not only the familiar triad of history, examination and investigation, but capacities for *pause, reflection and integration of more subtle and ambiguous information into clinical assessment* (p. 85, emphasis added).

If the authors quoted so far seem to agree on the goal of the humanities as that of training better doctors in medical educational settings, a more critical review of the social role of MH is offered by Shapiro (2012), who suggests two possible models for interpreting the relation between MH and medicine.

One is the model of *resistance*: MH should lead to questioning the preconceptions and prejudgments prevailing in the current healthcare system and provoke resistance in learners, in line with Engel’s arguments that opened this chapter.

The other model is that of *acquiescence*, according to which MH would basically have an ornamental function, in that they relieve medical students and professionals from the trenches of hospital life by adding aesthetical values to their clinical expertise, and developing skills such as

empathy. Yet, in this respect, MH would also be instrumental, as it would serve to maintain the medical power structures by making patients, medical students and doctors easier to manage and making them *function* within the rhythms of a hectic hospital rhythms. MH would then be relegated to a servile position within the biomedical model. Shapiro suggests a third synthetic interpretation of these opposed perspectives. Namely, MH can be regarded as an ornamental but not necessary subject in medical education, it is also true that the *smoothing* effect of humanities in an environment of rigorous evidence-based inquiry does not exclude critical thinking and self-reflection:

Simply encouraging physicians to engage in the self-care that results from relaxation might be considered a subversive act, as despite the voluminous professional literature on burn-out, there is still painfully little attention to supporting the actual wellbeing of physicians and student-physicians in the clinical setting (Shapiro, 2012, p. 5).

In other words, exposure to non-medical subjects can challenge uncritical assumptions about the culture of medicine, even though those subjects are perceived as enjoyable or relaxing. According to Shapiro (2012): “A true attitude of empathy, derived from reflective processes leading to heightened self and other awareness, may result in diverse outcomes ranging from a small gesture of kindness to agitating for single-payer healthcare” (p. 9).

So, the continuation of medicine and humanities at opposites ends of a line, along which several forms of interaction between the two fields may be placed, would still bring the idea of opposition and risk, oversimplifying their relationship. In addition to Shapiro’s view, an alternative representation of these dynamics can be found in the critical perspective of Fitzgerald and Callard’s (2016) notion of “entangled medical humanities” (p. 44): they question the *integrationist* approach according to which the humanities are something external to medical sciences and just introduced and integrated into medicine. As already suggested by Arnott (2001), MH should be viewed as *integral* to and constitutive of medicine and not additional to an essentially scientific conception of health.

This observation has been the subject of further reflections based on the concept of *entanglement* suggested by Fitzgerald and Callard (2016):

What holds together much of the research employing ‘entanglement’ is an intuition that some set of things, commonly held to be separate from one another (indeed, that define themselves precisely with reference to their separability) – science and justice, humans and non-humans, settlers and natives – not only might have something in common, but also, in fact, may be quite inseparable from one another (p. 39).

In other words, these authors suggest overcoming the perspective of opposition, as well as that of integration of medicine and the humanities, highlighting how much these areas of knowledge *intrinsically* share in terms of concerns, objects, methods, and overall, their focus on humans as the centre.

The constitutive role of MH in medical sciences is also a claim of the *Critical Medical Humanities* (Viney et al., 2015). While confirming that humanities do not serve the clinical sciences but are part of it, this approach to MH calls also for stronger engagement with social equity issues, fair access to treatments, queer and disability studies and activist politics. This is a further point of contact with Chapter 4 and 5, as gender issues and gender-biased attitudes towards patients are one of these recurring themes in endometriosis experiences as reported in women’s stories. Finally, as illustrated in Chapter 3, in the *Critical Medical Humanities* it is suggested that rethinking narratives and their requirements in healthcare may expose their potential exclusionary function with respect to specific social and ethnic groups.

Medical Humanities and Humanizing Medicine: The Human Factor. Based on the discussion in the previous section, it can easily be inferred that a core meaning of *Humanities* in *Medical Humanities* is certainly connected to the need that emerged in the 1970s of re-including those disciplines that, following historical and cultural processes, had been conventionally classified as non-medical, into medical knowledge and practice. Yet, in this research project, the semantic

connection between “Humanities” and “human, humane, humanise, humanising” also requires some reflection.

A comparison between the meaning of “human” and “humane” from the Oxford Learner’s Dictionary (n. d.) can prove helpful. “Human” defines what is: “connected with people rather than animals, machines or gods; showing the weaknesses and desires that are typical of people” and “having the same feelings and emotions as most ordinary people”. The meaning of “humane” is interestingly related to suffering: “being kind towards people and animals by making sure that they do not *suffer* more than is necessary”, while humanise means “to make something more pleasant or suitable for people; to make something more *humane* (emphasis added)”. Interestingly, moving back to the specific healthcare context, Cassel (1982), by assuming the relief of suffering as the internal goal of medicine, advocates the idea that medicine must be humane by definition, otherwise it is not medicine.

According to the definition provided by the World Health Organisation on its website in 2021, the term “humanisation” refers to “a set of behaviours acquired by healthcare systems to provide a service that respects people’s relational needs, their humanity and their need for empathy.” Yet this definition of humanisation is based on a study conducted in the Italian healthcare setting and is concerned with a geographically limited area, the region Emilia Romagna (Regione Emilia Romagna, 2020).

A similar attempt to provide a systematic framework for humanisation in healthcare is in another study by Todres et al. (2009), who provide and investigate eight potentially humanising and dehumanising dimensions in care systems. This paper is informed by a strong philosophical approach, based on Husserl, Heidegger and Ponty’s perspective on the question: what does it mean to be human? In other words, it is assumed that once it is established what human means, then also the meaning of humanisation can be outlined.

The following elements are held to be representative and distinctive features of human beings:

- Subjectivity, meant as an inward sense of the world, the personal view of living life from the inside that everyone carries, vs. objectification, which is the reduction of this personal dimension to categories and standards in which one should fit. An example related to care contexts that Todres et al. provide for this first hallmark of “human” is the way health-related news is broken to patients during medical interviews. This is especially important when doctors are sitting in front of computer screens and explaining a patient’s condition through statistical data and categories, which apply to anonymous entities detached from their life context and not to the unique individual currently being attended to. As illustrated in Chapter 3, this point is crucial in Narrative Medicine where illness accounts are not standard cases, but different from each other and as such require different ‘human’ approaches.
- Agency: defined as the possibility to make choices, and to play an active role in decisions that concern oneself, vs. passivity, exemplified in medicine:
by the view of the person and the body as passively subjected to internal and external forces. A sense of agency appears to be very closely linked to the human sense of dignity. [...] Through excessive passivity, one is stripped of human dignity to varying degrees and this can be dehumanizing (Todres et al., 2009, p. 70).
- Togetherness: meant as a sense of community, as the possibility to share thoughts and to experience human interactions. Illness and treatments often lead to separation from social connections, causing the loss of a sense of belonging to someone or somewhere. In this regard, it may be noted that the physical layout and management of spaces and facilities where people are treated, and the set of rules to be observed within these environments, influence the perception of togetherness vs. isolation.
- Sense-making: the search for meaning through stories. Illness can have a disruptive effect on the ability to make sense of human events, an ability usually taken for granted in everyday life. Accounting for patients’ conditions through figures and test outcomes can sound

logical, and to a certain extent, even be understandable, but it does not create a connection with the human dimension. Stories can contribute to bridging this gap, in that they are constituents of human nature, as pointed out in this passage: “[...] we are story makers and storytellers. The search for narrative truth is often experienced as more humanly significant or felt to be more meaningful than the search for statistical truth.” (Todres et al., 2009, p. 72). In contrast, being deprived of the *caring* effect of stories can lead to a loss of meaning. This specific dimension, here identified as essential to human beings and held as a codetermining factor in humanising or dehumanising care, anticipates the theme of co-creation of meaning in Narrative Medicine practices, which is discussed in Chapter 3.

- Journey: this dimension is also concerned with continuity and disruption, as the previous one was, but in terms of the perception of time. Illness causes a split between the familiar past, the uncertain present and the unknown future. Communication during medical consultation focuses on the present and can reduce the perceived time of the disease as if the patient had no story, hence no identity. So a more biographical and narrative approach would be helpful and humanising.
- Embodiment: the body is not an object to fix but a more complex entity that experiences the world; likewise, wellbeing is not just the absence of illness, but a state connected to a positive quality of life as hinted at in the WHO definition.

As shown in the capture of Figure 1, the dimensions mentioned and outlined here are not meant as ideal categories opposed to each other but as elements developing in a continuum along which a system of care unfolds. Besides, the dimensions of “uniqueness – homogenisation” and “sense of place – dislocation” suggested by Todres et al. are not reported here, as I find their content very close to that of “insiderness – objectification” and “togetherness – isolation”.

Fig. 1

Conceptual Framework of the Dimensions of Humanisation (Todres et al., 2009, p. 70)

Forms of humanization	Forms of dehumanization
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenization
Togetherness	Isolation
Sense-making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

This table is just to help the reader imagine each dimension along a spectrum of possibility rather than indicating an either/or category in each case.

In a later study, Busch et al. (2019) argue that the ‘humanization of care’ still lacks conceptual clarity and a systematic definition of specific parameters, limiting its implementation in clinical practice. So they worked on the review of datasets of articles on the topic using the search terms “humanization/humanisation of care” and “dehumanization/dehumanisation of care” (p. 462), taking into account the different perspectives of patients, caregivers, and healthcare providers. By processing collected data using a thematic synthesis approach, they generated 30 key elements divided into three main areas: relational, structural and organisational and reported each of their related main features, barriers or implementation strategies. They are represented in Figure 2. The strength of this study lies in the inclusiveness of viewpoints of different stakeholders on humanised care, how humanisation can be reached, what might be preventing it, and in the representativeness of studies published in English, German, or Italian.

Empathy and respect for patients, sufficient human and material resources in healthcare management, and a balanced workload for professionals emerged from the study as important key factors in delivering humanized care. Although based on a more empirical approach than in the other study presented, an asset of Busch et al.’s investigation is the triangulation of the dimensions, which includes structural/organisational aspects that shape the possibilities for actually improving the relations between different subjects in healthcare.

Figure 2

Features, barriers and implementation strategies for humanisation of care (Busch, 2019, p. 469-470)

Key element	Main feature	Barrier	Implementation strategy
<i>Relational area</i>			
Respect for patient's dignity, uniqueness, individuality, and humanity	Patient seen as a person with his own values [16]	"Othering" (being treated as subhuman) [27]	Referring to the patient by his/her name [36]
Empathy towards the patient	Capacity of taking the other's position [35]		Accepting and understanding what the patient is going through and his/her emotions [32]
Relationship bonding	Closeness [26]	Lack of physical contact [32]	Welcoming patients in a kind way [36]
Holistic approach	Patient seen as whole person [36]	To work in a mechanical way [31]	Getting to know the patient's context [28]
Respect for patient's autonomy and patient involvement	Consideration of patient's rights [36]	Lack of decision-making by women [25]	Obtaining women's consent [25]
Verbal and non-verbal communication	Effective verbal and non-verbal communication [35]	Not looking into the eyes [26]	Actively listening to the patient [34]
Meeting patient's needs/demands	Personalized care [4]	No consideration of women's needs [40]	Verifying patient's needs [29]
Commitment	Responsibility [26]		Being fully present [39]
Moral and ethical principles	Respect for ethical principles [33]		
Relational support for the patient and patient's caregivers	Comfort [35]		Providing emotional support throughout the transplant process [37]
Being attentive/interested/concerned towards the patient	Receptiveness [36]	Negligence and lack of attention [39]	Showing concern about women's well-being [39]
Healthcare provider's competence	Professional suitability [32]		Demonstrating certainty and confidence [36]
Patience	Patience [35]	Being annoyed [39]	Not getting exasperated with the patient [32]
Transparency regarding the treatment	Truthfulness [32]	Not willing to answer questions [39]	Explaining the adverse effects of treatment [32]
Fair-mindedness/equity	Equity [32]		Doing good to any patient independently from his/her personality and behavior [30]
Healthcare provider's personal characteristics	Personal characteristics [29]	Bad-tempered [32]	
Psychological support for healthcare providers		Lack of psychological support for healthcare providers [35]	
<i>Organizational area</i>			
Adequate working conditions	Consideration of staff conditions [38]	Fragmentation of the work process [31]	Good use of time [29]
Adequate training	Technical and scientific knowledge [40]	Lack of professionals trained in HoC [33]	Training professionals according to HoC's principles [33]
Team work	Multidisciplinary team [28]	Lack of midwife authority in hospitals [25]	Defining adequate roles of healthcare professionals [33]
Continuity of care	Presence of the same professionals [26]	Change of professionals [26]	Close monitoring after transplantation [37]
Appropriate medical treatment	Differentiated treatment [26]		Preventing unnecessary medical interventions [25]
Organizational support for the patient and patient's caregivers	Family participation [40]	Companion restriction [25]	Monitoring of labor and delivery by family members [40]
Facilitated access to healthcare	Facilitated access to health services [33]	Limited access to secondary care [33]	Reducing waiting time [33]
<i>Vertical and horizontal communication</i>			
Pleasant hospital stay	Institutional/professional relationship [29]	Lack of cooperation from management [17]	
	Moments of leisure [37]	Interruptions of sleep [26]	Flexible visiting hours [37]
Adequate priority assessment	Compromise between security and humanity [4]	Life-threatening and emergency situations (high-risk pregnancies and deliveries) [4]	
<i>Structural area</i>			
Human and material resources	Sufficient human and material resources [17]	Lack of health professionals [33]	Performing volunteer work [26]
Adequate physical structure	Adequate infrastructure [17]	Lack of space [35]	Modifying the structure of the units [33]
Pleasant environment	Pleasant hospital environment [37]		Providing opportunities for entertainment [37]

Conclusions

The main stages in the development of Medical Humanities were outlined in this chapter not only to provide the necessary historical background to the understanding of the subject but also to highlight the way that medicine, health and illness are socially and culturally constructed practices and conditions, that change over time and space, as confirmed, among others, by Engel himself (2012): "The boundaries between health and disease, between well and sick, are far from clear and never will be clear, for they are diffused by cultural, social, and psychological considerations" (p. 387). The relationship between humanities and medicine, as well as that between body and mind

explored in this chapter, is informed by Western historical events and cultural trends and filtered by a Western lens.

The different research contributions reported in this chapter show that medicine and the humanities have always been in a dynamic relationship, as confirmed in the iconic sentence by Pellegrino (1979a): “Medicine is the most humane of the sciences, the most scientific of the humanities” (p. 16).

While the discussion on MH has focused mainly on medical education, the humanisation of care especially in Busch et al.’s view, appears as less theoretical, as it actually requires a process, and concerns the strategies and activities that can make care *human*.

Scientific literature agrees that the current healthcare system has been boosted by technological advances and increasing specialisation, but as a consequence, has also experienced the technification and fragmentation of care, resulting in dehumanisation. Two studies have been presented, and related strengths and limitations have been highlighted, but one of them has drawn my attention as it stands out for its focus on the feature of “being human” and its implications in healthcare. One of the dimensions of humanization defined in this approach is indeed subjectivity.

The emphasis on the unrepeatability of the human experience in my research is not only aimed at understanding Medical Humanities and humanisation beyond oversimplifications that would associate them with paternalism or moralism. It is also included in the Narrative Medicine approach, and the specific case study of endometriosis. The following discussion actually shows that the idea of uniqueness is also the hallmark of NM as defined by Rita Charon (2001), considered its founder: Unlike its complement, logicoscientific knowledge, through which a detached and replaceable observer generates or comprehends *replicable and generalizable* notices, narrative knowledge leads to local and particular understandings about *one situation by one participant or observer* (p. 1898, emphasis added).

I conclude this chapter with some reflections that anticipate the topic concerned in the next chapter: communication in healthcare settings.

Borrell-Carrió et al. (2004) comment on one of the claims Engel advanced in his critique of the biomedical model with these words “Unlike inanimate subjects of scientific scrutiny, patients are profoundly influenced by the way in which they are studied, and the scientists engaged in the study are influenced by their subjects” (p. 577). A statement which recalls Trotter’s (1932), according to whom medicine material “is not inert and disposable but an active factor in the art process” (p.93). Although bias and mutual influences between the researcher and their research subjects are commonly recognised to a certain extent, it should not be taken for granted that, in a doctor to patient relationship, the human dimension belongs to *both* participants. This provides an additional reason for the unpredictability of communication in healthcare contexts.

Chapter 2

Exploring the complexity of pain

In this chapter, I address the complexity of the illness experience by illustrating the multidimensional concepts of pain and suffering.

I chose and focused first on an article by Eric James Cassel, Clinical Professor of Medical Ethics at Cornell University Medical College in New York City, “The Nature of Suffering and the Goals of Medicine” (1982).

Although many of Cassel’s claims have been confirmed by later research, based on more sophisticated computational methods such as artificial intelligence–based approaches (Noe-Steinmüller et al., 2024), I chose his article as a starting and orienting point of my analysis because of the characterizing concept of the person’s “intactness” and because of his broad, all-encompassing view of pain and suffering and their related meanings and constructs.

In this chapter, I also consider, as parallel objects of analysis, the role of language in medical interactions and that of its relation to society, culture and power, as they work in close connection to each other. This is in line with Foucault’s broad and diverse understanding of discourse (1972), and I provide arguments to support this approach.

The complexity of suffering

In the previous chapter, the theme of ambivalence in medical communication emerged from different researchers’ arguments, as (re)quoted here:

[...] many verbal expressions derive from bodily experiences early in life, resulting in a significant degree of *ambiguity in the language patients use to report symptoms*. (Engel, 2012, p.385, emphasis, added)

[Practitioners’ skills must include] capacities for pause, reflection and integration of more subtle and *ambiguous* information into clinical assessment. (Hurwitz and Dakin, 2009, p. 85, emphasis, added)

The question I would like to start to address in this chapter is the following: is this ambiguity real or does it just reflect the complexity of the illness experience?

Phillipps et al, (2023) noted how, although the relief of suffering is considered the primary goal of medical sciences, there is little agreement on the definition of suffering itself, and little attention is given to this topic in medical research, practice, and education. It is relegated to some preclinical *humanities* curricula: surprisingly, suffering draws more attention in Medical Humanities than in natural sciences, confirming the controversial and yet essential role of humanities in medicine.

Cassel (1982) offers an illuminating perspective on *suffering*, a word that, for now I introduce as an umbrella concept for what a sick person experiences in many respects and at many levels, before detailing it throughout the chapter.

According to Cassel's studies (1982), the lack of knowledge about suffering would depend on the fact that medical literature mostly identifies suffering with pain: his search in the databases *Psychological Abstracts*, *Citation Index*, and the *Index Medicus* revealed that the word "suffering" was most often coupled with the word "pain," while they actually refer to *phenomenologically* distinct concepts, i.e. they manifest themselves in different ways.

For Cassel (1982), "Most generally, suffering can be defined as the state of severe distress associated with events that *threaten the intactness* of the person" (p. 131, emphasis added). I highlight here two points in Cassel's definition: firstly, it does not mention anything specifically related to the body. Secondly, the reference to threat and intactness conveys ideas of suffering and illness as complex systems and as experiences involving *meanings*.

Echoing (although temporally anticipating) some of the traits that make healthcare human according to Todres et al. (2009) and discussed in section 1.4, the intactness of which Cassel speaks results from the interaction of different factors that determine a person in their unique and structured identity. He mentions past as the first of these elements, defined as the set of experiences, achievements and failures gathered in an individual's life and in that of his or her family, which

contribute to the meanings given to illness and to the attitude more or less consciously adopted towards illness. The idea of the past naturally evokes that of story, which anticipates and accounts for the key role of narratives in constituting people's identity and life (Chapter 3) and conveys concepts of entirety, wholeness, and intactness. The past and a person's history do not necessarily imply continuity and logical sequence of events; as Frank (1995) explains, illness narratives can also follow a non-temporal order. The second feature determining one's integrity in Cassel's view (1982) is their cultural background, along with the mutual relationships between society and the individual: "Just as a person is part of a culture and a society, these elements are part of the person" (p. 136). Social rules influence the understanding of health, sickness, ageing and disease, as well as the sick person's self-perception and the behaviour of others toward the sick. Behaviours such as inclusiveness or isolation of the sick, hiding or sharing of health-related topics are strictly influenced by their cultural background.

A person's integrity, threatened by sickness, depends also on political functions, usual activities and tasks, social or private roles, says Cassel (1982). Sickness can change the rights and obligations of a person as a citizen and, on one hand, support them through targeted welfare policies (e.g. special sick leave), on the other hand, it can disempower or make them feel under-represented.

In my view, this is in turn closely connected with the cultural factor just examined earlier, as it could interfere with the relationships in the work environment or in the government's financial involvement in healthcare. I can exemplify this correlation with reference to two case studies.

As elucidated in Chapter 5, women with endometriosis have for a long time been mistrusted by the medical establishment, as the symptoms they reported were considered normal and unavoidably related to their female nature. So, the gender issue has determined the way even doctors (not only laypeople) see the sick, confirming the influence of the cultural background on healthcare mentioned earlier. As a consequence, raising awareness on endometriosis took a long time. In addition, the delay in research and the reduced availability of funds (Smith, 2023) deriving from this framework also saw laws protecting women affected and forms of economic support for

them were approved late (in Italy in 1998). Women affected have to account for their reduced productivity at work, which is due to endometriosis symptoms, but is often misjudged as laziness. At the same time, in order to obtain sick leave, they have to explain what they are experiencing by touching on subjects socially labelled as taboo, as they relate to intimate parts of the female body (Facchin, 2023).

The other case is a preliminary study I am conducting on the language used to express the psycho-physical impact of aphasia, a condition in which the ability to speak, understand language, read and write is impaired to varying degrees. Although the number of people living with aphasia (PLWA) is 15 million worldwide (Ivanova, 2022), aphasia awareness is below 20% across a range of populations and countries (Bennington, 2024). PWLA are underrepresented in research and aphasia awareness campaigns because of their communication disability (Simmons-Mackie et al., 2020), namely the fact that they cannot convey their experience verbally, or even physically, as aphasia often follows a stroke that compromises also movement. This limits knowledge and research on this topic, which, in turn negatively affects awareness-raising activities and funding resources for treatment of the condition. So the cultural, political and social factors are linked to each other.

An incidental but necessary reference to the social implications of health and sickness and to Kleinman's work (1988) clarifies one more time his conceptual and terminological distinction between illness, disease and sickness. I have already mentioned Kleinman's understanding of disease in Chapter 1, where this term represented exactly the limitedness of the biomedical approach. In this section, it is the concept of "sickness" that relates to the threat to patients' rights or disempowerment, as exemplified a few lines ago.

Sickness describes "the understanding of a disorder across a population in relation to macrosocial forces (economic, political, institutional)" (Kleinman, 1988, p. 4): other examples provided by Kleinman concern the relation between the tobacco industry, its political power and

lung cancer in North America or that between tuberculosis and poverty and malnutrition in certain populations.

Moving back to Cassel's (1982) idea of suffering, the emotional world of the individual and, of equally importance, the *ability* to express such world to *others* are other constitutive elements of integrity that are under threat when disease enters one's life: "It is in relationships *with others* that the full range of human emotions finds expression" (p. 136, emphasis added). Now, as reminded by Peabody (1927), "one of the outstanding features of hospitalisation is that it completely removes the patient from his accustomed environment" (p. 819), which is made of people (from family to caregivers and neighbours), as well as objects, places, smells, colours and habits connected with these people, even only in memories. I would add that this isolation is concerning, as broadly speaking, it is the patient's closest human community, and society. Not only does Cassel (1982) underline the existence and value of the person's emotional side by stating that "most students of human behaviour accept the assertion that such an interior world exists" (p. 136) but this world demands to be conveyed to others: so, in line with Cassel's definition of suffering, preventing or invalidating acts aimed to share this inner dimension threaten people's intactness and cause suffering. In chapter 3, I argue, through references to scientific literature how stories, serving, among other thing, this expressive function, are helpful and reconnective for this purpose, and denying or downplaying the expression of emotions in patients' reports removes a constitutive element of integrity, especially when the intended addressees are doctors who show no interest in the inner sphere, which is an inseparable part of a whole. As a direct extension of the emotional life just discussed, Cassel (1982) mentions three other traits of integrity that I find quite related to each other: "perceived future", "secret life" and "transcendent dimension" (p. 137-138).

These can include dreams, fears, hopes and expectations bound to a fulfilling project, may it concern private life (motherhood in the endometriosis case will prove a common hope in patients) or professional success, etc. In the specific case of transcendence, which is represented in the individual's spiritual orientation, it still concerns the perception of future, in that believing in

entities or anything more enduring than one's human life extends the idea of limited time that a serious illness may entail.

Last but not least, the body perception. The relation with one's body can change from identification with it to fear of it and alienation: "[...] the body is no longer seen as a friend but, rather, as an untrustworthy enemy" (ibid.: 137), a theme documented also in the endometriosis stories in Chapter 5. In Chapter 1, I outlined the controversial issue of the dualism between body and mind in modern thinking. Cassel's observations (1982) confirm the thesis that sickness, and more than it, the biomedical model, can intensify this culture-bound opposition and, vice versa, the mind-body dualism experienced in sickness and assumed in modern culture can justify the maintenance and perpetration of the biomedical model.

Yet, Cassel (1982) challenges this mirroring pattern: resuming his definition of suffering and reconsidering it in the light of the analysis conducted in this section, there emerges that suffering arises from the threat of one or more of the factors discussed - the patient's life story, cultural background, emotional inner world, perception of own body etc., - in that each of these features contributes to the intactness of a *person*. By "person", clarifies Cassel (1982), he means something that includes mind and body, a unit, which links back with the idea of intactness.

"Person" does not mean only mind, non-bodily, non-physical, as elucidated here (p. 132):

[...] so long as the mind-body dichotomy is accepted, suffering is either subjective and thus not truly "real"--not within medicine's domain--or identified exclusively with bodily pain. Not only is such an identification misleading and distorting, for it depersonalizes the sick patient, but it is itself a source of suffering. It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person. An anachronistic division of the human condition into what is medical (having to do with the body) and what is nonmedical (the remainder) has given medicine too narrow a notion of its calling. Because of this division, physicians may, in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer (p. 132).

In other words, Cassel's understanding of suffering contrasts with medical dualism and exclusionism and warns against their possible dangerous effect on patients' health, and against the chance of intensifying the sick's suffering.

In the next subsection, I show how Cassel's view not only overcomes the body-mind opposition but also reshapes it by clarifying the relationship between pain and suffering, a point accepted and formalised in the latest official scientific definitions of these two concepts.

Pain and suffering

While Cassel's analysis has focused so far on suffering, other attempts to define such a complex concept make reference to pain. An instance of this perspective is offered in the digital Dictionary of Psychology by the American Psychological Association (2018), according to which suffering is "the experience of *pain* or acute distress, *either physical or psychological*, in response to a *physical trauma or a significant event*, particularly one that is *threatening or involves loss* (e.g., the death of a loved one)." Whereas the theme of the *threat* is accompanied by that of *loss* as sources of trauma, the frequency of disjunctive prepositions in this definition, as well as the mention of pain, absent in Cassel's one, suggests a choice between physical and non-physical, even though both are included as qualifying conditions for suffering. Subsequently, also the relation between pain and suffering, formally raised here but already addressed by Cassel himself and other authors I quote next, has been acknowledged as challenging. This is also true for research contributions based on disciplines other than psychology, e.g. including evidences from nursing studies, anaesthesiology, neuro-sciences, medical ethics, etc., that include more evidence of this:

Suffering in the context of physical pain is one of the key challenges for both clinical care and pain research. [...] However, there is currently no consensus on how to conceptualize suffering, *whether it is related to pain or to diseases in general* (Noe-Steinmüller et al., 2024, p. 1434, emphasis added).

In the documentary film "Quel qualcosa in più" (Smith, 2019), Sartori, Italian surgeon and, among other things, having a double experience as a doctor and as a patient survived to cancer,

defines suffering as an epiphenomenon of pain: epiphenomenon is “a mere by-product of a process that has no effect on the process itself” (Online APA Dictionary of Psychology, 2025) or, in more plain language, “a phenomenon (something that exists and can be seen, felt, etc.) that exists at the same time as another one but is not related to it” (Cambridge Dictionary n. d.): in other words, there is no causal influence between pain and suffering, although they often co-occur.

Concurring with this point, Cassel (1982) had already deepened the discussion on pain and suffering, introducing aspects related to meaning-making, experience, and cognition. He points out that although it is a common belief that the more severe the pain is, the more it is commonly associated to suffering, pains endured in childbirth, for example, are associated to a reward, even though the event of delivery is physically challenging, as well as in some theologies pain is seen as glorifying and relieving in that it brings one closer to spiritual and divine dimensions, reducing the suffering. I can add that in the endometriosis case, covered in chapter 5, it is shown how affected women suffer because of the life projects or daily activities they have to give up, even when they have no painful symptoms.

So, three main points can be inferred from these arguments: pain is one possible but not necessary precondition for suffering; the way patients and their caregivers or beloved regard suffering depends on the experience context in which it is embedded and on the meaning it takes on in one's life; non-clinical view of suffering does not include a distinction between physical and non-physical sources, as in the clinical practice, where the focus seems to be on pain. In Smith's documentary film (2019), Becarelli, medical doctor and anthropologist, says that the modern healthcare system focuses on anaesthesia:

Il dolore che la medicina vuole prendere in carico non è la sofferenza umana, che è decisamente declinata in una vastità di modalità diverse, la medicina vuole occuparsi delle afferenze neurologiche, dei neurotrasmettitori e lavorare per eliminare quelli. Quindi da un certo punto di vista è l'anestesia che ha in mente la medicina [...]. La medicina

preferisce azzerare il sintomo, renderlo così silente che poi tu lo prendi e lo butti (min. 10:37-11:23).³

In contrast, Cassel (1982) argues that suffering includes but is not limited to symptoms and, more importantly, for this very reason, it is not possible to anticipate what a given patient would describe as a source of suffering as long as he or she is not asked about it. The importance of asking the right questions, of asking them in the right way, and listening carefully to the answers are discussed in depth in Chapter 3. Here, it suffices to say that the patient may report some features of the illness experience as painful, but not necessarily as causing suffering and vice versa, depending on factors that Cassel exemplifies.

The fear of the unknown, according to Cassel (1982), increases suffering: if patients know what they have they feel less suffering, whereas even if they have something very trivial, as long as they don't know where it comes from, they suffer more: patients can bear severe pains from kidney stones and declare themselves as not be suffering, just because the fact that they know the source of pain relieve them somehow. This aspect is directly tied to my further discussion, as ignorance of causes and long waiting times for diagnosis are other relatable issues in endometriosis.

Another case in which suffering is reported as connected with physical symptoms is when patients feel that they cannot control these, regardless of the stage of the disease they are affected by: just being aware that medication to control pain is available makes them willing to bear the same pain without any medication, if this allows them to avoid the side effects of treatments. Knowing that controlling one's pain is possible relieves suffering.

Last but not least, suffering intensifies when pain is chronic or not validated by doctors:

³ The pain that medicine wants to address is not human suffering, which is decidedly expressed in a vast array of different ways. Medicine wants to address neurological afferents and neurotransmitters to eliminate pain. So from a certain point of view, it is anaesthesia that medicine has in mind [...]. Medicine prefers to eliminate the symptom, make it so silent and take it and throw it away. The English translations available in this thesis were provided by DeepL software and post-edited by me.

In the absence of disease, physicians may suggest that the pain is “psychological” (in the sense of not being real) or that the patient is “faking.” Similarly, patients with chronic pain may believe after a time that they can no longer talk to others about their distress. In the former case the person is caused to distrust his or her perceptions of reality, and in both instances social isolation adds to the person’s suffering (Cassel, 1982, p. 134).

Not recognising or misjudging the patient’s suffering brings more suffering in different ways: not only is the source of pain unknown, which causes distress, but doctors are not interested in investigating it, patients question themselves and feel socially isolated. As mentioned in the previous chapter, this last point, which recalls Engel’s criticism to the biomedical model (Chapter 1), is extremely important for the endometriosis case discussed later.

In summary, according to Cassel, patients tend to relate suffering to the intensity of pain just when the pain is out of control, chronic, not validated, and when its source is unknown. Conversely, relating the illness experience to a broader meaning can mitigate suffering.

So far I mentioned pain along with physical symptoms, and I argued through references of existing literature that it is a feature of illness that does not necessarily cause suffering. Now I would like to add a short analysis of the definition of pain, as I did for the concept of suffering.

The current definition of pain by IASP, the International Association for the Study of Pain (Raja et al., 2020) is: “an unpleasant sensory and emotional experience associated with, *or resembling that associated with, actual or potential* tissue damage” (p.14, emphasis added). The fact that the official definition is accompanied by clarifying notes (Figure 3) accounts for the complexity of the concept of pain, which, like that of suffering, has its own critical and controversial aspects. While the adjective “unpleasant” calls into question an emotional dimension, the alternative concepts of association and resemblance, as well as of actual and potential, included in the definition are explained as follows: [...] although tissue injury is a common antecedent to pain, *pain can be present even when tissue damage is not discernible.* [...] Many people report pain in the absence of tissue damage [...] (Raja et al., 2020, p. 3). The authors add that:

usually this happens for psychological reasons. There is no way to distinguish their experience from that due to tissue damage *if we take the subjective report*. If they regard their experience as pain and if they report it in the same ways as pain caused by tissue damage, *it should be accepted as pain* (2020, p. 13, emphasis added).

So, tissues are the physical entities called into questions in the pain definition, but their damage can be real or potential, which implies that the patient's reporting on pain legitimates pain itself in the health professionals' eyes and hence deserves targeted adequate treatment. For the same reason, a person's report of an experience as pain should be respected according to the fundamental human right to access pain management, as recognised in 2010 in the Declaration of Montréal (fourth note in Figure 3).

Figure 3

IASP Definition of Pain (2020)

Pain

An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

Notes

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.*
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain.

Etymology:

Middle English, from Anglo-French *peine* (pain, suffering), from Latin *poena* (penalty, punishment), in turn from Greek *poinē* (payment, penalty, recompense).

* The Declaration of Montréal, a document developed during the First International Pain Summit on September 3, 2010, states that "Access to pain management is a fundamental human right."

As for the first and third note, it is worth underlining that pain is subjective, linked with biological, psychological and social factors, and it is also dynamic in that it depends on and varies across life experiences: the association between pain and experiences recalls the relation between meanings assigned to experiences and suffering claimed by Cassel.

As for the second note, according to the website of the European Pain Federation (2025): nociception refers to the “nervous system’s encoding of potentially damaging events (e.g. touching a hot stove, accidentally cutting yourself). But one can experience pain without nociception and have nociception without pain. Pain does not equal nociception. *Nociception is objective, but pain is subjective* and does not emerge solely from activity in sensory neurons.

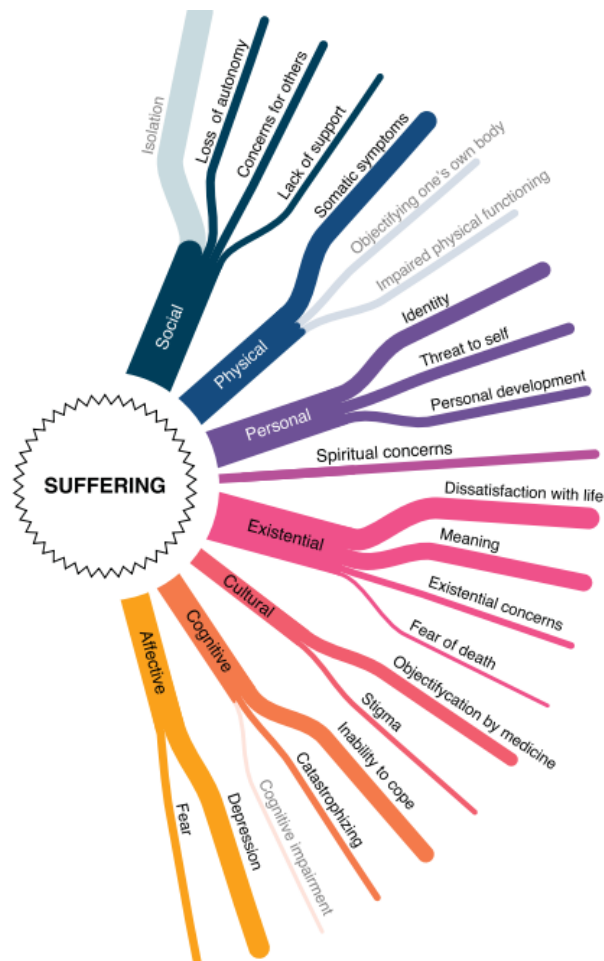
Another similarity between the description of pain and that of suffering lies in the fact that both cannot be inferred merely from neural activities.

The last note refers to the inclusivity of language used to describe pain, and to nonverbal forms of pain reporting that may yet provide essential information, especially in subjects with impaired cognition or language skills (the aphasia case briefly mentioned in the previous section is a relevant example in this respect, as well as that of non-human animals).

The analysis I carried out in this chapter draws on different conceptual references to grasp the wide array of meanings of pain and suffering in human experience and clinical practice. It illustrates two complex and distinct phenomena that are not reliant on each other, nor *necessarily* implied by each other, but are related. To return to a term already used in Chapter 1, particularly suitable for this context, the concepts are *entangled* in a dynamic relationship, potentially still subject to future research and development. To conclude this analysis, I would like to feature a visual representation of the topics addressed, whose original title confirms my interpretation (Figure 4): “The multidimensional conceptual framework of *pain-related suffering*”, by Noe-Steinmüller et al. (2024).

Figure 4

The multidimensional conceptual framework of pain-related suffering by Noe-Steinmüller et al. (2024, p. 1439)



The authors systematically reviewed the existing literature on current theoretical approaches to pain and suffering, such as, among others, Palliative Care, Psychosomatics, Gerontology, Psycho-oncology, etc. and developed a conceptual framework for pain-related suffering. The expression “pain-related suffering” allows us to overcome any alleged dichotomy between pain and suffering as conveyed in a new encompassing definition by Noe-Steinmüller et al. (2024): “A

severely negative, complex, and dynamic experience in response to a perceived *threat* to an individual's *integrity* as a self and *identity* as a *person*” (p. 1440, emphasis added).

Additional explanatory notes have been provided for this definition, too (Figure 5).

Figure 5

The multidimensional conceptual framework of pain-related suffering, Noe-Steinmüller et al. (2024, p. 1440).

Integrative definition of pain-related suffering.

Definition

A severely negative, complex, and dynamic experience in response to a perceived threat to an individual's integrity as a self and identity as a person.

Expansions

Pain-related suffering is experienced to different degrees on a physical, spiritual, existential, personal, social, cultural, affective, and cognitive level.

Pain-related suffering is often associated with feelings of loss, lack of control, illness, alienation, and reduced quality of life. However, none of these can in itself be considered suffering, if it is not experienced as a threat as defined above.

Pain-related suffering is often a long-term experience but not necessarily so.

Pain and pain-related suffering are related but distinct phenomena. Either can cause or enhance the other.

The experience of pain-related suffering depends on the complexity of the affected individual. Newborns do suffer, but their suffering is not taking place on, eg, an existential or spiritual level, and they are not threatened as persons but rather as selves.

This definition shows that pain-related suffering is “a multidimensional phenomenon that is *closely related to but distinct from pain* itself” (Noe-Steinmüller et al., 2024, p. 1434, emphasis added), so pain and suffering are closely connected while retaining their conceptual autonomy.

Without delving into specialist fields, and recognising that I do not have the expertise nor a professional or academic background in medicine, it is important to highlight the strengths of this extended definition. According to Noe-Steinmüller et al. (2024), suffering is not only caused by pain, but it can, in turn, worsen pain and even give rise to physical pain through somatization (p. 1445). Yet while pain as a cause of suffering is explicitly discussed in the existing literature, the influence of suffering on pain has received far less attention. In contrast, Noe-Steinmüller et al. (2024) shed light on the necessity to consider the bidirectional character of the relationship.

Also, the notes point out that the experience of threat, consistent with Cassel's propositions, remains the determining factor in the feelings that accompany suffering. As mentioned in the first section of this chapter, this analysis does not claim to be representative of the existing or potential

critical views of the research featured, but it is noteworthy that, while sharing Cassel's other tenets of *integrity* and *person*, Noe-Steinmüller et al. (2024) also add a reference to "beings who are potential sufferers, but might *not* be considered as persons, such as preverbal children" (p. 1444). Actually, this clarification relates to a broader attempt to address criticisms of Cassel's idea of personhood, which could be considered vague (e.g. Tate & Pearlman, 2019) or exclusive of other forms of existence in which pain-related suffering can be experienced. In contrast, Noe-Steinmüller et al. (2024) clarify that the concept of person, although concerning mainly adult people, is intended as a comprehensive term: "to describe essential aspects of (adult) suffering, namely, a high level of complexity, reduced quality of life, fear of the future, loss of meaning, and a breach of one's personal narrative" (p. 1445).

The last two features are extremely relevant to my future discussion in Chapter 3, and I add that Cassel's human traits, such as past, emotional world, perceived future, etc., discussed in the previous section, actually clarify and define what he means by "person".

Moreover, Noe-Steinmüller et al. (2024) highlight that pain-related suffering cannot disregard the person as a pivotal element, as it interrupts, breaks and prevents the fulfilment of their identity:

it deeply affects the individual at their core to an extent where *they cannot continue to be who they are* [...] transform(s) the sufferer into something different from themselves, which is intolerable for the sufferer. We suggest that this intolerability lies at the core of pain-related suffering (p. 1445, emphasis added).

Lastly, the study identifies several nuanced and interacting factors that contribute to the experience of pain-related suffering. Their graphic rendering reflects the diverse levels, branches along which the relation between them develops.

Precisely, their study investigates eight dimensions which contribute to a conceptual framework of pain-related suffering: social, physical, personal, spiritual, existential, cultural,

cognitive, and affective; these, in turn, are represented and quantitatively differentiated through lines with varying degrees of thickness, and furtherly defined by different descriptors (Figure 6).

The existential aspect in pain-related suffering was the most documented in the literature reviewed (33%) and includes experiences such as dissatisfaction with life or the feeling of loss of future; On the relevance of the existential dimension I have expanded in the following section, where I'll underline how, although it relates to the attribution of meaning to a universal condition such as life and vulnerability, it is culture-dependent. 32% of the literature mentioned social experiences, such as isolation, and 26% described personal experiences as a threat to the self. Only 24% focused on the physical dimension of pain-related suffering, such as general somatic symptoms. 20% referred to the affective dimension exemplified, among others, by depression. 18% described cognitive aspects of pain-related suffering, such as the perceived inability to cope with one's pain. 13% described the cultural dimension of pain-related suffering, such as being objectified by medicine. The least frequently mentioned dimension was the spiritual one.

A Comprehensive Clinical Approach to Suffering

Now that suffering has been explored from different perspectives and its entanglement with pain has been explained, the next question is how to comprehend and address such a diverse condition coherently in clinical practice. This question demands more attention, especially considering the emotional challenges that medical students and doctors face in their daily working lives. The enlightening article from which I quoted the following excerpt highlights how, thanks to scientific progress, doctors are more and more prepared and equipped to understand, predict or *kill* pain (as in the iconic term “pain-killer” for analgesic), but are less prepared to face suffering, just like their patients. Besides the predictable effects of this void on patients, this concern also affects clinicians' wellbeing, which, incidentally, is another issue with which NM deals, as I explain in the next chapter:

Biomedical culture and education do not prepare trainees to manage suffering.

Students focus on biomedical diagnosis and treatment of disease, not the

patient's personal experience of illness and suffering. Without guidance, training, and support, witnessing suffering can be stressful for students, and burnout hampers their ability to *engage* with it (Phillips et al., 2023, p. 5, emphasis added).

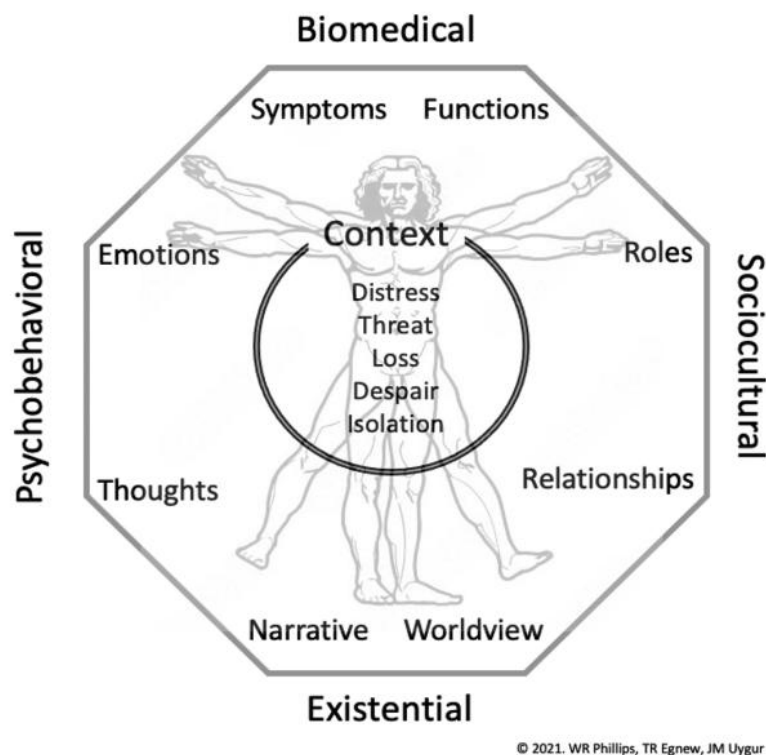
Not only are doctors not ready to deal with those challenges (to the same degree as their patients), but also not ready to *express* this inability, as I discuss in the next section. In this respect, uncertainty in the face of suffering and unpreparedness for suffering, is very common ground between doctors and patients, and I analyse this commonality in the specific case study on endometriosis in Chapter 5, after illustrating which role NM plays in managing uncertainty.

In light of the multidimensionality of pain-related suffering analysed in the previous section, I found it pertinent and relevant to present here Phillips et al.'s (2023) proposal of a *Comprehensive Clinical Model of Suffering* (CCMS), which, as the name itself suggests, approaches whole-patient care.

Phillips et al.'s model features four axes: biomedical, sociocultural, psycho-behavioural, and existential, which, in turn, include eight domains: symptoms, functions, roles, relationships, emotions, thoughts, *narrative*, and worldview.

Figure 6

The Comprehensive Clinical Model of Suffering (Phillips et al., 2023, p. 3)



Each of the eight dimensions includes losses or threats of loss that can contribute to suffering. The biomedical axis is at the top because it is the *initial* focus of physicians' and patients' concerns, and the circle-like shape of the model reflects the breadth of suffering through the other axis. The circle surrounding the patient picture, at the very centre of the model, represents the patient's perception of context and hence the different and unique ways in which they can experience suffering, from distress to isolation.

To offer a practical example of the model's application, in addressing a back pain complaint, or even better, the threat that arises from back pain, the clinician could start by inquiring about the domain of symptoms and abilities affected, which relates to the biomedical axis. These have different varying meanings for a rescue worker, for a professional runner dreaming to compete at the Olympic Games, for a mother wanting to hold in her arms her baby or a father wanting to play hide and seek with his children. In these patients the threat does not affect only the domain of professional or personal roles, or that of material needs to be met (sociocultural axis), but also the array of feelings and connections with the loved ones (psycho-behavioural axis), of expectations

and life projects, of the future, (existential axis). These contribute to the experience of pain and to the related suffering.

Figure 7

Axes and Domains of Suffering with Clinical Examples. (Phillips et al., 2023, p. 4)

Axis	Domain		Threat or Loss
Biomedical	Symptoms	Comfort	Pain, Nausea Dizziness, Insomnia
	Functions	Ability	Mobility, Self-Care, Sleep, Control
Sociocultural	Roles	Performance	Worker, Caregiver, Provider, Protector
	Relationships	Connection	Family, Friend, Colleague, Lover
Psychobehavioral	Emotions	Emotional Distress	Fear, Anger, Sadness, Loneliness, Grief
	Thoughts	Psychological Distress	Worries, Regrets, Confusion, Loss, Worthlessness, Hopelessness
Existential	Narrative	Personal Identity Wholeness Meaning	Expectations, Acceptance, Future
	Worldview	Spiritual Distress Value Conflicts Traditions	Conflicts in perceptions, values, guilt

Figure 8 offers a practical example of how medical consultations based on CCMS could unfold:

Figure 8

Patient Care Example of Using the Comprehensive Clinical Model of Suffering and domains of suffering in the patient's experience (Phillips et al. 2023, p. 10)

AB is a 51-year-old married woman consulting, Dr. C., who has been her family physician for 25 years.
Dr. C - Good to see you, Anne. How are you?
AB – Well, I haven’t been great recently, so I thought I should come and talk to you.
Dr. C – Tell me when you noticed things starting to change?
AB – I guess I started to notice a change when Clara went off to college.
Dr. C - That’s a big change in your life – and hers!
AB - Yeah, it’s a bit quieter around the house, but I’m getting used to it.
Dr. C – What started happening for you around that time?
AB – I started having a lot of difficulty sleeping. At first, I thought it was just worry about how Clara would manage on her own. But since then, I’ve started waking up so hot that the sheets were soaked with sweat.
Dr. C – OK. What else are you noticing?
AB – It’s hard to explain but my brain is just not functioning properly. It feels like I am in a fog. At the same time, I feel on edge. Little things get to me. I find myself snapping at people for no reason.
Dr. C – That must be making things tough for you day to day
AB - Yeah, I feel like I’m not switched on at work. I’ve been so exhausted. And I’m stressing non-stop about my kids and my dad. We had to put him in a nursing home. And I feel like ... (tears)
Dr. C - It’s OK, Anne. Take your time. (Offers a tissue). It sounds like others around you are also being affected by all this. Is that right?
AB – Yeah. It’s hardest on my husband, Bob. He doesn’t know what to make of me right now. I’m so emotional. I’ve gained weight and can’t lose it (partly because my joints ache and I am not running anymore). With all that, I don’t feel attractive. I’m not really interested in sex, not to mention that it’s so much more painful now. I think that is really impacting our closeness as a couple.
Dr. C - I’m sorry you’re going through all this. What is your biggest worry right now?
AB – I’m at a real loss. I feel like a mess at home and pretty much useless at work.
Dr. C – What are your ideas about what might be going on?
AB - Well, at first, I wondered if Clara’s leaving bothered me more than I thought. Then I realized that I’m having fewer periods. I wonder if I’m going through the menopause.
Dr. C - You may well be right. The symptoms you’re describing do sound like menopause.
AB - You don’t know how good that is to hear! I thought maybe I was losing my mind!
Dr. C - Many women experience this, though many don’t talk about it. It’s great that you’ve come in so we can talk it through. We have lots of ways to treat your symptoms. We’ll get some labs to check we’re not missing something and make an appointment in 2 weeks to discuss options. How does that sound?
AB - Sounds good to me. Thank you. I just want to feel more like my old self again
Dr. C - Menopause is a real transition process with many changes. You are entering a new stage of life and that can bring up lots of questions.
AB - Yeah, I guess so. It’s hard to put my finger on it but I suppose I feel like I am getting older and it’s all a bit scary.
Dr. C – Well perhaps we could explore some of your thoughts about this phase in your life when we review your treatment options next visit. Sometimes it helps to share these things with someone, to help you process things. How does that sound?
AB – Sounds good. Thank you, Doctor. I’ll see you in a few weeks.

Axis	Domain	Threat or Loss
Biomedical	Symptoms	Night sweats, brain fog, fatigue, joint pain, pruritis, vaginal dryness, decreased libido, weight gain
	Functions	Insomnia, not running due to joint pain
Sociocultural	Roles	Hard to perform at work due to brain fog and fatigue
	Relationships	Sexual relationship with partner affected due to decreased libido, fatigue, and dyspareunia
Psychobehavioral	Emotions	Fear, sadness
	Thoughts	Anxious thoughts about teenage children and ailing father
Existential	Narrative	Realizing that a significant part of her identity has been defined by her sexuality, attractiveness, and reproduction, she wonders who will she be as she becomes a post-menopausal woman?
	Worldview	Entering a later stage of life, she asks herself: What is her life all about? Where does it fit in the life of her family and the big picture of why she is on the planet?

As emerges from the dialogue example, after asking how the patient is feeling, the first question does not focus on possible symptoms that she is likely to report, but on when she noticed them: not on what changed, but on when it changed. This allows the patient to identify not necessarily a specific temporal start, but a situation, or an event in her life with which she associates the onset of symptoms. This association, which reflects the *patient's* view of her distress, also reveals a basic meaning association process, in that it recognises which aspect of the patient's world is perceived as under threat, in which respect her intactness is at risk, and what her current experience means to her. The comprehensive description of her suffering unfolds through the axis and domains related to the functions she cannot perform as usual (sleep quality, reduced physical activity), the roles and relationships currently affected by her discomfort (work life and intimacy with her partner), her emotions (fear and worries), and her view of life, the sense of her life now that certainties about her motherhood, her femininity and her profession seem to be questioned.

In other words, the dialogue raises issues on how she can cope with changes, since illness means changing *per se*.

I would like to add two more observations on this dialogue, specifically in the patient's words. One is the sentence "You don't know how good that is to hear! I thought maybe I was losing my mind!", a statement that reveals the relief in knowing what may be causing the patient's distress (probably starting menopause): this response illustrates how uncertainty about the reasons for one's

suffering may increase suffering itself, as pointed in the second section of this chapter, about factors that amplify suffering according to Cassel.

Second is this meaningful sentence “I just want to feel more like my old self again”, which expresses the loss of identity and intactness and the need for reconnection to the *older* self, to rebuild the person’s wholeness. These themes recur often in NM, as is argued in the next chapter.

The authors of the model point out that it is based on family medicine, which has the unique opportunity (and responsibility) of attending to patients through long-term relationships. Over time, doctors can develop a deeper and comprehensive understanding of their patients’ problems, which contrasts with the rising trend towards specialism in modern medicine, as mentioned in Chapter 1. Although it presents this limitation, it remains a valid framework as it revolves around the complexity of the human being and their experience of illness as it unfolds at multiple levels and questions multiple meanings connected to life, as well as to suffering and loss.

Moreover, this approach is not disease-oriented but person-focused, or with Balint’s words (1969), not “illness-oriented” but “patient-centred”:

[...] Michael Balint spoke about two classes of pathological conditions: Class I comprises conditions in which a localizable 'illness' can be found. In this class scientific examinations can identify a fault either in the body or in one of the part functions in the body. In this way of thinking, the prime aim is to find a localizable fault, diagnose it as an illness and then treat it. This is what we call 'illness-orientated medicine.'

In contrast, there is another way of medical thinking which we call 'patient-centred medicine'. Here, in addition to trying to discover a localizable illness or illnesses, the doctor also has to examine the whole person in order to form what we call an 'overall diagnosis'. This should include everything that the doctor knows and understands about his patient; the patient, in fact, has to be understood as a unique human-being (p. 269).

This proposition may sound similar to the comprehensive approach to suffering just presented, but it focuses on and explicitly bolsters the aspect of the *diagnostic power* of such an approach, shifting the focus from the comprehensive attitude towards the patient to the “overall diagnosis” (Balint, 1969, p. 269).

Michael Balint (1896–1970) was a psychoanalyst working in London from the late 1940s to the 1960s. His interest in the work of general practitioners (GPs) inspired the launch of group seminars for GPs, who at that time seemed to face more and more patients presenting with undefined symptoms, and conditions hardly relatable to any diagnosis explained in textbooks.

The GPs who joined the first Balint groups did not actually find specific advice on how to manage such cases, but they were trained to become familiar with and to tolerate uncertainty. As my research is on NM as a method facing uncertainty, I do not describe in detail how Balint groups work, but I am mentioning them here because of the common features between these two approaches, such as the role of the patient, the self-reflection and reflection among peers and the role of uncertainty.

Another reason for this swift but meaningful mention of Balint’s work is that I hold important how the definition “patient-centred” could be easily associated with the priority given to the patient’s world, even though, interestingly, Balint’s group activities basically consisted of *doctors’* accounts of critical medical cases, of patients’ stories shared with other colleagues. So, from my stance, while the focus is on the patient’s (medical, but not only) story, the pivot in the Balint method is the teller of this story, the physician, who has a medical perspective, filtered by the uncertainty that a doctor feels when managing a given case. With this comment I would like to draw attention to the fact that the *centeredness* of the care approach moves and oscillates between the patient and the doctor, and from doctor to other doctors (peer listeners) in the Balint groups, since they are all involved in different relationships, which leads to the later more inclusive concept or relation-centred care (Tresolini, 1994).

Objectivity and Ambivalence in the Language of Healthcare

The analysis of the idea of pain and suffering and their interactions offered in this chapter is meant as a conceptual basis for understanding the complexity of experiencing illness and framing it as the premise of the equally complex nature of doctor-patient communication. This brings us back to the ambiguity of patients' information that I mentioned at the beginning of the chapter. A quote from Rita Charon may help to clarify this sense of ambiguity and expressive uncertainty (2008):

I had to follow the patient's narrative *thread*, identify the metaphors or images used in the telling, tolerate *ambiguity* and *uncertainty* as the story unfolded, identify the *unspoken* subtexts, and hear one story in light of others told by this teller. I was the *interpreter* of these accounts of events of illness that are, by definition, *unruly and elusive*. I saw that, while I had very demanding "listening" tasks, the patient's "telling" tasks were even more demanding, because *pain, suffering, worry, anguish, and the sense of something not being right are conditions very difficult, if not impossible, to put into words* (p. 4, emphasis added).

Also Virginia Woolf recognised, long ago, the difficulty of talking about illness even in literature (1926):

[...] to hinder the description of illness in literature, there is the poverty of the language. English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache. It has all grown one way. The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready made for him [...] (p. 34).

This does not mean that writing on pain is not feasible, as novels and poems on pain speak volumes about it, and literature informs most of the medical and research activity carried out by Rita Charon, conventionally regarded as the founder of NM (Marinelli, 2022). In the last decade, even a specific genre that raised increasing interest has been labelled as "sick-lit" (a short form for

sickness literature), an expression widely used in British media to define novels on illness, death, and trauma, usually targeting teenagers and young adults, and documented also in medical anthropology by Rachel Hall-Clifford (2015) in a paper entitled “Autopathographies: How ‘sick-lit.’ shapes knowledge of the illness experience”. In 2023, Ada D'Adamo's novel *Come d'aria*, based on the writer's experience of illness while raising her daughter with special needs, won the prestigious Italian literary award “Premio Strega”.

It must be recognised that a patient's struggle to find words for pain remains a key feature in sickness as well as in any trauma experience. It suffices to say that temporary or prolonged mutism often arises as a post-traumatic condition (de Mol & Deleval, 1979; Ferrara, 1985). Besides, although endometriosis stories are the topic of Chapter 5, I find it particularly meaningful to quote an excerpt from the corpus-stories here that I collected and analysed in that chapter, shared by an Italian patient about the challenge of reporting her pain to her doctor. She interestingly named the short note she wrote in her symptom diary “Consapevolezza” (Self-awareness):

Difficile comunicare cosa non va se non ti rendi conto di cosa non va. Difficile dire a un medico qual è il problema se non capisci cos'è normale e cosa no. Qualunque dottore cerca in base alla sua specifica competenza, ti suggerisce una possibile soluzione. Non sono mai stata in grado di spiegare che cosa volevo⁴.

In this case, symptom reporting is no doubt made more difficult by the lack of references against which distress is to be considered abnormal, since menstrual pain is accepted as part of a specific and culturally rooted idea of female nature and considered normal. But still, this sentence suggests the inability to realise, to figure out, even before saying it, what is wrong.

The different excerpts I quoted suggest that illness experiences and pain, viewed as undesired conditions, are something humans are not prepared or easily willing to talk or write about, although Western modern thinking plays a crucial role in this.

⁴ It is difficult to communicate what is wrong if you do not realise what is wrong. Difficult to tell a doctor what the problem is if you do not understand what is normal and what is not. Every doctor inquires, according to their specific expertise, and suggest a possible solution. I was never able to explain what I wanted.

Nevertheless, these expressive efforts have also been interpreted under a different, cultural perspective, which sheds light on the relationship between man and suffering. In the preface to his book *Limits to medicine. Medical nemesis: the expropriation of health* (1975), Illich puts forward a view of pain language that differs from Woolf's one through an interesting analysis of the term "coping".

According to Illich (1975), each language offers a wide and rich vocabulary for dealing with different forms of suffering, but it seems that the word "coping", a term attested since the 15th century and originally meant as "come to bows with someone", became increasingly common, taking on a different, softened meaning, which made it suitable in more contexts. There was no word available for describing general disarray, so the term coping filled this void and "People learned to cope with husbands, jobs, treatments, unemployment, flu" (p. 33). The consequence, says Illich (1975), is that "as soon as you understand suffering as coping you make the decisive step: from bearing with your flesh you move towards managing emotions, perceptions and states of the self conceived as a system. (p. 34)"

Based on Illich's (1975) view of health and medicine in the 20th century, the difficulty of talking about suffering could reflect the loss of the cultural ability and *willingness to deal with* pain, sickness and the time limits of human life, and to make sense of them: "Man's consciously lived fragility, individuality and relatedness make the experience of pain, of sickness and of death an integral part of his life" (p. 275).

According to Illich, the view of the human body and health is determined by the relationship individuals have with the sweet and bitter sides of life and their attitude towards others' suffering. Illich confirms the cultural root of this relationship, when he says that culture allows people to bear suffering, illness and make meaning of death. Yet, from a cultural perspective, pain is construed as a challenge that requires a response *from and inside* the *individual*, the medical market turns this search for answers into technical problems that can be managed or abstracted from the existential dimension. Culture makes pain tolerable by integrating it into a meaningful framework, while

modern medicine removes pain from any subjective context in order to eradicate and suppress it, so that the individual does not need (or is not able anymore) to accept suffering as part of reality.

Illich's viewpoint is part of a more comprehensive critical analysis of modern medicine and refers particularly to the pharmaceutical industry and to the economic drive that often determines actual trends in healthcare service. Yet its relevance to this chapter lies in the centrality of different meanings of pain that cultural systems integrate into the illness experience, which modern medicine, in contrast, regards as unnecessary and skips. In the next chapter I explain how NM allows patients and doctors to reconnect themselves to the disregarded search for meaning through story-sharing.

If one of the factors determining this uncertainty is the multidimensionality of pain-related suffering, in which, as detailed in the previous sections, the physical aspect is just one among others, I now explain and discuss how other reasons lie in language, power and their mutual influence.

My arguments and sources for this section are the outcome of a selection of literature which I hold functional and proportionate to my research questions. They do not claim the exhaustiveness of an in-depth analysis of medical language, especially in spoken communication, to which they would not add anything innovative from my thesis scope, but they aim at highlighting those aspects connected with the verbal complexity that accompanies the illness experience.

“Medicine uses one lingua franca but speaks with many tongues”, as Baethge says, (2008: 37), as the basis of its terminology is internationally shared, but it was influenced by Greek, Latin, French and Arabic.

As noted by Serianni, (2005), historically, medicine has been practised by people who spoke a different language from that of their patients, namely, Greek in ancient Rome and Latin in the 16th century France. This fact describes, per se, a distance between clinicians and healthcare receivers, which originates in the different fields of expertise pertaining to doctors and patients but is in turn

reflected, conveyed and enabled by language as if in a cycle. Language is the form in which this distance is expressed and the vehicle through which it is perpetuated.

This relationship between language and power, which fuels a specific distribution of knowledge, has been widely investigated by Foucault (1972) and falls within the broad and variously defined and interpreted notion of discourse. Mills (1997) offers a comprehensive and thorough analysis of the term discourse and of the variety of meanings it has accrued in different disciplines, from linguistics to psychology. I decided to draw on her work, because she starts her examination by recognizing that Foucault himself defined discourse in three different ways (1972): [...] sometimes as the general domain of all statements, sometimes as an individualizable group of statements, and sometimes as a regulated practice that accounts for a number of statements (p. 80).

In addition to this differentiated description, Macdonnell's work (1986) has shown that other discourse theorists, (among which, Mikhail Bakhtin, 1984) have contributed to this research, even though Foucault is one of the most often referred to. I draw here on Mill's overall description of discourse, just based on Macdonnell's comparative work (1986):

a discourse is not a disembodied collection of statements, but groupings of utterances or sentences, statements which are enacted within a social context, which are determined by that social context and which contribute to the way that social context continues its existence. Institutions and social context therefore play an important determining role in the development, maintenance and circulation of discourses (p. 10).

With a set of examples representative, but not an exhaustive list, of the medical discourse understood as from the definition above, I try to show how these processes work in practice.

According to Serianni (2005), medical language presents properties typical of a special language, such as specific lexis and morpho-syntactic structures, according to Cortelazzo's definition (1990):

per lingua speciale si intende una varietà funzionale di una lingua naturale, dipendente da un settore di conoscenze o da una sfera di attività specialistici, utilizzata, nella sua interezza, da un gruppo di parlanti più ristretto della totalità dei parlanti la lingua di cui quella speciale è una varietà, per soddisfare i bisogni comunicativi (in primo luogo quelli referenziali) di quel settore specialistico; la lingua speciale è costituita a livello lessicale da una serie di corrispondenze aggiuntive rispetto a quelle generali e comuni della lingua e a quello morfosintattico da un insieme di selezioni, ricorrenti con regolarità, all'interno dell'inventario di forme disponibili nella lingua⁵. (p.5)

This definition suggests that vocabulary plays a particular role in special languages, as well as in medicine. In line with the theoretical introduction to MH that I offered in Chapter 1, medicine also features at the linguistic level a trait that makes it more similar to the humanities than to the hard sciences. Serianni (2005) identifies precisely this with terminological richness and productivity. He claims that this is due to the diversity and complexity of anatomy and pathologies, but also to what he defines as “individualismo” (individualism, p. 116) inherent to the medical profession: the purpose to heal sufferers, the task of inquiring on symptoms, *interpreting* them and identifying their causes requires more than specific knowledge or the systematic application of a method:

Di qui l'ambizione di lasciare una traccia della propria presenza nel mondo: e il segno per eccellenza è il segno linguistico, si tratti del proprio nome fissato in una delle tante denominazioni eponime, della coniazione di un neologismo per designare una sindrome fino

⁵ Special language refers to a functional variety of a natural language, dependent on a specific field of knowledge or sphere of activity, used in its entirety by a group of speakers smaller than the total number of speakers of the language of which it is a variety, to meet the communication needs (primarily referential) of that specialist field. At the lexical level, the special language consists of a series of additional correspondences with respect to the general and common ones of the language, and at the morphosyntactic level, it consists of a set of regularly recurring selections within the inventory of forms available in the language.

a quel momento mai descritta o modificare l'accezione di un tecnicismo già in uso[...]⁶. (p. 116)

Besides this ideal-based explanation, the remarkable extension of medical vocabulary is due to the need for and pursuit of unique identification of the phenomena, processes and objects referred to (De Mauro, 1971), from parts of the human body to diseases and surgical equipment. Establishing a one-to-one relationship between signifiers and meanings limits or even removes semantic relationships like synonymy and polysemy. These are typical of standard language and essential for its proper functioning, yet would raise misunderstandings or vagueness in a field where high precision is required.

I remark how these two facets of medical vocabulary - the terminological creativity and the search for semantic objectivity – coexist with a doctor's human subjectivity. He interprets symptoms and patients' reports on the one hand, and applies the rigour of the sciences, grounded in standardised, replicable methods on the other hand. In other words, doctors need to *interpret* complex states reported verbally, which do not always manifest physically, and they are mainly trained and educated with a language that is *not interpretive*, and on the contrary, must be *free from interpretations*.

Comparing the transcript of a medical interview with the chart or the report issued at the end of it, it is soon eye-catching to see the difference between the intertwined, often overlapping or contradictory sentences of the patients and the visual structure and conciseness of what is written down on paper or typed on screens. The patient's narrative *thread* mentioned by Charon at the beginning of this section turns into a graphically straightforward and linear record, often a list or table of acronyms in tests.

This different approach to language in patients and doctors is not casual. Among the frequent features of medical language, Cortelazzo (1990) identifies nominalisation and the

⁶ Hence the ambition to leave a trace of one's presence in the world: and the sign par excellence is the linguistic sign, whether it be one's name fixed in one of the many eponymous denominations, the coining of a neologism to designate a syndrome never before described, or modifying the meaning of a technical term already in use.

preference for passive voice, which leave the actor unnamed or unidentified, as shown in these examples from Linares et al. (2017): “After five years of counselling, a significant effect on life style was seen, with a substantial reduction in the prevalence of smoking, improved dietary habits, sustained physical activity, and a decrease in binge drinking” (p. 57).

Two purposes underlie these specific features of special languages, according to Cortelazzo (1990): the reduction or omission of agency, and condensation. The first feature reflects the need in medical language to focus on objects, events and processes as abstract, generalizable entities, which do not require any particular reference to the agent. Condensation, as a direct consequence of nominalisation, allows time saving in the clinical workflow, particularly in emergency cases. Acronyms are the most evident form of condensation (e.g. Magnetic Resonance Imaging, MRI). According to Bigi and Rossi (2020), the use of these specific linguistic patterns depends on the idea of “territory”, meant as a context with which speakers feel comfortable, familiar and a setting that they master:

it is likely that, [...] doctors are inclined to take for granted the mind-set, knowledge, procedures and requirements of [their] context [...]. These are primarily expressed through language use, be it the use of technical terms (e.g., glycaemic values, instead of blood sugar) or of formulaic language (e.g., the habit of using acronyms). When in the exercise of their professional practice, doctors are in their ‘territory’ and it is likely that they lose awareness of how distant it is from their patients’ ‘land of origin’. (p. 30)

In addition to the terms typical of medical language, Serianni (2005) also introduces the concept of “tecnicismo collaterale” (“collateral technical term”, 2005, p. 128), which does not serve the specific communicative purposes of the medical field, for which a specific vocabulary is already used, but it bridges the gap between standard language and special language, moving along different registers⁷. Unlike communication between experts, the distance between special and standard

⁷ Halliday defines register as “a cluster of associated features having a greater-than-random (or rather, greater than predicted by their unconditioned probabilities) tendency to cooccur” (1998: 162).

language is reduced when communicating information on technical topics with speakers who do not master (or only partially master) the special language, hence between experts and laypeople, in our case, between doctor-patient (Cortelazzo, 1990). Some examples of “tecnicismo collaterale” can clarify this process of linguistic variation (Serianni, 2005): Un paziente dirà che *sente (avverte, prova) un forte dolore alla bocca dello stomaco*, mentre in una cartella clinica il medico tradurrà così: “Il paziente *accusa (o lamenta, o riferisce) vivo dolore nella regione epigastrica*”⁸ (p. 128)

It is true that verbs such as “accusare” are not common in standard Italian and fit into that cushion sphere between medical and standard vocabulary.

Yet, the substitution of sensory verbs with reporting verbs does not affect just the lexical level in medical language, but also the semantic and socio-pragmatic one: it introduces a “hedge” in the message reception and in the re-coding process of that message, it conveys a distancing attitude toward the patients’ words, those same words that, as I have investigated in this chapter, originally aim at representing a complex experience with no distinction between the physical, (sensory) and the non-physical dimension.

Once again, these dynamics are expressed through language and enabled by language: as in the last example, doctors distance themselves from what the patient says and choose the verb “accusare” (complain); this verb in turn marks the doctors’ position on the patient’s report. It must be acknowledged that the doctor’s interpretive role in managing complex and uncertain data unavoidably requires this vocabulary and does not necessarily imply mistrust of the patient. Words simply have a “frame-activating power”, as they may “elicit conceptual structures, frames or schemes, which are rooted in the cultural, social and personal context of each individual” (Bigi & Rossi 2020, p. 24–25).

This link with conventionally accepted social roles and language has long been investigated and, although my research project focuses on *written* communication in paths of care, it is worth

⁸ A patient is likely to say that they *feel (sense, experience) severe pain in the pit of their stomach*, while in a medical record, the doctor will probably translate this as: “The patient *complains (or reports) of sharp pain in the epigastric region*”.

noting that a wide range of literature has investigated the asymmetric power relationships that emerge from oral communication in healthcare settings, specifically in turn-taking during medical interviews (Heath, 1992).

As Bert states on therapeutic relationships (2007):

In principio la relazione è un rapporto coinvolgente e paritario. [...] A prima vista il rapporto tra medico e paziente sembra diverso da una vera e propria relazione: Il malato è quello che chiede aiuto e il medico è colui che possiede le conoscenze e gli strumenti su cui l'aiuto si fonda. Egli ha inoltre il potere di dare un nome alla malattia e, entro certi limiti, di prevedere il futuro del malato in termini di guarigione, di cronicizzazione, di morte.⁹ (p. 11-12)

It is the healthcare professional who typically directs the interview toward a defined goal, e.g. toward diagnosis, framing the questions in such a way that the range and type of patients' responses is oriented or restricted: this allows for only short *factual* answers and leads to overlooking or ignoring those aspects of patients' reports on subjective experiences, personal and social conditions. According to what the sociologist Mishler called the "context stripping" approach (1984, p. 164), a search for context-free laws is typical of the positivist model.

Furthermore, physicians tend not to account for the questions they ask, nor for possible topic changes during the conversation, which, even when abrupt, are not marked as such (ibid.), as is evident in the following figure from Ariss (2009).

Figure 9

Disagreement between patient and doctor (Ariss, 2009: 916)

⁹ In principle, a relationship is engaging and equal. [...] At first glance, the relationship between doctor and patient seems different from a real relationship: the patient is the one who asks for help and the doctor is the one who has knowledge and tools on which that help is based. The doctor also has the power to name the illness and, within certain limits, to predict the patient's future in terms of recovery, chronicity or death.

1 Pt: [bu]t I mean .hh is it just old age? because I mean
 2 me dad's like th[is]
 3 Dr: [we]ll you're not old yet huh hih hih
 4 h[ih hih heh heh] heh
 5 Pt: [I feel it ah ↑huh huh]
 6 Pt: .hhh ha[h huh] .hh it makes me feel=
 7 Dr: [°huh huh°]
 8 Pt: =extremely old when I can't chase after them when they
 9 run off .hh huh huh=
 10 Dr: =Can I just check on here as well yugh ogh ugh er are
 11 you still taking the ventalin inhaler
 12 Pt: Yeh=I[:=am y e h r :]
 13 Dr: [er and how about]t the (flixatide) inhaler

The patient in question has long-term experience of severe anxiety and ongoing breathing difficulties, which limits her ability to care for her children. She suggests through a direct question (“is it just old age?”, line 2) that the cause of her problem could lie in her age. The GP disagrees with her hypothesis (“you’re not old yet”, line 4) and the patient talks about her feelings about breathing and how this impacts her life habits (“it makes me feel extremely old when I can’t chase after them when they run off”, lines 6, 8 and 9). The GP then drops the topic and returns to his clinical agenda (“Can I just check on here as well yugh ogh ugh er are you still taking the ventalin inhaler”, lines 10 and 11). In this way, patients have no understanding of the doctor’s reasoning process, although this is likely to determine initiatives and decisions about them. It follows that decisions on one’s health are mainly based on the doctor’s perspective on the case, while what is relevant to patients from their viewpoint and their direct lived experience of pain-related suffering is in the background (Paget 1983; Fisher 1984; Todd 1984). Even when patients try to counter these tendencies, the interaction is framed by specific expectations and boundaries, beyond which the outcome of the medical encounter can be compromised.

Pilnick (2023) recognises the difference between “medical expertise”, which is knowledge in medicine, and “medical authority”, that is the right to determine a given course of action, and to

decide what should happen, based on that knowledge (p. 1787). Ariss (2009) focussed his research on the asymmetry of knowledge and epistemic authority, revealing that the former does not necessarily imply the latter: a topic can be discussed with great authority by someone with little actual knowledge on it.

On the concept of *epistemic* authority, I am quoting two definitions here: one refers to an expert with specific properties, and the other to a particular relationship between two subjects. I adopt the latter, which is referred to throughout this chapter, because it is clearer and more relatable in a medical context.

Someone who does what I would do if I were more conscientious or better than I am at satisfying the aim of conscientiousness – getting the truth. (Zagzebski, 2012, 109)

L'autorità epistemica è una speciale relazione tra due [...] soggetti [di cui uno è detto autorità e l'altro dipendente] che non si basa solamente sulle conoscenze o sull'esperienza ma anche sulle garanzie (o sulle impressioni) che l'autorità può dare di guidare e consigliare il dipendente. (Badino, 2022, p. 129).¹⁰

Ariss (2009) demonstrated that patients who have frequent contact with health care professionals due to chronic, recurrent or long-term illnesses (“frequently attending patients”) are relatively more knowledgeable regarding their condition and treatments. So, their consultations are potentially more symmetrical, and yet they might unfold in a problematic way. He explores how the medical encounter unfolds when “patients claim entitlement to topics within the doctor’s realm of authoritative knowledge” and identifies four possible outcomes: unless professionals agree with patients, or elaborate on the topic they are discussing together, i.e. providing further or different information and observations on the patient’s stance, they can show lack of engagement with the topic or totally disagree with the patient.

¹⁰ Epistemic authority is a special relationship between two [...] subjects [one of whom is called the authority and the other the dependent] that is based not only on knowledge or experience but also on the guarantees (or impressions) that the authority can give of guiding and advising the dependent.

But even in the case of overt disagreement, discussion or debate is avoided, and resolution is quickly established. The speakers' identities as doctor and patient and their separate roles in the interaction are newly recognised "as both parties 'retreat' to their realms of epistemic authority" (2009: 918): The patient in the last example uses the limits of her condition on her daily routine - on "her realm of epistemic authority", the one on which *she* is the knower - to support *her age thesis*. In this case, final agreement and shared understanding are more of an illusion than the result of a participative process.

Wide research (Parsons, 1951; Mishler, 1984, Heath, 1992) has confirmed asymmetrical patterns during medical consultations in which the patient's role emerged as a "passive recipient of care" (UK Department of Health, 2001, p 23).

In response to these asymmetries in health service delivery that I outlined, more recent academic literature has been investigating the latest government policies, awareness-raising movements of active citizenship and consumer associations, concerned with the need for greater patient participation and partnership in medical consultation. By recognising the role of the patient as a knower, these approaches promote patient-centred care, shared understanding of information and participative decision making.

One representative concept of the focus on the patient is "health literacy", defined by the WHO as (2021):

[...] the *personal* knowledge and competencies that accumulate through daily activities, social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to *access, understand, appraise* and use information and services in ways that promote and maintain good health and well-being for themselves and those around them. [...] *It is not the sole responsibility of individuals*. All information providers, including government, civil society and health services should enable *access to trustworthy information in a form that is understandable and actionable for all people*. [...] Health literacy means more than being

able to access web sites, read pamphlets and follow prescribed health-seeking behaviours. It includes the ability to exercise *critical judgement of health information and resources*, as well as the ability to interact and *express personal and societal needs for promoting health*. (p. 6-7, emphasis added)

The incipit of this definition, with its reference to daily activities and social interactions echoes Mishler's "voice of life world" (1984, p. 104). Health literacy seems to restore a balance in terms of authority, in that it includes the individuals' possibility to exercise critical judgment, but it does not concern only individuals: all healthcare stakeholders, from government to professionals, participate actively in this empowerment process.

Foregrounding one more time how this shift in healthcare affects language and is expressed through it, I would like to finally mention two topics.

One is the promotion of "plain language", a language variety that stands out for its property of being comprehensible the first time it is seen or heard, and using succinct and grammatically correct complete sentences with active-voice and more common terms whenever possible (Warde et al., 2018). I provide an example of plain language in the analysis of institutional communication on endometriosis in Chapter 4.

The other topic is the concept of reflecting the refocusing process on the patient, and the reset of epistemic authority in the terminological shift from "compliance" to "concordance". The former implies that a patient follows instructions and behaviours prescribed by the health professional, reproducing a unidirectional pattern. The latter recognises that the health beliefs and priorities of the patient, may not only differ from those of the professional, but "are no less cogent or important", hence they need to be included in the choice of treatment. Real concordance means also that patients can decide not to accept the professional's advice - which, from the clinician's perspective, is the best - and that their disease development may differ from the one the clinician expects. Concordance requires an agreement that leads to a shared and meaningful decision. It

follows that the epistemic asymmetry is compensated in this case by a renegotiation of authority, as Bert puts it metaphorically (2007: 13):

La relazione è una danza e per danzare bisogna essere in due, anche se è uno quello che guida. Non si può guidare un partner riottoso; è egualmente violenza sia trascinarlo a forza sia lasciarlo cadere a terra.¹¹

Conclusions

In this chapter, I investigated the concept of suffering and pain, particularly focusing on Cassel's definition of suffering, which can be considered as a milestone in that it raises this issue in research and clinical practice and highlights the ideas of threat, person and intactness on which the following studies were based and expanded.

Cassel's contribution deserves recognition also because he sees the division between mind and body as the main threat to the integrity, in that it removes from patients' identity some integral elements that contribute to their wholeness. As Cassel himself recognises, it's no coincidence that people recovering from illness, loss or trauma are said to "rebuild" their life, a verb that suggests the process of rearranging parts or pieces of themselves, to reach the same complex unity in a new way. I tried to show how these pieces, these traits, were differently explored, graphically represented and interwoven in the following literature and research while keeping their core meaning.

The concept of pain-related suffering is the result of this development and entanglement, which best conveys, in my view, the bidirectional and multidimensional nature of pain and suffering. The study on pain-related suffering also shed light on the centrality of the existential and social dimension as the most affected throughout the patient's illness experience, exemplified as loss of the sense of future and threat to the self.

¹¹ The relationship is a dance, and to dance you need two people, even if one is the leader. You cannot lead a reluctant partner; it is equally violent to drag them along by force or to let them fall to the ground.

Subsequently, the fact that suffering - as a comprehensive, holistic concept of human distress – can exist also in and despite the absence of pain, as an unpleasant and equally multileveled phenomenon, lays the foundation for the idea that illness is a complex, multifaceted experience too.

Finally, in this chapter, I returned several times to two concepts - that of dualism and that of integrity – and the stress on these aspects was not casual. I recursively made reference to the dichotomy between body and mind as interpreted by different scholars to highlight its intrinsically cultural essence. In contrast I drew attention to the spontaneous and unfiltered way body and mind are included in the patients' "ambiguous" language, as it emerges from the quotations with which I opened the chapter, and to the understanding of the patient as a whole, a unit for which the meaning of experiences and the perception of time matter.

The reasons for this twofold focus emerge more clearly in the next chapters: firstly, stories hold both these peculiarities, as they pursue unit and meaning. So, if stories are not elicited or attentively listened to, they do not emerge and cannot reveal potentially essential nuances of the illness experience, an in turn, influence the quality of care. Knowledge of illness experience would be just partial, and I argue in the next chapter that NM can fill this gap and allow clinicians to better grasp the breadth of pain-related suffering. Secondly, I link the topic of integrity introduced here with that of "stylistic integrity" at a narrative level, quoting Bruner's expression (2008, p. 21) from an interview with Charon, and referring to the reconnection with illness stories.

In the chapter I also highlighted how the complexity of illness corresponds to a complex way of talking about it, to express pain-related suffering, and, for this purpose, I outlined the linguistic challenges of medical communication and the different control transfers that words may mark. I decided to elaborate on the language topic while discussing at the same time knowledge asymmetry, epistemic authority and medical paternalism based on the assumption that language and power are strictly and unsuspectedly correlated (Foucault, 1972; Mishler, 1984; Fairclough, 1989). I tried to show with different references to literature that it is unfruitful to place control just with one

of the parties involved, even if this is the weaker from an epistemic viewpoint (the patient), as this would lead to the feeling of abandonment and increasing uncertainty in decision making. Whereas negotiation is more representative and inclusive, although it is never a condition set once for all, it is cooperative and variable.

I quoted Illich's work in relation to the expressive difficulties that inform the language of pain, because part of his critical perspective on modern medicine (not far from Engels' position), focuses on the existential dimension of suffering, namely on the loss of meaning and on the interrupted search for meaning. This dimension has emerged as one of the prominent ones in literature, and it is the one which culture used to care for, and now the medical industry tries to diminish or make it redundant by primarily addressing the physical dimension. In the next chapter I present different arguments to show that NM can restore this search, reconstruction, and negotiation of meaning in the doctor-patient relationship.

Chapter 3

Uncertainty in Medicine and Narratives

In chapter 1 and 2 I introduced the theme of uncertainty in different respects: the hybrid essence of medicine as a field of knowledge placed between sciences and practical arts concerned with contingency, variability of subjects and experiences, especially in Trotter's and Pellegrino's view; the multidimensionality of pain and suffering and their interaction, the power dynamics at stake in medical consultation that, contributing to the overall complexity of the illness experience, make it difficult for patients to realise, express clearly and find the meaning of what they are going through when they seek medical advice.

The difficulty of reporting on such a comprehensive list of variables should make it difficult to understand. Therefore, in this chapter, I keep explore the theme of uncertainty, focusing more on the clinician's perspective. In particular, I examine whether and to what extent doctors are aware of the uncertainty that informs their profession and the fact that such uncertainty does not depend only on their patients, but on the epistemic approach of medicine itself.

Medicine, uncertainty and narratives: what do they have in common?

The key to understanding medical judgment is knowing that it is fundamentally the management of *uncertainty* (Cassel, 2004, p. 215).

Medicine is itself a more *narratively* inflected enterprise than it realizes [...] (Charon, 2006, p. 39).

I decided to start my discussion with two quotations on uncertainty and narratives because I would like to highlight the close relationship between these two features of medicine. Stories can help us face uncertainty. They are a resource already available within clinical practice, not just an external tool introduced in medical communication, *borrowed* from the humanities.

The author to whom I mostly refer in this chapter to support this view is Kathryn Montgomery, one of the founding scholars in Narrative Medicine, widely recognised for exceptional contributions to Bioethics and Medical Humanities.

In her book “*How doctors think: Clinical Judgment and the Practice of Medicine*” (2005), she notices that despite the technological advances and solutions they can rely on nowadays, “physicians still work in situations of *inescapable* uncertainty” (p. 12, emphasis added). Also Buchbinder (2015) confirms the relationship between medicine and uncertainty at different levels: in epistemic terms, when determining the source of another person’s suffering, knowing how and whether they are truly in pain is not always possible; ontological uncertainty concerns the possibility to identify the nature of symptoms and verify that they match diagnostic categories, (which is not the case of the so-called ‘medically inexplicable symptoms’, for instance); finally, prognostic uncertainty about how illness can impact the patient’s future involves, even more than the first two, not only patients but also the family members who live with them. Moreover, doctors have access to huge amounts of useful but often conflicting information. They need to decide which and how this applies to a specific patient in a specific situation, since the care of patients is characterised by contingency, says Montgomery (2005).

She illustrates how the unpredictability of the medical profession, of illness and, in a broader picture, the odd paths that cross both the doctor’s and the patient’s life, is singularly represented in the frequent expression used by American physicians when they tell stories about their patients in anecdotal form: “the patient walks in” (p. 160) is the sentence that often opens up the story doctors are about to tell. What Montgomery finds puzzling in this frequent phrase is that, considering the US healthcare settings and facilities, physicians are unlikely to see a patient walk in, whether the place in question be an examination room or the reception area.

The frequency of this phrase, observes Montgomery, emphasises the fundamental uncertainty of medical care, always on the edge of potential surprise, of the as-yet-unknown. The physicians’ professional and existential situation can be visualised as a scene of someone, a stranger at least at first consultation, walking in for unknown - and potentially not fully or easily understandable - reasons and requesting help. Physicians are expected to resort to their knowledge, experience, energies, and most of all attention, for something that may fit into some patterns, but is

not always clear and known at the beginning. So “walk in” marks the situatedness of the clinical task.

Curiously, the casualty conveyed by the action of walking in emerges also in a totally different context, the hospitality management, where if a traveller or a tourist looks for accommodation and arrives at a property without a reservation, he or she is often defined as a walk-in, since their stay is not booked, but is unplanned and unexpected.

In addition to being subjected to uncertainty, according to Montgomery (1991; 2005) clinical practice is imbued with narratives, because medicine’s method is narrative and historically case-based; the approach to clinical uncertainty shares various features with narrative-based research in the social sciences.

To begin with, Montgomery notices, individual patients’ conditions are described narratively, first by patients themselves. As shown in the example by Phillips et al. (2023) provided in the previous chapter, these patients’ accounts are likely to refer not only to their symptoms but also to their personal life context, such as family, work or projects for the future.

An Italian patient’s account in Bert’s book *Medicina Narrativa Storie e parole nella relazione di cura* (2007) exemplifies the wide range of details that flow into medical consultation:

Paziente: ... Vado al mercato due o tre volte la settimana... sono tre isolati da casa, è comodo. La spesa grossa la faccio al sabato, e torno a casa con delle sporte pesanti... Io sto al quinto piano senza ascensore, ma la cosa non mi ha mai dato problemi fino a qualche tempo fa. Adesso invece mi viene il fiato corto e devo fermarmi già al secondo piano per riprendere fiato... Per fortuna c’è la signora del secondo piano che quando mi sente sul pianerottolo esce, è così carina, e mi porta su i sacchi... Lei è giovane, ha due bambini adorabili e così educati...

Medico (un po’ spazientito): Va bene... Ma da quanto tempo esattamente ha notato questo fiato corto?

Paziente: Ah, questo lo ricordo bene, perché è cominciato due settimane fa dopo che hanno cercato di rubarmi il portafoglio al mercato... Ho avuto tanta paura... Quel giovane mi ha dato uno spintone, per fortuna il fruttivendolo se ne è accorto... mi conosce da tanto tempo... sa, al mercato mi conoscono tutti, dopo tanti anni... e si è messo a urlare e ha anche rincorso il ladro ma quello era un ragazzo ed è riuscito a scappare... Poi mi hanno accompagnata al caffè a bere qualcosa... Sono stati così gentili... Io tremavo tutta... Insomma, dopo quella storia ho cominciato a fare fatica a camminare e a fare le scale...¹² (p.19)

The patient's account is the first story and at the same time the first interpretation of the facts, as patients arrange events according to their own perspective, memories, omitting some aspects and highlighting others as relevant to themselves, as held by Montgomery (1991): "stories [...] are themselves readings or interpretations of events as they have been represented in patients' narratives or as they have left their marks on patients' bodies" (p. 9).

This view of *story as interpretation per se* is not limited to the contingent state of patients, but depends on the fact that narration contributes to creating every individual's identity and to understanding the world around us, as claimed in psychology, narratology, philosophy, by—among others—Bruner (1987 and 1991), Ricoeur (1984), Eco (1994), Gottschall (2012), Han (2024), as I discuss in the next sections. Bert puts it in simple explicative words: (2007)

In altre parole la nostra identità è costruita narrativamente e consiste di numerose narrazioni diverse, nostre e altrui. Va infatti sottolineato che anche la descrizione che noi diamo di noi stessi è in realtà un insieme di descrizioni: non è cioè una narrazione unica e definitiva ma un intrecciarsi di storie differenti che variano col tempo e coi contesti.¹³ (p. 23)

¹²

¹³ BT: In other words, our identity is constructed narratively and consists of numerous different narratives, both our own and those of others. It should be emphasised that even the description we give of ourselves is actually a collection of descriptions: it is not a single, definitive narrative but an interweaving of different stories that vary over time and context.

Incidentally, I would like to devote a little attention to a personal experience, which I find relevant and interesting from a semantic point of view. In a recent medical consultation one of the doctors I was visited by did not start the conversation by saying “mi dica” (please, go ahead, tell me, from *dire*: say, tell), which is something one says in Italian even if they work as a shop assistant or in a public office, meaning ‘what can I get you?’, or ‘how can I help you?’, ‘what can I do for you?’ in terms of delivery of products, information or service. He said “mi racconti”, he chose a verb that in Italian refers specifically to a tale, a fairy tale, anyway a longer story, and does not require an answer to a specific question or request: the collocations for ‘raccontare’ and “storia” are much stronger than the ones for ‘dire’¹⁴, and an Italian native speaker is more likely to ‘raccontare una storia’ or ‘raccontare una bugia’ (‘tell a story/lie’), than to ‘dire una storia’. Other languages do not differentiate between these verbs when referring to stories, so to non-Italian native speakers, this might not sound as familiar as it is to me or as it would be to German speakers (‘erzählen’ vs. ‘sagen’).

The same reasoning applies to the less frequently used word ‘recount’ in English, which the Oxford dictionary (2025) features as related to the Old Northern French ‘reconter’, i.e. ‘to tell again’.

The expression “mi racconti” made me feel at ease, at home, and I remember I also felt relaxed during the physical examination despite the worries of the outcome. However, this short linguistic digression on my experience aimed at upholding that telling and listening to stories is something familiar to patients and doctors and that *telling*, even when it stems from the primary source, acts as the first interpretation of the events recounted. This starts the interpretive loop with which Montgomery describes the doctors’ reasoning.

The patients’ stories are followed, or more frequently interrupted, by the doctors’ questions. A new story then ensues from the doctor’s observations and from patient’s information, whether

¹⁴ By interrogating the Italian Trends corpus and Italian Web corpus (itTenTen) through Sketch Engine software, the verb that most frequently collocates with “storia” (story) is “raccontare” (to recount, tell).

this is spontaneously shared or elicited and guided by the doctor. The original patient's account is thus "augmented", but also "edited and encoded in a chart or in a report to eliminate the 'irrelevancies' and highlight the abnormal physical details" (Montgomery, 1993, p. 6).

An excerpt from a patient's written story (a woman, Lidia, 44 years old) shared by Bert, can work as an explanatory first step of the process by which information is screened, reduced in some ways and expanded in others (2007):

...Ho cominciato non so come mai a non sentirmi troppo bene con agitazione incredibile, tremagione e addirittura crisi di panico, ansia con crisi di tremori; sono andata subito dal mio medico che mi ha diagnosticato una sindrome ansiosa, avevo forti problemi respiratori, sono riuscita a chiamare mio marito dal lavoro che subito si è precipitato per accompagnarmi dal dottore. Prima cosa mi chiese se dove lavoro mi sono arrabbiata, se avevo problemi col marito, cognati, genitori, fratelli e sorella, niente di tutto questo, anzi sono felicissima! Ho detto che sono andata da un bravo pranoterapeuta... mi alleviava anche l'ansia...mi ha dato delle erbe preparate dal loro laboratorio, passiflora e artiglio... la prima volta che mi sono sentita questi attacchi mio marito era morto di paura... io terrorizzata da brividi di freddo, formicolio, forti tremori, mi hanno messo l'ossigeno, stavo per morire! Avevo paura di avere qualcosa al cuore, invece è accelerato... [...] Ora prendo una pastiglia di X da 75 mg, una di Y da 20 mg, una di Z da 0,1 la sera e le crisi non sono passate completamente! Perché?¹⁵ (p. 23-24)

¹⁵ BT: ...I started feeling incredibly agitated, shaking and even having panic attacks and anxiety with tremors, and I don't know why. I went straight to my doctor, who diagnosed me with anxiety syndrome. I had severe breathing problems, but I managed to call my husband at work, and he rushed over to take me to the doctor. First, he asked me if I had been angry at work, if I had problems with my husband, brothers-in-law, parents, brothers and sister, but none of that was true. In fact, I am very happy! I said that I had gone to a good pranic therapist... who also relieved my anxiety... and gave me some herbs prepared in their laboratory, passion flower and cat's claw... The first time I had these attacks, my husband was scared to death... I was terrified by cold shivers, tingling, and severe tremors. They put me on oxygen. I was about to die! I was afraid I had something wrong with my heart, but instead it was racing... [...] Now I take one 75 mg tablet of X, one 20 mg tablet of Y, and one 0.1 mg tablet of Z in the evening, and the seizures haven't completely gone away! Why?

In doctors' clinical reasoning, data provided by patients is selected and organized according to their relevance to the story they – the doctors – are going to reshape and retell. They interpret the patient's story to produce a new story, their own, in which events, emotions, and details are filtered and likely to be omitted, as the first sentence of the anamnestic report of Lidia's complaint proves (ibid: 24): "Riconosce di essere un soggetto emotivo."¹⁶

The doctor attending to this patient needs to pick and sort information from the wide and vivid narrative flow and reorganise it through the anamnesis. It seems meaningful to me to suggest a brief overview of the translations - across three languages and cultures - of the word "anamnesis", which defines one of the most basic tasks any doctor performs during a medical interview.

In Italian, German and English, the first meaning of the word "anamnesi", "Anamnese" and "anamnesis" (from the Greek ἀνάμνησις) relates to the action of recalling past events, and in medicine, to the collection of memories from the personal and family health history (Merriam Webster, Oxford, Duden and Garzanti, online dictionaries, 2025).

In German and English, anamnesis is a lemma regularly reported in non-medical dictionaries (Langenscheidt, Duden, Collins), but "history taking, storia clinica, Krankengeschichte, or Krankheitsgeschichte, Vorgeschichte", (clinical history, and from the German, respectively, patient's story, illness story and previous story/prequel) are other possible options along the continuum of diastratic and diaphasic language varieties, in which the idea of a story is more overtly expressed in less technical terms. Incidentally, the English phrase "history taking" evokes in one's mind the scene of a doctor literally writing down notes on the story they are listening to, more figuratively than in the other two languages. Yet, on the other hand, the title of Freud's well-known book *Krankengeschichten*, literally illness or stories of sick people, was interestingly translated in Italian as "Casi clinici" (clinical cases), shifting the focus from the subjective illness experiences of the protagonists of these stories to the technical objective categories by which doctors consider

¹⁶ She acknowledges that she is an emotional person.

them, with two different narrators, the patient's, in the former case and the doctor's, in the latter, as Bert notes (2007). It must be recognised that in the book, Freud shares his own observations on these stories, so he retells them, but still the effect of the translation conveys something more abstract than the contingency which informs clinical practice, as discussed at the beginning of this section.

Anyway, curiously, "history taking", by containing the word history/story, confirms that narratives are something doctors – and broadly speaking, health professionals – intrinsically depend on, both as human beings and because of their profession. As in any human experience and communication form, there are signs – verbal and non-verbal (in the latter case, the human body and all its regular or unpredictable phenomenology) that are coded and decoded in different ways: symptoms, words, clinical tests, body language, diagnoses. These are somehow connected in what we may temporarily call a story, which, for now, can be meant as the minimal basic unit allowing communication partners to make meaning and sense out of these signs.

Now, some critical observations on the transformation of Lidia's story into her doctor's anamnesis are to be made: the doctor's listening to the patient's story or reading of their body signs is necessary and a preliminary act of diagnosis. The fact that the clinical chart or anamnesis turns the ill's wide and hardly describable subjectivity into a "knowable, narratable and treatable case entity" (Montgomery, 1993, p. 12) is an unavoidable necessity too, since even in the light of objective tests, which in turn need to be interpreted within a larger clinical picture, patients are varied and changing. This diversity can be hard to manage in logical and mnemonic terms.

Interpreting, succinctly but effectively defined as the "discernment of meaning" by Greenhalgh and Hurwitz (1999, p. 49), entails editing the patient's story, but this is not harmful per se. It's part of the narrative nature of medicine. The difference lies in the care for the patient (Greenhalgh and Hurwitz, 1999): "The medical reading ideally does no violence to the person and does not intervene in or alter the illness. Potential for comfort or amelioration lies in what happens next, the physician's therapeutic act" (p. 12-13).

The narrative process is not only the foundation of clinical practice - especially diagnostics - as just described, but also of medical education and transmission of knowledge in teaching hospitals and academic settings, since case presentations in conferences, classes and residents' trainings are also a ritual: Residents report to their colleagues and professors on patients in their care and in this daily oral ritual, the medical narrative is a means of demonstrating the teller's understanding of the illness.

So, narrative activity is also rooted in medical education, as it is one of the tasks that doctors learn first. More importantly, the editing and encoding task, through which the patient's story takes on a new narrative form (the chart) brings about changes at a formal, semantic and pragmatic level: no doubt the tone of the "chart text" is flatter than the patient's one, and its style is strictly descriptive, in order to fit the subjective experience of discomfort into a medical objective framework.

But this does not alter the narrative properties of the clinical chart, argues Montgomery (1995), which is written in such a way to *retell* the patient's story: the task performed, and the goal achieved are those that the patient expects. Patients resort to medical advice to have their account retold in the form of medical feedback in the frame of a *common search for meaning* of the events reported, in other words, to have their stories interpreted by a listener/reader. It is in this respect that medicine confirms its interpretive drive:

Diagnosis is interpretive, therapeutics is interpretive, and the care of patients includes the interpretations of what is regarded as brute facts: the symptoms, the test results. [...]

As narrative, they [stories] are capable both of generating and of testing *hypotheses* about illness and disease. (Montgomery, 1995, p. 8-9, emphasis added)

The reference to the hypotheses on illness and disease that doctors create from their own narratives, hints at the diagnostic function of medicine as a search, a set of attempts to find a meaning.

As pointed out by Greenhalgh and Hurwitz (1999), narratives are indeed powerful tools for diagnosis thanks to their *phenomenal* function, in that they *show* verbally what patients perceive as distress, how they experience illness and provide useful information to generate new diagnostic hypotheses.

This hypothetical approach is based of course on experience and theoretical grounds, but it is limited by an unpredictable degree of uncertainty that periodically emerges in a doctor's clinical reasoning. Montgomery (1995) outlines the steps of this reasoning, through which the doctor identifies and focuses on parts of the whole, for instance, on what the patient reported as the most distressing symptom, or the most painful limb, the organ that is not working as it should, or the test results, and tries to connect these pieces together. When an overview is available, the physician reasons back to the details and tests them against the newly outlined general picture looking for any missing data that may confirm or subvert the most likely hypothesis and opting out from others through differential diagnostics. The point of this interpretive process is that, every time a part is re-contextualized, "the patient will be reinvested in a narrative, [...] re-storied" (Montgomery, 1995, p. 10).

Verbal and non-verbal stories in clinical practice: the doctor-reader

Alongside the patient's verbal story, unfolds their body's story, with its own code, at least as complex as the verbal one. Doctors are supposed to consider and also manage - if not first and foremost in the biomedical model - the physical manifestation of illness, what the body is trying to say, as also Charon (2006) confirms.

Our 'reading' of disease takes place at the level of the body's surface and its pathophysiological structure underneath the skin, while our reading of what a patient says takes place at the level of the evident meaning of the words and their implications buried in the clinical and/or personal state of affairs represented. (p. 109)

As much as in verbal communication, *body reading* requires interpretation.

With reference to the stories metaphorically written on patients' bodies, from a semiotic perspective, Nessa (1996) clarifies the interpretive function of clinicians, who are supposed to include in any clinical judgment both signs (objective evidence of disease, i.e. a patient's temperature, etc.) and symptoms (subjective expressions of disease perceived by the patient, i.e. as pain, anxiety).

Symptoms generally need to be reported to the healthcare provider, and so are linguistically mediated. The signs "may be regarded as a text, a story embedded in a body language", whereas the symptoms expression "represents a "handing-over" of experience". Interpretive practice requires "listening to, seeing, feeling, touching and tasting the complex message from the patient" (ibid.: 374, my italics).

Seen from Jacobson's perspective (1960), many layers emerge that stand between the sender and the receiver of this message, between the patient and the doctor, who, are made unsuspectedly close and similar to each other by their common humanity, vulnerability and subjection to uncertainty.

Montgomery (2005) argues that this overlooked and unrecognised relationship with uncertainty is due to the Newtonian and positivist representation of the physical world assumed in medicine, based on certain, replicable, dependable facts. This view of the world is approved not only by physicians, but also by patients, and society as a whole (as in Engel's "folk model" discussed in chapter 1).

Medicine is instead based on retrospective (as suggested in the word "anamnesis"), narrative investigation, more precisely, according to Montgomery¹⁷ (1996), medicine:

shares its epistemological predicament and its methods of knowing with history, law, economics, anthropology, and other human sciences less certain and more concerned with meaning than the physical sciences. But unlike those disciplines, it does not explicitly

¹⁷ This citation corresponds to Hunter in the References of this thesis, since the author published her works with two different names, but I refer to her always as Montgomery in the text.

recognise its interpretive character or the rules it uses to negotiate meaning [...] As readers of signs, physicians are engaged in an interpretative practice. (p.229)

The role of the doctor as a reader of “signs” adds one more piece to this complex and epistemologically uncertain framework.

Montgomery (1991) takes a cautious stance towards the metaphor of the body as a text and the physician as this text/body reader: physical signs as well as medical tests can corroborate or contradict the patient’s report, but despite all the findings on the human body that surgery and imaging can yield, doctors still rely on the patient’s verbal report of symptoms as the most reliable source of information. Launer (2024) notes too that also in the medical educational context, the patient is often referred to as a text that requires an interpretive effort and provides the best teaching sources, just as also the physician William Osler (1922) stated: “a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself” (p. 322).

Drawing on her lived experiences as a doctor, Danielle Ofri also confirms the centrality of the patient’s story (2017): “In some ways this seems almost anachronistic, given how advanced so much our technology is now. [...] Yet the simple verbal exchange between patient and doctor remains the cornerstone of medical diagnosis” (p. 5).

This thesis is also implicitly supported by the anthropologist Buchbinder (2015), who critically analyses the role of vision in contemporary biomedicine, meant as the technology-mediated ability to see what is inside humans through scans, tests, and micro-surgery.

By making the body legible and enabling doctors to read it, vision gives them a new privileged epistemic approach, a new way of knowing patients. Yet, notes Buchbinder, trust is the result of a specific cultural and historical change that (2015): “generated a crucial epistemological shift—from a view in which text-based learning generates medical knowledge to one in which knowledge emanates from the physician’s ability to penetrate the body and see its hidden, underlying truths” (p. 11).

This would account, holds the anthropologist, for the reasons why chronic pain (which, incidentally applies also to the endometriosis condition) is surrounded by uncertainty and not sufficiently addressed: it seems not to fit into the visual and imaging technologies.

The research findings presented, along with the statements quoted, give prominence to *verbal* means, but other researchers question this alleged priority, as I demonstrate in the next sections.

For now, I would like to elaborate on the role of the listener/reader of the patient's account—the clinician in the medical context. I have compared the perspectives that I hold consistent with the scope of this discussion and representative of different and critical stances on the idea of authoring and readership, and of the limits and potential of both roles.

In her writing on “Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust” (2001), through one of her several references to literary works, Charon argues how teller and listener, writer and reader, physician and patient co-work in the meaningful construction of the illness story. She specifically recalls that in 1886 Henry James had already commented on the possible challenges posed by George Eliot's novels to her readers. James's words on Eliot's work “the reader does quite half the labour” (in Charon, 2001, p. 1898) are indicative of the interpretive work in which the reader finds himself involved, and actively engaged with the moral and intellectual issues raised by Eliot's characters and plots. Eco wrote something very similar in his “Sei passeggiate nei boschi narrativi” (1994):

ogni finzione narrativa [...] accenna, e per il resto chiede al lettore di collaborare colmando una serie di spazi vuoti. Del resto, come ho già scritto, ogni testo è una macchina pigra che chiede al lettore di fare parte del proprio lavoro. (p. 3)

The links with these literary works hint at the physician's effort to *absorb* the patients' stories and enter their world, not just passively receiving them.

Both Montgomery (1991) and Charon (2001) suggest a parallelism between the concept of literary authorhood in reader-response theories of the late 20th century and clinical authorhood,

meant as the doctor's task and responsibility of interpreting patients' stories. From a Structuralist perspective, authors cannot control all the potential meanings of their texts, and it is the reader who actively decodes the message, and construes those meanings through clues (Barthes, 1970).

Also in medicine, when doctors take medical history, they partially turn into ethnographers, biographers, sociologists, historians and so on, drawing on other specific research fields and orientations depending on the social, temporal, psychological and other aspects on which they focus when approaching the patient.

But I highlight that in this view all of these approaches are intertwined to different extents with narrative research, production and interpretation, as for each particular kind of interest, from enquiring about the environment in which the patient works to considering their daily food habits or psychological balance, information is elicited, a short or long story is told and sense, is made out of it. Moreover, whatever the reader's stance toward the text/patient, could alter the meaning.

The point is that story interpretation and restructuring create a "metastory of the illness from the events of the patient's narrative and the observation of physical signs" (Montgomery, 1991, p. 13).

As Balint (1969) used to say about his psychiatric training, the physician and the patient are *co-authors* of a single story, although Montgomery (1991) holds a slightly different view, highlighting that the patient's and the physician's stories are not the same, and one illness can correspond to two different stories with meaningful peculiarities.

First of all, among these peculiarities is language and all its implications: the fact that the biomedical scientist model of medicine has also pervaded the *folk* health beliefs leads to a linguistic hybridisation of two linguistic varieties originally different from each other.

It is also true that technical terms are indicative of knowledge asymmetry and reduce the control of patients on communication. I have also discussed in the previous chapter the concepts of concordance, active involvement in health-related decisions, and promotion of plain language:

these, alongside the popularisation of medical sciences, which make technical information available to larger masses of population, contribute to patients' empowerment in therapeutic relationships.

Yet, I shared Pilnick's findings on how, on the one hand patients, reject paternalism, and on the other they feel uncomfortable, unsatisfied, and abandoned if clinicians give up their epistemic authority and limit their role to purely explanatory communication on the state of the disease and the available treatment options. The introduction and assimilation of technical terms into everyday non-medical language, as noticed by Montgomery (1991), reflects a tendency to level up the patient's and the doctor's story by reducing the linguistic differences between the two, and, subsequently, the content, and the gist of each story:

The creation of the second, medical, story is the immediate goal of the patient-physician encounter. Yet the importance to medicine—and to the patient—of this reinterpretation cannot alter the priority of the patient's experience. Nor should the fact that ordinary people use medical terms to describe themselves obscure our perception that it is the patients (or, properly, the people who become sick) who are the authors of themselves as the primary texts in medicine. [...] The patient's account of illness remains the fundamental fact in clinical medicine. (p. 14)

It is as if the patient's story, now narratable through the newly gained knowledge of medical technical language lost its identity and the meanings that it used to carry. Flattening the differences at the epistemic as well as linguistic level can therefore have its drawbacks and diminishes the specificity of the patient's story as the original one, compared to which the doctor's story is a derivative one (Montgomery, 1991): "It is interpretive work that the physician is doing, not original composition" (p. 12). Bert (2007) upholds the argument of the necessity to preserve the identity of the doctor's and the patient's code when he specifies that:

Si tratta in effetti di due codici differenti; avviene talora che il medico cerchi di avvicinarli sforzandosi di parlare il linguaggio del paziente; più spesso è il malato che cerca di apprendere almeno i rudimenti del codice medico, nella speranza di essere ascoltato e capito

meglio. L'esperienza insegna che ciò non avviene: un codice ha le sue regole e un codice alterato e deformato non rende di certo il testo più comprensibile e provoca inoltre malintesi o gag involontarie.

Il metacodice è appunto la narrazione, il racconto, che permette di descrivere non il fatto ma l'esperienza del fatto.¹⁸ (p. 18)

Linguistic and coding issues do exist, recognises Bert, but this is the stage at which narratives can bridge gaps, allowing patients and doctors to not merely describe data and events but to interpret how the teller and the listener *experience* what happens *to* and *around* themselves.

Differences that give the patient's story and the clinician's interpretation two independent identities cannot be ignored or altered, but narrative can create a common ground of meaning negotiation, and understanding, as Bert still underlines (2007): "Sa, dottore, sembra che stiamo scrivendo due storie diverse, quella che io vivo e quella che lei pensa. Qualche volta si avvicinano, però restano separate. Le sono comunque grata per questo suo sforzo di capire¹⁹" (p. 17).

In conclusion, I highlighted that Montgomery claims the priority of the patient's verbal account over the physical signs in medicine: the story told is the primary narrative source on which clinicians need to build their clinical reasoning and judgement.

It is important that the stories of patients and clinicians cross each other in the search for the meaning of uncertain facts, as I included in the discussion. Also, reasons identified by different researchers can legitimate the distinction of narrative and interpretive viewpoints.

¹⁸ These are, in fact, two different codes; sometimes the doctor tries to bridge the gap by making an effort to speak the patient's language; more often, it is the patient who tries to learn at least the basics of medical code, in the hope of being listened to and better understood. Experience shows that this does not happen: a code has its own rules, and an altered and distorted code certainly does not make the text more understandable and also causes misunderstandings or unintentional gags. The metacode is precisely the narrative, the story, which allows us to describe not the fact but the experience of the fact.

¹⁹ You know, Doctor, it seems like we're writing two different stories, the one I'm living and the one you're thinking. Sometimes they come close, but they remain separate. I'm grateful to you for your effort to understand, though.

Balint, Charon (2001), Bert (2007) and Montgomery (1991; 2005) agree on the fact that narratives constitute the common ground on which communicative and epistemic gaps can be bridged.

Through communicative gaps I refer to the different language codes used by the participants, and by epistemic gaps I mean, broadly speaking, the different fields in which the patient and the clinician are knowers, each one in their own way. A patient knows more than anyone else what they feel and how they feel, and reports their *lived individual* experience: as Montgomery says (1991), medicine is “a science of individuals” (p. 27) (with the limited meaning of the word “science” that Montgomery maintains). The doctor, on the other hand, draws upon the technical knowledge and expertise that make him or her a doctor. Both of them are knowers in different respects and none of their contributions to the healing process can be transcended.

The Narrative Features of Medicine

So far, Montgomery’s arguments have proved the connection between stories and clinical practice, the physicians and patients’ natural attitude to understanding what is going on through a narrative explanation and organisation of data – meant in a broad sense, as words and physical signs.

But the scholar further underpins this idea showing the narrative—literary in particular—*roots* of medicine. If the use of figurative language (the metaphor of body as a text) may have already suggested this kinship, Montgomery proves the link between the development of the medical case and that of the detective story. The most representative example is the character of Sherlock Holmes, created by the physician Arthur Conan Doyle, in turn inspired by the lectures of Dr Joe Bell, a legend for his acuteness in clinical reasoning and deduction. I requote here Lidia’s story from Bert’s excerpt, particularly the verb “riconoscere” in the sentence “Riconosce di essere un soggetto emotivo” (“She acknowledges that she is an emotional person”), which exemplifies how verbs such as to “acknowledge, admit, confess” relate to a crime investigation but are also used

in medical communication. Like the verb “riferire” marked the distance between the doctor and the patient’s account, these connotative verbs convey a more investigative search for truth and causes.

Attention to details, open-mindedness, generating hypotheses on the sequence and causality of events, looking for further evidence, confirming hypotheses, analysing facts, piecing them together, would be typical features of both detectives’ and physicians’ investigations, reminds Montgomery (1991).

Another important skill used in both professions is the record of previous or similar crime/medical stories that become comparison terms or “templates” based on which new cases can be examined.

Next to retrospection, meant as looking back at past events, identifying what in a given moment may have triggered a reaction, and the last but not least common element in detective stories and medicine is interpretation, the construction of meaning through stories.

The interpretive nature of medicine is a view so firmly held by Montgomery that she does not indulge in the long debate on medicine as science or art, or both of them, she simply and directly asserts that (1991): “*Medicine is not a science*. Instead, it is a rational, *science-using*, interlevel, interpretive activity undertaken for the care of a sick person” (p. 25, emphasis added).

In other words, clinical practice is imbued with stories and interpretations of these stories. The daring statement “Medicine is not a science”, but a “science-using” activity, thus confirms the relationship between medicine and uncertainty, despite the claims of the biomedical model and the unlimited trust in evidence.

While Montgomery analysed the narrative structure of medical knowledge, practice and transmission, in contrast, present the narrative features of medicine from Charon’s perspective (2006) based on her book *Narrative medicine: Honoring the Stories of Illness*.

The first one, temporality, concerns the different perceptions of time by clinicians and patients. For the former, entering a hospital room to carry out the physical examination, or to medicate, are actions clearly planned, related to specific moments and following a temporal and

causal order, whereas for the latter, time is endless or suspended, or even imbued with a synchronic perception of reality, as if past present and future are overlapped with and revolving around the onset of the illness, in a petrifying moment. This relates to the threat to the sense of past and future identified by Cassel in his view of suffering (Chapter 2). Also, during the medical interviews, especially in the history-taking process, doctors tend to quantify the temporal dimension of the pain experience and to spot specific moments or duration ranges (when did it start exactly? how long was it?), whereas the patient tends to connect the onset of symptoms to an experience, to something they were performing when they started to feel something unpleasant, or to the people they were with. Illness alters the usual chronological setting in which we frame events, as in Frank's chaos narratives, presented in the next section.

Singularity and intersubjectivity are two other narrative features of clinical practice. The same symptoms that Lidia reported (Chapter 2) to her doctor could be recounted by another patient with the same health issue in a completely different way, with more or less words—but most importantly with different words—different references to one's daily life and how this has changed, with priorities and expectations that differ from Lidia's ones. Lidia may want to regain a balance through psychological consultation over time, but someone else may request as soon as possible a timely therapy that allows him or her to keep performing at work for financial reasons or professional achievement. Every story is as different as its narrator, and its listener or reader, and recognising uniqueness in a field that tends to use classification and generalisation is not to be taken for granted.

Intersubjectivity refers to the *transformative* process enabled by telling and reading or listening to a story, of how both the individuals sharing a story are entangled in such a way that they are changed by the story, and the original story has changed itself, has *breathed* in Frank's view (2010), as I show in the next section. Translated into medical practice, the way in which doctors and patients share stories can affect disease outcomes, diagnosis and treatment (Greenhalgh 1998; 1999).

I find intersubjectivity to be strictly related to the already discussed concept of authorship/readership and to the relationship that ensues between two subjects when they share a story, hence the relational function of stories that both Bert (2007) and Charon (2006) recognise, and on which I return in the next section and in chapter 4 with a specific reference to the endometriosis case. The following excerpt by Charon (2006) can exemplify my view of intersubjectivity as a consequence of readership and relationality:

Writing, or telling, gives a speaker the authority and the opportunity to reveal the self. [...]
 Reading, or listening, requires an equally perilous and daring ability to acknowledge another self, to open oneself to being penetrated by another. [...]

Within these acts of intimacy and trust arise notions of the erotics of text, championed by Roland Barthes [...] Two strangers, the reader and the writer, ultimately surrender themselves into one another's hands. [...] *The relationships that develop in medicine, as it turns out, bear an uncanny resemblance to the relationships between tellers and listeners in general* [...] *What literary studies give medicine is the realization that our intimate medical relationships occur in words.* Our intimacy with patients is based predominantly on listening to what they tell us, and our trustworthiness toward them is demonstrated in the seriousness and duty with which we listen to what they entrust to us. Yes, doctors touch patients and do rather extraordinary physical things to them, but *the textuality and not the physicality defines the relation.* [...] In fact, we are misled when we try to conceptualize *medical relationships* as if they were based on love, desire, power, or commerce. They *are based on the complex texts that are shared between doctor and patient* [...]. (p 53-54)

I decided to quote this long but emblematic passage because it clarifies why literature and texts find so much room in Charon and in the mainly American approach to NM, and why I covered the topic of authorship more than once. The recursive reference to novels and literary critics in Charon do not only stem from her academic background or personal interest in the subject, but is motivated by solid arguments, like parallelism.

Ethicality consists in the power of stories to orient the reader toward ethical decisions, concerning what to do or how to judge the actions of others, by displaying fictional characters, events, taking critical decisions, behaviours, and doubts. In clinical practice, ethicality is a routine narrative feature, since any medical interaction in the illness experience entails making decisions that could benefit the patient. In this respect, clinicians take on a remarkable responsibility, from discussing the options to interrupt therapy to recognising the limits of their epistemic authority and their advice while respecting the patient's preferences, just to mention some of the many examples: ethics is a meaningful field in this respect.

Before moving to the next and last of Charon's narrative features, I would like to suggest another property of stories that applies to medicine, and although not formally recognised among the five traits presented here, plays a special and constant role: healing. This word should be interpreted with a critical attitude and in a broader sense. I do *not* imply that stories can make disease magically disappear, but they can channel suffering and fear into words. As Han (2024) observes, telling stories has a therapeutic effect in critical situations. The act of narrating can place adverse events in the past through a symbolic temporal shift reducing the burden of distress on the present. He refers to, among others, two major personalities to substantiate this view: Sigmund Freud and Walter Benjamin.

In Freud's thinking, suffering can be rooted in a blockage in one's life story: the person is no longer able to continue their story, and psychotherapy aims at freeing the patient from this standstill; also Cardinal (1984) synthesizes the whole therapeutic process in finding "the words to say it" (from the original book title *Les mots pour le dire*, 1975). In Benjamin's view (1932), fairy tales paradigmatically feature plots in which a crisis is happily overcome, and the ritual of telling a story to children when they fall ill helps them to face the hardship of illness.

Causality, the last of the five narrative features, is the very gist of narratives, says Charon (2006), since we narrate things in order to find reasons, to explain to ourselves and to others, what is unknown, uncertain, including the outcome of a disease and how it will impact one's life.

Causality is discussed in greater detail in the following section, since it closely relates to the notion of meaning in my view. What we learn stories is not why one event has caused another one, but, more deeply, by asking the existential question, “Why did this happen to me?”.

Which meaning?

Returning one more time to Lidia’s story (Bert, 2007), the closing question of the story²⁰ is “Why?”, which, from a medical point of view, could call for an explanation of the ineffective therapeutic dosage, but Lidia’s real, unsaid question is: “Why me?”. This is the meaning looked for, the existential dimension of pain-related suffering and the core of uncertainty, the absence of a logically coherent and soothing understanding of the contingent situation of illness. Once again, narratives can help to answer questions similar to Lidia’s.

To give a better understanding of how this goal can be achieved, I summarize here the highlights of the research contributions that I analysed so far on this topic: Montgomery (1991) and Bert (2007) agree on the idea of uncertainty that underlies medicine and illness. The former argues that medicine is inherently narrative because stories are the foundation and structure of medical knowledge, education and clinical practice (from patients’ accounts to case presentations, to diagnostics, to medical charts). From Bert’s (2007) perspective, the link between stories and medicine lies in their therapeutic relationship: while a technician is expected to repair a broken or ill-functioning device, the clinician is called to heal somebody who is more than the sum of their parts, and who might not resume *functioning* as before. Telling, more than informing, someone about a change they are going through requires a relationship, and there is no such requirement between a technician and an object to be repaired. The involvement of two communicating individuals creates a relationship, hence an exchange of narratives, as a form of reciprocal knowledge and understanding. Charon confirms this view by saying (2006): “Like medicine, narrative situations always join one human being with another, and, indeed, one can argue that the

²⁰ I recall here the end of Lidia’s story: “Now I take one 75 mg tablet of X, one 20 mg tablet of Y, and one 0.1 mg tablet of Z in the evening, and the seizures haven't completely gone away! Why?”

joining of one human being with another always requires narrative acts of one kind or another” (p. 52).

The different focuses, which I call the relational and the structural, converge in this question: “How else can the individual be known?” (Montgomery, 1991, xviii). How else if not narratively, she implies. Sacks, furtherly develops this idea by highlighting the unicity of stories (1998):

If we wish to know about a man, we ask ‘what is his story—his real, inmost story?’—for each of us it’s a biography, a story. Each of us is a singular narrative, which is constructed, continually, unconsciously, by, through, and in us—through our perceptions, our feelings, our thoughts, our actions; and, not least, our discourse, our spoken narrations. Biologically, physiologically, we are not so different from each other; historically, as narratives—we are each of us unique. (p.110-111)

Also, from Sacks’ viewpoint, the narrative serves as a tool of search and interpretation of our and others’ identities, and also for understanding the meanings of our and others’ experiences.

So far, I have often mentioned the concept of meaning in the context of search and interpretations that patients and clinicians undertake, but I have not actually defined what kind of meaning it is.

I would like to do it now through a reference to Kleinman’s idea of illness, so that I can also complete the triad of semantic differences that we overlook in the all-encompassing noun of “malattia” in Italian, or “Krankheit” in German, but we necessarily imply (especially in the English language) when we refer to a condition of non-wellbeing.

By illness, Kleinman (1988) means the *innately* human experience of *symptoms and suffering* and more specifically, “how individuals experience illness, live with and react to symptoms and disability in the context of their family or social network” (p. 2).

It is quite eye-catching how, for Kleinman, illness is a *human* experience, something that belongs to human existence *innately*, as much as other conditions, such as health, birth or death do.

Moreover, this experience includes symptoms and suffering, recalling Cassel's comprehensive idea of suffering discussed in Chapter 2, and lastly, it does not take place in a vacuum, but in a given society.

Greenhalgh, (2013) defines "illnesses as the lived experiences and *symbolic meanings* of sickness, healing, coping and dying" (p. 25) and recognizes that they arouse uncertainty since they unfold in nor fully predictable nor controllable ways [...].

The meaning of illness lies in its consequences for the individual, on their everyday life at home or at work, including, for example, giving time to managing symptoms, and in significance, that is, with the array of connotations and imagery associated with how individuals regard themselves, and how they think others view them (Greenalgh, 2013). Kleinman's and Greenhalgh's analysis is the source to which I refer when I use the word "meaning" in this thesis, a concept that points to the experience, life attitude and reaction to the process of falling ill, not only from a subjective perspective, in terms of a private condition, but within a social context.

Since the word "experience" occurs in both authors quoted, it must be clarified that, as in Kleinman and Seeman (2000), it describes "the intersubjective, felt flow of events, bodily processes, and life trajectory, which always takes place within a social context" (p. 34). This definition recognises the link between the personal, the cultural, and the social aspects of experience.

The following analysis investigates the narrative search for meaning when falling ill as a way to reduce uncertainty. Why and how can stories reduce uncertainty in illness?

Bruner (1987 and 1991) claimed that narratives are crucial to the meaning-making process and inherently connected with the process of shaping human thought, knowledge and reality. Regardless of the cultural or professional context in which stories take place, they create continuity and unity in humankind, as everyone is always "in the process of making narratives" (in Charon, 2002: 4). White and Epston, representing that form of health care known as Narrative Therapy, and upon which Charon herself declares to draw, also write that meaning, "is derived through the

structuring of experience into stories, and [...] the performance of these stories is constitutive of lives and relationships” (1990, p. 27, as cited in Charon 2006, p. 198). As Frank (2010) noted, according to the most commonsensical understanding, life experiences would precede stories; they are the living material on which stories draw upon and against which stories imitate reality.

But it has also been argued that stories shape our perception of reality, a point supported by anthropologists such as Mattingly (1998), for whom lived experiences are an “enactment of pre-given stories”, in that stories inspire, induce and conduce the set of human action, and so “There is no reality without narrative” (p. 33). For Rosaldo, (as cited in Frank, 2010) “stories often shape, rather than simply reflect, human conduct” (p. 22). Questioning the mimetic function of stories and reversing the order events-experiences-stories, noted Frank (2010), are the core assumptions of socio-narratology. In the medical field, this has important consequences: given the pervasive presence of stories in our individual and social life, the way in which we experience illness is influenced by narratives (Greenhalg & Hurwitz, 1999): “Episodes of sickness are important milestones in the enacted narratives of patients' lives. Thus, not only do we live by narrative but, [...] we fall ill, get better, get worse, stay the same, and finally die by narrative too” (p. 48).

Illness can have a disruptive effect on the ability to make sense of human events (an ability usually taken for granted in everyday life) in that it alters the patient's system of cognitive, emotional, relational and social meanings (Bert, 2007). Bury (1991) uses the vivid expression of “biographical disruption” (p. 453) to describe the effect of the onset of chronic illness, which can be perceived as an attack on the person's physical self, identity, and self-worth (Charmaz, 1983), giving rise to uncertainty.

As Bruner states in an interview with Rita Charon (Charon & Montello, 2002), human beings try to order and selectively manage the complexity of reality by telling each other what is expected to happen according to a canonical pattern, but they are constantly caught off guard by unplanned events, or what Aristotle defines “peripeteia”, things that happen suddenly and differently than expected, such as, for instance, changes, breakings, illness and death. In reaction to

the unexpected dimension of life, according to Bruner, humans attempt to restore legitimacy by rebuilding stories with “stylistic integrity”, in a way that reconciles the disruptive surprises with the regularity that used to mark their lifetime before the sudden turn. Also, Charon argues (2006):

The sick person needs to continue to be, somehow, the self he or she was before illness struck. For the sick patient to accept the care of well strangers, those strangers have to form a link, a passage between the sick and the healthy who tender care (p. 21).

Bruner’s reference to style as the determining factor in creating consistency between expected and unexpected, patterns and exceptions, has also been addressed interestingly from a sociological perspective. In Bury (1991), the term “style” defines “the way people respond to, and present important features of their illnesses or treatment regimens” (p. 462) but, though in this respect it is closely relatable to terms such as strategies, or coping (strategies), which focus on action, “style” foregrounds the “variations in symbolic meanings, and social practice” (p. 462).

Based especially on Radley’s studies of chronic heart diseases (1989), the so called "active-denial" style, for instance, features an “increased engagement in everyday activities” (p. 242) which I hold can be interpreted as a reaction to counteract the break brought about by illness, to restore, continue and even enhance symbolically and actively the narratives of the usual life led before getting sick (how things used to be and were expected to be). In this respect, style as a sociological response to illness, and style as a feature of verbal stories to cope with the “peripeteia” discussed by Bruner serve the same need.

To better explain what he means by “stylistic integrity”, Bruner refers to a situation representative of the attitude one may adopt in recovering from illness.

He refers to his personal experience with some kids seriously injured in car accidents and to how they were motivated to do recovery exercises in specific classes: the tasks they had to complete were presented by therapists in terms of games, as bear chasing or imaginatively rowing through a channel.

Setting medical instructions and treatment (whether pharmacological or requiring a change in habits and lifestyle) in a narrative that reflects the patient's biography and context creates a connection, in this case related to childhood and playing, for instance.

As Bury notices (1991), following Williams's (1984) studies on rheumatoid arthritis, the "explanatory coverage" (p. 455), that is the explanations doctors give their patients based on their medical knowledge of a given disease, is relevant to patients for symptoms management but is not perceived as satisfactory if not supported by "narrative reconstructions", that is by stories in which information is framed and intertwined in the patient's more "meaningful biographical context" (p. 455). The following story exemplifies the difference between the explanatory and narrative approach (Greenhalgh, 2013).

Aisha, a 63-year-old British Afghan woman with a painful hip. She has come to tell me about her experiences in the orthopaedic department. She has had X-rays, blood tests and scans. A firm diagnosis of advanced osteoarthritis has apparently been made. Aisha has been advised to have a total hip replacement as soon as possible. She asks me what I think. She is an educated woman and fluent in English, but she politely rejects my offer of a leaflet and video giving the facts about total hip replacement. It's not the details of the operation she is interested in but its relevance to her own situation. I ask what issues are uppermost in her mind. She explains how much she hates hospitals, how her case was dealt with solely by a doctor in training rather than the renowned consultant hip surgeon to whom I had referred her and how her children (who work in medically related professions) feel that she should have the operation. She has been on the Internet and found out that the small dose of diclofenac which she takes at night is 'bad for you', but the other painkillers we have tried are less effective. (p. 24)

Aisha is not interested in explanations on the risks of surgery, on the statistics that can potentially answer her questions and doubts and reassure her. She wants direct feedback from her clinician, not from the anonymous leaflet, as she wants to be seen through, to be recognised as a

subject with her own priorities (enduring reasonable pain over the hospital: how could the leaflet see this?).

Through the conversation with the doctor, she also needs to listen to (herself telling) a story that connects with her life (Bruner's stylistic integrity), with her fears of being hospitalised, with her children's advice that makes her decision hard. In this context, paying attention and trying to interpret the patient's behaviour to identify its possible meanings, and subsequently asking them what they are worried about, instead of providing data and sketching the expected course of the disease, exemplifies the point of another tenet of in NM, that is, "close reading" (Charon, 2006, p. 113), or in this case, close *listening*. The choice, the detail of ignoring the leaflet, and more effectively, the doctor's sensitivity to this detail, have changed the development of the consultation and of the medical judgment. Again, as Charon (2006) says, "Like narrative acts, clinical practice requires the engagement of one person with another person and realizes that authentic engagement is transformative for all participants" (p. 11).

The theme of the meaning of illness requires a reference to Frank and his book *The Wounded Story Teller: Body, Illness, and Ethics* (1995). The search for meaning can result in restitution stories, in which after a long suffering comparable to a hard fight, health is restored as a victory; chaos stories, which do not feature the narrative property of temporality, and as such are considered anti-narratives: they are characterised by disorder and by an experience that is not possible to talk about. This applies to Lidia's story, in which events are not in a chronological order, even though it is a written narrative and the writer has more time to arrange information according to a causality and logical criteria. Another story that can ensue from illness is that of a quest, comparable to a long journey with a departure, marked by suffering, and a return to health restoration. Along the journey, the teller learns something that changes them, and the illness experience will leave a long-term mark on their life.

Narrative Medicines

Columbia's Approach. Now that a theoretical background to understand the relationship between stories, medicine and uncertainty has been provided, I finally introduce Dr. Rita Charon's major contribution to Narrative Medicine (NM). My use of the word "contribution" is due to the following reasons: the American physician and literary scholar is among the first names with which NM is associated, and even though she is identified with the founder of NM, and I acknowledge the objective originality and scope of Charon's work. Yet, it is also true that many of the topics that inspire her are works have already been covered in fields from outside medicine, including narratology, literary theory, (both recognisable in Charon's narrative features of medicine and in the concept of close reading); continental philosophy (European and American thinkers, among others, are frequently cited in her 2006 book *Narrative Medicine: Honoring the Stories of Illness*),. This shows that medical interest in the study of narratives goes back a long way, as Launer & Wohlman (2023) and Marini (2016) observe: the field of NM had already emerged in the late 20th century with other foundational texts such as *The Wounded Story Teller: Body, Illness, and Ethics* (1995) by Arthur Frank, a sociologist who directly experienced cancer, and *Narrative-Based Medicine: Dialogue and Discourse in Clinical Practice* (1998), which collects essays edited by two British academic general practitioners, Trisha Greenhalgh and Brian Hurwitz.

Under this premise, in my analysis, I highlight the following aspects of Charon's research method that I hold deserving recognition: providing a solid theoretical framework to NM, adopting a systematic approach to illness stories, and renewing the state-of-the-art *aware* use of narrative in healthcare. Deep knowledge of literary works and their critical interpretation informs all of Charon's activity that has already emerged in the previous sections, with particular reference to the role of the doctor/reader/listener and to the narrative features of medicine. Specifically, I have highlighted how, among these features, intersubjectivity stands out as the original interpretation of the doctor-patient relationship in terms of textuality. The parallelism between the writer-reader connection typical of literary studies and the doctor-patient connection in the medical field foregrounds the power and limits of words, and those of their users, in a context where delicate

matters such as illness and health, life and death are involved. Although the interactions between sender and receiver inform every form of communication, such as, the literary perspective, usually relating to written language, it sheds new light on interactions that are usually spoken. Connected to this reason is also Charon's literary education, which provides a background for the rootedness of her approach in writing, and differs in this respect from Launer's approach (2018), for example.

As for the first points of my discussion (the theoretical level), Charon (2012) defined NM as a "method of fortifying the capacity of the physician to reach, understand, and ally with the patient in care" (p. 3). This definition can be easily understood through the three fundamental principles of NM that Charon (2006) puts forward, the so-called triad of "attention, representation, and affiliation" (p. 140).

Attention describes the attitude that doctors adopt toward the patient from the beginning of medical consultation and corresponds to the action of *reaching* them, in Charon's definitive words (2012). It requires open-mindedness, willingness to leave our expectations and possible prejudices aside and focus on what the patient wants to share with us and how they want to do it. Agreeing with Launer & Wohlman's interpretation (2023) of Charon's approach, the practical version of attention is close listening to or close reading of (given the preference for writing in Charon's approach) patients' stories: it is about paying attention to content and form, to the possible metaphors, and the pauses. Reading Lidia's story attentively, the diagnosis as Osler (1922) would say, lies already in the patient's words: her story is imbued with terms such as "anxiety, shaking, fear, feeling like dying, fright"; the narrative rhythm is compelling, the flow of details endless and growing, unstoppable, as unstoppable as her agitation, which she cannot explain to herself: the doctor writes on the clinical chart that she *recognises* she is emotional and he is likely to base any treatment option on this feature, rather than investigating other causes. In this respect narrative and its close listening, its interpretation, have a performative function: they determine the clinical judgement and the therapy: "the narrating of the patient's story is a therapeutically central act" (Charon, 2001, p. 1889).

In Charon's approach to NM, close reading (2006) is a systematic method applicable to the way patients' stories are listened to and read. Its name and importance is due to the New Criticism, a formalist movement in Anglo-American literary studies that spread to universities in England and the United States after the Second World War and counted T. S. Eliot among its representatives. New Criticism regarded "the literary work as a naturally occurring object, similar to the objects of scientific study" (Klages, 2012, p. 251) and argued its autonomy from factors such as history, psychology, or biography. Yet, this does not imply that there is just one mere literal objective meaning, warns Charon (2006), but that meanings are *inside* the text: New Critics pay "close attention to the text itself and all the *ambiguity, irony, paradox*, and 'tone' contained within the words themselves": (p. 113, emphasis added). In line with this view, Charon (2006) compares training for close reading of literary texts to that of medical students learning to read X-rays, to capture the various elements of the *visual* text, e.g. regularity of shapes, quality of the film etc. Hence, she develops a drill based on five aspects to consider when reading texts (patients' stories): "frame, form, time, plot, and desire" (2006, p. 114).

The frame is the set of information on who produced the story, when, and why. It represents the patient's social, professional and cultural context, as well as their emotions, ideas and expectations (Moja, 2000; Marinelli, 2022). The form includes features related to genre, structure, narrator, metaphors, allusion (intertextual references), diction (the linguistic register which clearly distinguishes, for example, a medical record from a parallel chart although these texts share common contents). As for the feature of time, the clinical temporal frame, based on chronology and duration of symptoms, differs from the time perception in patients, who relate time to the illness experience, lived as a sudden pause or as a chaotic moment (Frank, 1995), in which past is lost and future is uncertain. The plot does not only define what happens in the patient's life and its resolution, which is of course the main concern, (as Brooks argues in his emblematic work, titled *Reading for the plot*, 1984), but also how the patient arranges events in their narratives. Desire is a complex concept that refers to the reasons for which a story is enjoyable by both the reader and the

teller: as Charon (2006) puts it to her medical students: “What was satisfied in you by virtue of reading this text? What seems to be satisfied by the writing of it?” (p. 124). In Chapter 5 I exemplify this taxonomy by applying it to the case study on the stories of the EndoNar Project.

The third step in Charon’s triad, “representation”, it refers to how the patient’s experience is represented from the physician’s perspective. This usually happens in administrative and legal charts where, “perhaps the writers are not free to express their own realisations about what the patient endures” (Charon, 2006, p. 145). The parallel chart is a non-clinical document invented by Charon in 1993, as explained in this excerpt (2006):

In 1993 I invented a teaching tool I called the “Parallel Chart,” and I have been using it since. It is a very simple device. I tell my students, every day, you write in the hospital chart about each of your patients. You know exactly what to write there and the form in which to write it. You write about your patient’s current complaints, the results of the physical exam, laboratory findings, opinions of consultants, and the plan. If your patient dying of prostate cancer reminds you of your grandfather, who died of that disease last summer, and each time you go into the patient’s room, you weep for your grandfather, you cannot write that in the hospital chart. We will not let you. And yet it has to be written somewhere. You write it in the Parallel Chart. These are the only instructions the students get. (pp. 155-156)

Students at Columbia, wrote Charon in 2006, were asked to write at least once a week a Parallel Chart and to be prepared to read aloud to their classmates and a supervisor. From these writings diverse feelings and impressions emerge: deep attachment to patients, sense of helplessness and rage at disease’s unfairness, and memories triggered by hospital life.

This is the parallel chart of a medical student who attended to a patient waiting for a lung transplant. The student learned then that the patient had been taken off the list because of his age (Charon, 2006).

My mind began to wander as I put down the phone and started writing in the chart...I had just finished talking to Mr. Encarnacion's pulmonologist, Dr. M, about why Mr. Encarnacion recently had been taken off "the list" for a lung transplant and a new life. Dr. M had rather matter-of-factly informed me that the age "cut-off" for lung transplants was around 60, and that Mr. Encarnacion, being 65, became ineligible because his age boded poorly with respect to prognosis... Irrespective of the reason for taking Mr. Encarnacion off the list, what I was faced with was that he had been taken off of it, and was now left without the only known cure for his inexorably progressive disease. And as I had started writing my note, the word "cut-off" had stared up at me from the crisp white page below. A funny word, I thought; did Dr. M even realize the twisted pun within his own phrasing? To him—in fairness, to the rationalist—the cut-off was an austere, unprejudiced number that signified that the risks for transplant outweighed the benefits. But to me, the "cut-off" was a concept that conjured up the image of a vivid dream of falling off a rocky cliff...This "cut-off," little black letters with the trace of an ink smudge, signified to me the cutting off of a life. Due to the simplicity of one designated number, all Mr. Encarnacion's hopes for the last nine years were effectively now extinguished, and he was being left to die.

I couldn't help but think how Mr. Encarnacion had dealt with the news when he had first found out, and how I would deal with such news if I ever were on the receiving end. How in the world had he gotten to the point where he could tell me with a wry smile that barely crept out from behind his green oxygen mask, "I used to be strong like a bull. That will never again be possible."

Had he cried when he found out? Had he been strangely relieved that his wait in *uncertainty* was over? Or had he simply taken things in stride, knowing all along that hope was futile? At the time, I didn't have even the ability to guess. I figure now that I could have asked him—I could easily have mustered up the courage to get up and walk down the hall, past my own fears that made the hallway so uninviting, and over the threshold of his room... He

would have answered me calmly and I would have been crushed by visions of my own mortality and fleeting, fragile existence; I would have left the room an enlightened and broken student.

But I never went into his room; I finished my note and went to lunch because I just didn't have the strength to confront the inevitability of my own death— possibly, hopefully, many years ahead of me. At that moment, it was way too close; so close that I couldn't face Mr. Encarnacion's acceptance of his fate; it was just too eerie, much too unnatural, and very frightening. (pp. 166-167, emphasis added)

This parallel chart results from one only event about which nothing can be done, but the author rewrites an entire story, actually two stories, Mr. Encarnacion's one and his own story. Although a doctor and not a literary scholar, he uses metalinguistic functions, he reflects on the ambivalence of the verb cut-off, he quotes the patient's similis ("strong like a bull"), but most of all, his chart is full of questions: in other words, he puts his uncertainty into words. He retells the patient's story from his viewpoint and channels his uncertainty, his fears into a text, as he confirms in a later chart, when the student finally visited the patient, accompanied by Rita Charon (2006):

[...] I realized that my thoughts became [...] structured, and that what had previously simply been an expression of "not feeling right" was now able to be translated into *something more meaningful*. In other words, I attempted to transform feelings into organized themes. As a result of this I was able to find that what really made me feel uncomfortable about Mr. Encarnacion and his ordeal was the fact that *I found it difficult to confront my own weaknesses and mortality*. I do not think that I would have been able to discover this had I simply written down my thoughts and left them there without editing directed at *finding a meaning* within what I had written. Likewise, I certainly would not have been able to discover this had I simply spoken about the topic... I think that this *self-discovery* enabled me to improve upon how I dealt with... individual patients; becoming more comfortable with my own feelings enabled me to focus on the problems of the patient. For example,

when we broached the subject of death with Mr. Encarnacion, I was certain of how I felt about it and was able to concentrate my efforts on attempting to make Mr. Encarnacion feel better. (p. 168, emphasis added)

Also the words I marked as italics in this chart show the student's search for a meaning, the earlier unknown feelings that prevented him from facing the patient, and that now make him ready to assist that patient. The patient's stories often intertwine with the medical students' biographies. Doctors are narrators too, stories are a common ground between doctors and patients, who are not only healthcare providers and recipients of healthcare service, (or in the latter case, 'clients', to use the language of health insurance companies, a trend to which the modern healthcare system seems to bend to in many countries, (Costa et al., 2019). They are both humans searching for meaning: the student was also afraid of death and vulnerability before meeting the patient, but he did not realise it. Admitting common vulnerability is not a naïve, moralistic act, it may rather influence the way patients are attended to and doctors regard their profession.

It is hardly surprising that although this method aims at enabling future doctors to better grasp what patients endure in Charon's conception, students also report benefiting from the writing practice in terms of emotional wellbeing.

I connect the students' feedback with another skill that improves medical practice and awareness, which is self-reflection, as also Charon recognises (2001): [...] narrative medicine provides the means to understand the personal connections between patient and physician, *the meaning of medical practice for the individual physician*, physicians' collective profession of their ideals, and medicine's discourse with the society it serves (p. 1897, emphasis added).

Like Charon, Pellegrino argues that self-reflection allows doctors to have a better human and professional experience and to treat better their patients (1979b):

Medicine is whatever physicians do. [...] Many other physicians, however, cannot accept so unreflective a view. They refuse to spend their whole lives in an enterprise without trying to comprehend its nature [...] Whether conscious of it or not, every physician necessarily has

an answer to what he thinks medicine is— *with real consequences for all whom he attends*.

(p. 43, emphasis added)

I highlight that the originality of Charon's method lies in its institutionalisation, and the fact that it has become a systematic part of medical training: clinicians can become better observers of the patient's wholeness, write about patients by using their own imagery and expressive means, and treat them accordingly. Charon introduced and developed NM in mandatory courses within the medical curriculum at Columbia University (USA), thereby turning it from a pioneering pilot project into a world-renowned practice that spans the whole professional life of clinicians, from specific training sessions during residency and internships to everyday hospital routines.

“Affiliation”, the last step of this triad is the process of engaging with the patient in light of this new representation, and of sharing the reshaped care experience with colleagues or other listeners. The parallel chart writers read aloud their texts to colleagues, or caregivers, patients' associations etc..., they share their stories, now become polyphonic, and they go back to their hospital routine and to their patients (affiliation): the young student is finally able to face Mr. Encarnacion and to reconnect with him, having a different self-awareness.

The triad of attention, representation, and affiliation accounts for that specific requirement of NM called “narrative competence” [...] meant as the ability to “absorb, interpret and respond to stories” (Charon, 2001, p. 1897). Narrative competence is strictly connected to the centrality of stories: in Charon's view, Narrative Medicine does not consist of a mere collection of illness stories, but of the narrative competence itself, that is, what to do with narratives and how to co-construct their meaning in order to cope with clinical and human uncertainty.

The British approach. In addition to Columbia's approach to NM, based on reflective writing about illness stories through parallel charts, John Launer, a British general practitioner and medical educator, offers another narrative approach to uncertainty in care termed “narrative-based practice or narrative practice” (Launer and Wohlman, 2023, p. 98). It aims to apply narrative ideas and skills not to writings but to clinical conversations: in these live encounters, time for text reception, (close

reading in Charon) retelling and self-reflection (Charon's parallel chart) differs from those of written texts. Training is by peer supervision and discussion, and is facilitated using Launer's approach, which is oriented towards oral communication and recognises the unpredictability of conversations, where participants are "intrinsically *uncertain* and open to multiple interpretations and outcomes" (Sommer & Launer 2013, p. 148, emphasis added). In training sessions and narrative practice, participants are invited to consider how to integrate evidence and clinical norms with close attention to the narrative. A supervisor and supervisee, with observers acting as a reflecting team, also take part in the session. This more applied approach shares with NM "the need to protect practitioners from burnout and the psychological risks to professionals of trying to "fix" everything" (Launer and Wohlman, 2023, p. 99).

This method is especially suggested for cases in which data are insufficient, uncertainty prevails, and multiple answers are possible, or a professional cannot make a decision because ethical issues are involved (e.g. continuing, changing or stopping the treatment, lack of concordance with therapies etc.).

I present here a story that involves three voices, all from the medical field (Launer, 2022). Actually, the fourth voice belongs to the patient but is represented just indirectly.

Recently I offered this kind of supervision to a young GP who felt stuck with a patient. He was seeing a woman with multiple symptoms that had eluded diagnosis or successful treatment. He was trying to help the patient see things in a different light—as the consequence of life experiences perhaps or in a way that might be tackled through her own strengths. Nothing he did or said seemed to make a difference. This is of course the familiar stuff of general practice. Although he wanted my advice, I couldn't think of anything he hadn't already tried [...] As it happens, there was someone else in the room: another experienced educator I've often worked with. So I turned to her and explained my dilemma. I wanted to persuade my young colleague to change, I told her, just as he wanted to do with

his patient. The other educator (you might call her my super-supervisor) listened and asked me some questions about my dilemma.

The young GP listened in to our conversation too. And then something budged. He started to talk in a different way. He explained that his patient had suffered a tragedy some years ago and that perhaps it was taking longer for her to come to terms with this than he expected.

Even though he found their consultations frustrating, the patient always expressed gratitude and said their meetings brought some relief. The conversation with me, but especially my conversation with my colleague, had freed something up. “It may take time,” he reflected.

(p. 379)

The story by John Launer is about a general practitioner (GP) who “gets stuck” when he feels that all of his interventions with one of his patients have failed, but he does not want to give up on her. He reports on the case to Launer, who, acting as this GP’s advisor, in turn gets stuck in his attempt to change the GP’s attitude and suggests him to let the patient go. The dilemma is also reported also to a third subject, Launer’s counsellor, whose voice is involved in this story-sharing and expresses some questions about the case.

The case offers insights into the transformative power of stories when facing uncertainty in clinical judgement. After listening to the conversation between Launer and his counsellor, the GP makes a decision. His patient just needs time to adapt to a new life setting due to a recent trauma and to respond to medical prescriptions.

I found this story very reflective of the choral dimension of story-sharing, of the plurality of viewpoints (Bakhtin, 1984) as a pre-requirement for negotiation and collective re-creation of meaning. In this case too, narrating is a performative act and results in a new medical decision.

I also want to draw attention to the fact that this polyphonic approach is overlooked in Evidence-based Medicine (EBM), (Greenhalgh, 2013), but the diversity of voices in NM entails a more circular movement, in which the different subjects involved go back repeatedly to the same event, symptom, or change, and each time with a new perspective, as if adding a new nuance to a

canvas or a piece to a puzzle: the NM path is to realise, accept and cope with uncertainty. To the doctor's eye, the patient's non-compliance represents the deviation from the regular development of medical encounters, an unexpected outcome of the well-established clinical practices he has already tried, unsuccessfully. After looking at the patient's story through the lens of his conversation partners, the doctor takes on a new viewpoint that allows him to add meaningful details to the patient's story and current conditions. The GP was certainly aware of what seemed to be a new piece of information (the trauma), but did not know how to connect it to the plot that ties him to the patient. The GP is able to recall new features of the patient's situation, in this case also connected to changes in her psycho-emotional state, and after listening to his advisors, changes his perspective and his future course of action.

The supervision practice involved more subjects, but it turned into a very intimate and introspective act, as it actually improved the GP's attitude to self-reflection, which, as Charon (2001) confirms, is a fundamental practice in medical routine: "It may be that the physician's most potent therapeutic instrument is the self [...] (p. 1897). By retelling the patient's story, the GP is actually also self-reflecting because while talking to his colleagues, he is talking/listening to himself. John Launer highlights the importance of the "inner speech", namely of talking to oneself in silence (Alderson-Day and Fernyhough 2015), an activity in which, according to Heavey & Hurlburt (2008), individuals spend one fourth of their conscious waking life doing. The authors highlight how inner voice works in terms of self-reflection and autobiographical reasoning. The GP retraces the steps of his consultations with the patient throughout time, what he might have done wrong, what he overlooked, what he could still do; reflection on others (on why the patient does not respond as expected, what she could do more of, or less of); memory (the GP can refresh his understanding of the issue when he remembers the patient's acknowledgments of his efforts); problem solving (the GP concludes that the best solution is doing nothing and letting her patient recover from whatever trauma she experienced).

Besides, as exemplified by Launer's story, narrative medicine considers uncertainty "in terms of the open-endedness of the story form and the creative space in which storytelling is performed" (Greenhalgh, 2013, p. 26). The example also shows the steps of a process in which the story breathes: this suggestive image coined by the sociologist Arthur Frank (2010) refers to the changes that occur in stories as they are told, as if they were animated and breathing, as living beings. This is made possible only through "listening to people's stories and carefully creating a space for them to evolve at their own pace" (Launer, 2022, p. 379), just like the GP lets his patient (and not his own) decision evolve at her own pace. In Launer's reported experience, the characters are the same along the GP's story, and yet they change: the patient seems to evolve from the reluctant and un-collaborative subject depicted in the initial presentation to a suffering woman trying to cope with her difficulties in the last comment, because the narrator changes his perspective while telling the story and listening to two more accounts of the same story. Stories are constantly in progress. Changes induced by story-sharing are detectable in the GP too: he moves from figuring out his possible failures with the patient and envisioning next possible strategies, to simply recognising both the reasons that legitimate the patient's attitude and his own efforts in trying to help her, to remembering her gratitude, and to finally resolving that all she needs is time to readjust. This self-awareness-raising process sets him free from the sense of inadequacy and uncertainty that stuck with him at the beginning, and it prevents him from making the "mirroring" mistake, that is, trying to mould the patient in his own image, so changing the patient and not himself.

The Italian approach. Staying in the theoretical framework illustrated so far, I also find it important to mention the approach to NM in the Italian scene. In 2015, ISS, the Italian institution in charge of healthcare management at the national level, issued official guidelines on NM:

Con il termine di Medicina Narrativa (mutuato dall'inglese Narrative Medicine) si intende una metodologia d'intervento clinico-assistenziale basata su una specifica competenza comunicativa. La narrazione è lo strumento fondamentale per acquisire, comprendere e

integrare i diversi punti di vista di quanti intervengono nella malattia e nel processo di cura.

Il fine è la costruzione condivisa di un percorso di cura personalizzato²¹. (p. 13)

As much as Charon did at educational level, the Consensus Conference clearly identifies NM as a method at institutional level, recognizing its status in the Italian healthcare system.

An original point in this definition is the involvement and active participation of the stakeholders in the illness and care experience, patient, doctor, and caregiver, three roles that I tried to take into account in the case study presented in the next chapter. Among Italian scholars and doctors actively engaged in definitions and explanations of the core tenets of NM, Marinelli (2022) deserves recognition for his dictionary on NM.

Spinsanti adds some details to the Consensus Conference definition and introduces his book *La medicina vestita di narrazione*²² (2016a) with an important distinction between medicine and care, clarifying that medicine is just a part of care. Medicine concerns us when we fall ill or want to prevent illness, while care encompasses the whole lifetime and includes also those fields of medicine based exclusively on the use of words like psychotherapy.

An interesting approach in Spinsanti (2015) is the metaphor of the tailor, which leads to the concept of “tailored medicine”:

Come un abito che esce dalla sartoria è diverso da uno a taglia unica, fornito dai grandi magazzini, così la medicina su misura tende a considerare nelle scelte il profilo singolare di ogni persona²³. (p. 59)

This comparison was very helpful to interpret the different reactions of the participants to the EndoNar project presented in the last chapter: the communicative form of medical consultation also depends on the patient’s expectations. If a patient aims simply at reducing a symptom and is

²¹ The term Narrative Medicine refers to a clinical care methodology based on specific communication skills. Narrative is the fundamental tool for acquiring, understanding and integrating the different points of view of those involved in the illness and the treatment process. The aim is the shared construction of a personalised treatment pathway.

²² I would suggest this translation to account for Spinsanti’s metaphor of the tailor-made medicine that will be explained in a few lines: “Dressing up Medicine with a Narrative Suit”.

²³ Just as a suit from a tailor is different from a one-size-fits-all suit from a department store, so tailored medicine tends to take into account the unique profile of each person when making choices.

not interested in a path from which the transformative effect of illness as experience emerges, he just expects a short medical interview and sees no value in the narrative process. If, on the contrary, a patient wants to find a meaning in what they are going through, then both the doctor and the patient will benefit from a comprehensive narrative approach: doctors may adjust their communicative style accordingly. The same applies to the view of illness and health of a doctor: time spent in communication with the patient depends on what the medical profession means for the clinician: cure or care?

Moreover, NM is not a special area of medicine, nor a discipline, but it can be considered as a mental attitude (Bert 2007). NM acts as a habit of mind, or a posture, as in Trenta's book *La postura narrativa. I modi di essere della cura* (2024), where "postura" (posture) refers generally to the position in which one holds their body when standing or sitting, but also to an attitude to life, to a situation or a problem and how to deal with it. In this understanding, NM would be a mind set more than or in addition to a methodology, as originally stated in the official guidelines (ISS, 2014).

According to the first official guidelines that were issued after the ISS Consensus Conference on Narrative Medicine in Italy (2015), time is not the determining factor in practising NM: although many clinicians complain about the pressure they are put under and the performance they are expected to deliver, extra time is not the key. An uncommunicative doctor is likely to waste energy and time by entering data based on information filtered and reduced by repeated interruptions and by prescribing drugs that patients will never take. Patients, in turn, are likely to consult one doctor after another after feeling not listened to enough; time is wasted just because communication does not work. On this subject, the mentioned guidelines refer to the difference the ancient Greeks made between "krònos" time and "kairòs" time: the idea of the quantity and quality of time spent in consultation (ISS, 2015, p. 6).

According to Palla et al. (2024), no study has been performed on NM teaching in Italian medical schools, although Italy boasts 28 studies on NM implementation in clinical practice. The first Italian NM project (NaMe) started in 2006 in Florence, followed, almost 10 years later, by the

issue of official guidelines on NM approved by the National Institute of Health (ISS). So, historically and interestingly, in Italy, the implementation of NM preceded its official integration in academic studies and its formal definition by healthcare institutions.

Italy boasts a national association concerned with NM (SIMEN - Italian Society for Narrative Medicine) and a European one (EUNAMES - European Society for Narrative Medicine), and has also successfully explored NM in digital environments (DNM - Society for Digital Narrative Medicine), with which I collaborated for the project presented in the last chapter. Marini's internationally renowned books on NM (2016, 2019) and Marinelli's first *dictionary* of NM (2022) are other foundational works in our country. Yet, according to a recent survey conducted by Miodottore Connect (2024), 97% of patients and 57% of physicians in Italy do not know what NM is.

While I highlighted the systematic introduction of NM in medical studies and hospital training in Colombia's approach, to the best of our knowledge, (Polvani et. al., 2014) Narrative Medicine courses are not always mandatory in the academic programs of Italian medical schools, so part of the lack of NM awareness in Italy could be due to the current medical education system. In this respect, the role of literature in medical students' attitude towards their future patients has been recognised by Spinsanti (2016b): "Non ci può essere contrapposizione tra il tempo dedicato ad affrontare i manuali di chimica, di fisica di statistica, e la rilettura di classici [...]" (p. 60)²⁴

Consistent with this message, in the framework of Italian medical education, Zannini (2008) suggests resources based on autobiographies to improve narrative competence in doctors, while Lippi (2010) collects different literary texts on the themes of vulnerability, suffering, illness and the view of body in an anthology designed as a training tool for professionals, educators, and anybody interested in or involved in healthcare. Lastly, another important clarification in the Italian guidelines concerns the relationship between Narrative-Based Medicine and Evidence-Based

²⁴ There can be no conflict between the time spent studying chemistry, physics and statistics textbooks and rereading the classics.

Medicine, covered in the next section. In the Italian context, these two approaches to uncertainty complete each other.

Uncertainty in Evidence-Based Medicine

Greenhalgh (2013) reviews literature on clinical uncertainty, selecting and delving into ideal, not exhaustive and in some cases overlapping approaches that she finds particularly relevant to front-line clinical work and clinical judgement. I discuss here two of them, Evidence-Based Medicine (EBM) and the Narrative-Based Medicine (NBM) approach.

Proponents of evidence-based decision-making, of which Sackett and colleagues are the most well-known representatives in the 1970s, objected to the idea - pursued for centuries - of basing doctors' competence on the observation of other doctors' decisions made in an unlimited number of variable cases. On the contrary, they claimed the need for a shift from a decision-making based on anecdote (Greenhalgh, 2013) to a more systematic approach to clinical judgement, based on best research evidence.

That accounts for the definition of Evidence-based Medicine as “the use of mathematical estimates of the risk of benefit and harm, derived from high-quality research on population samples, to inform clinical decision-making in the diagnosis, investigation or management of individual patients.” (Greenhalgh 2010: 1).

Actually, argues Greenhalgh, evidence-based medicine is deeply rooted in epidemiological studies. Identifying and studying samples of populations, epidemiological research allows clinicians to predict the possible development of a given disease in a given patient, to estimate benefits, harms and risks accurately, and to classify sets of symptoms and tests in guidelines and protocols that are functional to diagnosis and clinical decision-making (Reilly & Evans, 2006; Eddy, 2005).

In other words, according to the EBM approach, patients can be classified and treated according to their compliance with the diagnostic and therapeutic criteria, set in these protocols, while statistics and probabilities are expected to guide the medical judgment of their cases with a scientific, objective and rational approach.

Drawing on Sackett's article, "Evidence-Based Medicine what it is and what it is not" and on the helpful explicative dictionary Marini's included in her book *Narrative Medicine: Bridging the Gap between Evidence-Based Care and Medical Humanities* (2016), it is important to dispel suspicions on an opposition between EBM and NBM, and to clarify how Evidence-Based Medicine (EBM) integrates the use of current best evidence with clinical expertise in making decisions concerning individual patients. It strives for the accuracy, precision and effectiveness of diagnostic tests, without ignoring the individual patients' worries, rights, and preferences in making clinical decisions: "without clinical expertise, practice risks becoming tyrannized by evidence, and without current best evidence, practice risks becoming rapidly out of date, to the detriment of patients [...]" (Marini, 2016, p. 138).

David Sackett aimed at introducing standardisation into clinical research methodology, by reducing bias and auto-referral approaches in clinical judgement and at counteracting these through the best available evidence.

Some diagnostic tests and clinical prediction scores, Greenhalgh admits (*ibid.*), work effectively in reducing uncertainty. However, very few treatments show high benefits and few serious side effects at the same time, so the risk calculation is not always functional for decision-making concerning treatments. As Montgomery adds (1991): "As all clinicians know, it is a mistake to regard test results as invariably hard evidence, for the numbers they yield are not infallible. Each test has its estimated sensitivity and specificity [...]" (p. 9).

The EBM approach also implies that evidence collected in population samples can be linearly applied to the patient and that patients' values and expectations line up with diagnostic or treatment options available and relate to them in a static, quantifiable relationship (do not change over time).

As Bert (2007) noted, there is no inherently negative quality in statistics; on the contrary, percentages are actually an implicit recognition of the fact that science does not provide certainties, but only probabilities, about the course and prognosis of a disease, the effects of drugs, and the risks

of surgeries. Issues arise when the doctor deals with the individual patient, which requires a shift from data and large numbers to the specific subject (not body, but subject, as a whole), from disease as an abstract and probabilistic concept to illness, as personal meaning given to it in Kleinman's terms. This change is possible thanks to narratives, which allow doctors to know the set of meanings that constitutes the world of the other.

EBM tries to cope with uncertainty by reducing it through evidence derived from probability. NBM pursues the same goal by sharing (telling and listening to) stories and seeking (and sometimes not necessarily finding) meaning coherence both in the disease trajectory (from the medical point of view) and in the illness experience (from the patient's point of view), when possible.

Powers and limits of Narratives in Medicine

I have already highlighted and exemplified the role of stories in medicine, but while I delved so far mostly into the way tellers, writers, listeners or readers engage with them, and how transformative and performative narrativity can be, now the discussion will concern the issue of what an (illness) narrative or story is and to which extent it can be "trusted" (to mention Kreiswirth's work title "Trusting the Tale: The Narrativist Turn in the Human Sciences", (1992) as a knowledge- and health-improving tool.

In my research, I did not embrace the task of clarifying what an (illness) story is to find a definite answer – as this would not ever be possible. I tried to critically select and review the possible answers to the question, with a special focus on the research contributions on the so-called "narrative turn" (Kreiswirth, 2005, p. 377), and on those by narratology theorists such as Mieke Bael, by sociologists and philosophers, and of course by clinicians concerned with NM.

The attempt to define a story also calls into question another related critical issue: defining what a text is, since any story requires a text. For the scope of this analysis, I adopted Halliday's (1989) notion of text as any language unit serving a function.

On this topic, I also find it noteworthy to consider Launer's (2024) comment on the idea of "text" and the alternative use of "story" and "narrative" as interchangeable but potentially confusing terms for the same concept in NM.

To Launer, the word "story" sounds related to a fictional work, while "narrative" can recall length and literature, although "In fact, either term can potentially mean a statement as short as "I've got a bunion" or as long as a life story" (2024, p. 384) and the more substantial difference lies in the fact that the word "narrative" better conveys the meaning of a flow, and, other than "story", can be turned into an action, hence a process, a change (someone narrates something).

This idea links with the dynamic nature of story-sharing, i.e. with the point that stories change as they are told. Launer (2024) detects in the word "text" an implicit reference to stativeness, which I would relate to the fact that the stories Launer is used to dealing with in his NM approach are primarily oral and as such they do not always share features such as coherence, and cohesion. Yet, it may be argued, that lack of consistency in meaning, lack of connective ties at formal level and, broadly speaking chaos, as a distinctive feature of many illness narratives (Frank, 1995), can characterise written stories too (Dubliners by Joyce and many other examples ranging from literature to comic strips and diaries confirm this hypothesis).

Moving back to the aforementioned narrative turn, this expression refers to a shift in the latter part of the 20th century, when the study of narratives for their own sake emerged and assumed an independent status as a discipline, with two key changes in the way it had been previously conceived (Kreiwirth, 2005). The first is that this discipline doesn't focus only on the analysis of one or more particular narratives, but it investigates the concept of narrative itself and the requirements by which a text can be defined as a narrative. The second consequence is that scholars usually engaged in fields of research traditionally considered other than the humanities – natural sciences, medicine, management - started to shift their attention to narratives.

Under this premise, narratives seem to transcend disciplines and their boundaries, as they are a ubiquitous, pervasive activity. As Bal confirms (2017), a first reason for the recent interest in narratives “may simply be the omnipresence of narrative in culture, [...] practically everything in culture has a narrative aspect to it, or at least can be perceived, interpreted, as narrative”, (p. 20).

In her work *Introduction to Narratology* (2017) an updated version of her previous work *Narratologie* (1977), informed by structuralism and inspired by the artistic and interdisciplinary experience of its author, Mieke Bal suggests a multi-layered definition of a story, distinguishing between “fabula”, the set of elements such as actors, events, time and location and their logical relationship with each other; a “story” that is how these elements are arranged, how the “fabula” is presented, which may differ for example from the chrono-logical setting of the “fabula” (deploying flashbacks or anticipations, for instance); a text, the verbal representation of “fabula” and stories.

Actually, although these concepts roughly recall those theorized by Genette with a slightly different terminology (1988), I chose to include Bal’s research (2017) in this work because her theory of narratives encompasses a wide range of expressive forms, not only spoken or written stories, but also “images, spectacles, events” (p. 3). More precisely, Bal defines narrative texts as texts “in which an agent or subject conveys to an addressee (‘tells’ the reader, viewer, or listener) a story in a medium, such as language, imagery, sound, buildings, or a combination thereof” and as “finite, structured whole composed of language signs” that can be “linguistic units, such as words and sentences”, but also “cinematic shots and sequences, or painted dots, lines [...]” (2017, p. 5).

This broad understanding of narrative text is relatable to the multimodal dimension of narratives, according to which all texts always involve the interaction and integration of several semiotic modes (words, sounds, pictures etc..), and the meaning-making process in multimodal texts is the result of this interaction (Kress and van Leeuwen, 2001). On the other hand, this idea is also reflected in the data collected for the endometriosis case study, as I show in Chapter 5, as well as in the diversity of prompts (songs, pictures, poems) administered by facilitators of Columbia University in the NM virtual training sessions that I had the chance to join in the last two years. The

collected during the COVID-19 pandemic, in a clinical centre for dementia care. The stories were later shared with the residents.

Figure 12

Multimodality in Stories: Example 3

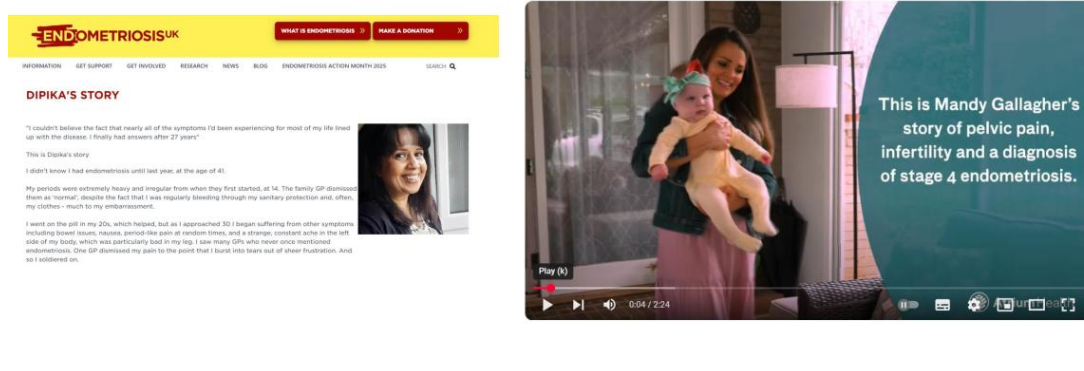


Figure 12 an example of a digital storytelling experience on women with endometriosis, in which visual, acoustic, and verbal signs are used.

Figure 13

Multimodality in Stories: Example 4



Live Virtual Group Session: 12PM EDT July 14th 2023

11 COMMENTS • JULY 14, 2023 • CNMCOLUMBIA

Thank you to everyone who joined us for this session!

For this session we took a close look/listen at [“Big God” by Florence and the Machine](#), posted below.

Our prompt was: *“Write about what happens when waiting.”*

Training in NM also makes use of multimodal texts. One of the prompts offered for self-reflection in the NM virtual training sessions by facilitators of Columbia University NM is a music video by Florence and the Machine (*Big God*, 2018), featuring visual (the scene), verbal (song lyrics), body language (dance) and sounds (the song).

Bal’s wide-ranging experience, not just as a theorist and literary critic but also as an artist and video maker, accounts for the special attention given to the multimodality in her work. Her definition is analytical and focused on the structure and levels of stories rather than on their essence. In fact, she clarifies to herself the relative importance of definitions, as “definitions are like a language: they provide something of a dictionary, so that one person understands what another means. But the definitions proposed [...] are provisional” (2017, p. 5).

Based on an equally cross-disciplinary background of literary and medical education, also Charon’s approach to a theoretical definition starts from the distinctive features she identifies in stories, namely “a teller, a listener, a time course, a plot, and a point” (2006, p. 3). On Bal’s same page, Frank overtly declares that he does not even try to define stories, as he aims at watching them

act, not “seeking their essence” (2010). As Ahlzén (2019) points out, there is no universally accepted definition of “narrative”, and several interpretations are possible.

It is clear, instead, that most of the research approaches agree on the fact that story and life profoundly influence each other in many respects.

Focusing on the extent to which narratives can support patients and doctors in facing uncertainty and suffering, Frank (1995) claims that narratives are a necessary reaction to illness and that the capacity to create a meaning-seeking story, a “quest story” on what happens to human beings when confronted with illness experiences, impacts the possibility of healing or living with that illness.

Strawson (2004) highlights the limits of conceiving narratives as a wide-reaching way of self-representing and giving meaning to one’s life, according to which “a richly Narrative outlook is essential to a well-lived life, to true or full personhood” (p. 428). To him, the thesis of stories informing every aspect of human life defended by the narrative turn implies a sort of continuity and diachrony that cannot be taken for granted or expected by anyone, and anyway, diachrony and narratives are not always relatable to a sense of unity, of rebuilding, or integrity. It must be acknowledged that Franks includes chaos among the possible narrative forms to represent illness and its temporal disruption, but as Woods (2013) notes, Strawson’s point is to question whether narrative should remain the only and privileged way of interpreting experience.

Woods (2011) suggests rethinking the debate on the role of narratives by overcoming the opposition between “narrativism” and “antinarrativism” in Health Humanities. To her, the interest in narratives arisen by the narrative turn, especially in healthcare, has shed light on aspects of human and illness experience which would have been overlooked in the traditional biomedical approach to care, but, in epistemological and ethical terms, it makes sense to “denaturalise narrative” (“Against Narrativity” section), to recognise that the way we relate to stories is representative of the Western medical discourse, as also argued by Schiff, (2006). If the search for significance is universal, narrativity is not universally shared, and different cultures will tell and

find meaningful different kinds of stories. Quoting the sociologist Hydén (1997), narratives are only “... one of several cultural forms available to us for conveying, expressing, or formulating our experience of illness and suffering” (p. 64).

The following short story can exemplify the discussed limits of narratives (Greenhalgh, 2013):

Faisal, a 24-year-old Iranian man who has booked a double appointment and attends with a professional interpreter. He thinks he has wax in his ears. I check them, confirm the wax and explain through the interpreter that he must put in drops and then see the nurse for syringing. As the interpreter gets up to leave, he hesitates and mumbles something. The interpreter explains that Faisal says he is depressed. On questioning, he has been depressed for 5 years. *He doesn't want to talk about the reasons.* A letter from the Medical Foundation for Care of Victims of Torture was scanned onto his electronic record 3 years ago, but I cannot open it because of a technical fault. *Faisal looks at the floor and makes no attempt to elaborate on his story despite sharp words from the interpreter* (‘I’ve told him to answer you, doctor’). I reflect on whether Faisal would be more forthcoming with a different interpreter or a different doctor. The interpreter appears uncomfortable with my apparent indecision and suggests I put him on Prozac. (p. 24)

In Faisal’s case, for example, forcing him to talk or applying a given procedure planned in protocols would be redundant, or would make him feel uncomfortable, or could even worsen the relationship with the doctor and push the patient to close up to him/her, which would make less information available and fewer elements on which to choose a treatment and make a decision. Along with Faisal’s tragic past and current depression, cultural differences cannot be ignored in the attitude toward verbal sharing.

On the topic of linguistic and cultural differences, I would like to add a quick reference to Natural Semantic Metalanguage, (NSM) which I had the chance to learn about during my course at ISTUD in 2023. This consists of a set of 65 universal core meanings, shared by all the languages of

the world (Goddard, 2009); using words that define universal concepts, communication would be made smoother and bias and misunderstandings reduced.

Figure 14

Semantic primes of natural semantic metalanguage (English exponents) (Goddard and Wierzbicka, 2014, as cited in Marini 2019, p. 19)

I, you, someone, something–thing, people, body	Substantives
Kind, part	Relational substantives
This, the same, other–else	Determiners
One, two, much–many, little–few, some, all	Quantifiers
Good, bad	Evaluators
Big, small	Descriptors
Think, know, want, don't want, feel, see, hear	Mental predicates
Say, words, true	Speech
Do, happen, move	Actions, events, movement
Be (somewhere), there is, be (someone/something)	Location, existence, specification
(Be) mine	Possession
Live, die	Life and death
When–time, now, before, after, a long time, a short time, for some time, moment	Time
Where–place, here, above, below, far, near, side, inside, touch	Space
Not, maybe, can, because, if	Logical concepts
Very, more	Augmentor, intensifier
Like	Similarity

Marini (2019) offers an example from the psychiatric field, where official formulations do not always reflect the patient's realistic description of their distress. The definition of intrusive thought is based on unwanted memories, violent and sexual thoughts (Cassidy, 2016; Baer, 2001 in as cited in Marini, 2019), but the narratives collected from many patients reveal that intrusive thoughts that can be different and arise from anxiety, fears related or not to underlying trauma, and many other possibilities, all of which can be summarised in NSM as follows: "I do not want to think about some kinds of things; when I think about these kinds of things, I feel something bad" (Marini 2019, p. 19). The NSM does not want to diminish the richness of language, it is rather a resource to support communication in healthcare especially when lexical or cultural issues are at stake, as Pinker clarifies to Marini herself (2019):

As is a tool or an instrument made out of language and used to talk about language, which is why it is called a metalanguage. [...] It is also used for describing ways of thinking that are culturally specific, i.e. so-called cultural scripts. NSM explications [...] are couched in

natural, or naturally occurring, language, as opposed to artificial, technical or esoteric language. (p. 21)

As Ahlzén notes (2019), the limits of narratives depend on the limits of language. I would like to add something to this observation.

The relationship between knowledge, narrative and language is, in fact, a complex one. Logical reasoning would lead one to think that if we do not set the potential and limitations of what can be really known, it is hard to set the potential and limitations of what we can talk about: the range of our knowledge determines the range of our narrative possibilities. And yet, narratives can unexpectedly exceed and broaden the limits of our knowledge, can unveil information that is difficult to spot, retrieve, and be aware of. As Charon says, talking about one of her patients: “Until my impressions were expressed in language, I did not know what, in fact, I knew about the patient” (2008, p. 6), or as Launer puts it: “I never realised what I thought until I heard myself say it.” (2024, p. 384). In the light of these statements, one could even turn the perspective on the relationship between (medical) knowledge and stories (and language) in such a way that it is what we tell and how we tell it that defines our thoughts, and shapes and construes the development of the medical relationship. On the other hand, the idea of the unfathomable relationship between language, thought and reality is supported by the insightful biblical view of the close temporal connection between the act of creating beings and that of naming them (Genesis²⁵) and by the wide-ranging linguistic relativity hypothesis (also known as “Sapir–Whorf hypothesis”) on the relationship between linguistic structures and patterns of thinking, according to which language influences our perception and construction of the world and our thinking about reality (see more in Lucy, 2001).

However, the idea that language shapes our view of the world has broad consequences on the social discourse in medicine.

²⁵ In the Bible, the creation of the world and the act of mentioning beings and natural events happen in parallel: “Then God said, “Let there be light”; and there was light” [Genesis, 1:3].

Patients who do not fit into the expected therapeutic attitudes, patterns and procedures or are not willing to abide by medical advice are often defined as "difficult", "crock," "troll," "turkey," "dirtball," (Cohen-Cole, 1990, p. 1045) or “not compliant²⁶”.

Buchbinder (2015) showed that the metaphor “sticky brains” was used for paediatric patients with mental and behavioural disorders and resistance to standard therapies, who reported distress for which no reasons could be identified. In the hospital where they were treated, their case ended up with the explanation that they allegedly “stuck to” the idea of being in pain because they tended to focus on one specific thought compulsively and obsessively because of their disorders. This language justified the fact that their mental condition was identified as the reason for otherwise inexplicable compliance with medical treatment.

Describing within a professional context these patients with such words (difficult, sticky or other judgmental and pejorative definitions) also legitimates a specific social view of a given disease out of that context (Kleinmann’s idea of sickness, 1988) and determines, in the patients affected, a specific self-perception and self-blame, supporting the idea of being difficult or exaggerating the issue for which they seek medical help. As anticipated, the misleading effect of these depictions is further illustrated and exemplified in the case study on endometriosis.

Translation and co-creation of meaning

I have often pointed out how recognising the mutual narrative contribution of doctors and patients is crucial to a full and consistent understanding of NM, which otherwise would be reduced to a mere collection of illness stories, just seen as something to be added to the standard daily medical routine in medical encounters.

Not only did I argue in chapter 1 that this view oversimplifies a more complex relationship between the humanities (and hence narratives) and medicine, by embracing the idea of entanglement as a more reflective construction of the issue, but also narrative itself is a very

²⁶ “Conceptually, compliance and persistence represent two constructs that are based on one’s belief in the efficacy of the medication, the severity of their illness, and their ability to control it with medication.” (Cramer et al. 2008, p. 46)

relational act (Bakhtin, 1984): as in any communication act, it involves at least two participants, entails telling and listening, and, vice versa. The opposite sequence can also be followed, listening, and decoding the story from the listener's different perspective, retelling it and reshaping its meaning(s), checking the consistency with the intended message and renegotiating it. In this light, narrating is not a subjective but a performative act, resulting in a new product, a new story (Charon and Montello 2002).

On this topic, I would like to add an extra, apparently disconnected, point of view to the discussion of narratives as a relational and self-reflective tool.

As a former translation and interpreting student and as a translator myself, I cannot ignore how much narratives and translations have a lot in common, as they require the analysis (a term that not by chance is used in medicine, sciences but also in linguistics, as well as in many other humanities fields), of a source text and the production of a target text, which are very likely to differ from each other.

According to functionalism in translation studies, the effectiveness of a good translation highly depends on its functionality, (Nord, 1997, 2001, 2018; Vermeer, 1996), that is, whether it works for the goal that both the author and the translator, want to pursue: what is the translation aiming at, which effect, among the many available ones, deserves priority in the target language and culture?

In this functionalist approach, based on the so-called "Skopostheorie" by Vermeer (1996) and revisited by Nord (1997, 2001, 2018), in a professional and self-aware translation process, the core message is processed according to the purpose the author aims at (or when the author is not alive anymore, the commissioner often referred to as "the client" in the contemporary jargon in use in big translation agencies).

There are different intended messages an author might want to convey, and different related, desired effects on the reader or listener he or she would like to achieve (i.e. humour, surprise, identification or disagreement with a character or situation). To do this, the author uses the

linguistic resources available in their own source language (e.g., climax, metaphors). The specific language and cultural framework of the target reader or listener may offer or limit - because of its own peculiarities - the possibility of achieving those intended objectives and conveying those intended messages: for example, humour-inspiring references differ from culture to culture, so what sounds hilarious to the source reader or listener might now work (function, be functional) in the same way and result in the same reaction in the target reader. The same applies to the way sensitive subjects such as health, illness, the human body, death, love, and any topics which fit into certain cultural expectations and related expressive means are addressed.

So, not only does the translator need to change the expressive means and strategies available in the source language to achieve the effect intended by the author/commissioner (for example using a metaphor instead of a joke or recalling a popular literary reference to make the reader/listener smile, disagree or empathize), but he may also need to review priorities among the functions pursued. The one exerted in the source language and culture and those expected in the target language and culture may not line up.

For example, the translator may give up the humour function of the source text as it does not fit into the expectations and values system activated for a given topic in the target culture (one may find relief from mourning and laugh at death through dark humour, but this option may not be available in the target language and culture).

So, in the end, the translator may prioritise a new function over others, arranging the target text in such a way that the final dominating effect differs from the most relevant in the source text. In this process, translators become - willingly or not- authors themselves, as they reshape, rewrite the story they are telling - whether it be a novel, or a piece of news, or an advertisement, according to the intended effect.

In medicine, assuming Pellegrino's view (1979a, 1979b) as universally accepted, the intended effect is to heal the patient, or, as I suggest putting it, to improve the patient's health

condition. If health is not only the absence of illness but a wider and more complex condition, then healing is just one of the options available in a complex path of care.

In this respect, sharing stories to achieve this (these) goal(s) requires a constant adjustment in terms of:

- expressing the desired meanings and functions in the source text: a patient would ideally say sentences as: *I don't feel good, something is wrong with me, I will do my best to explain what, because I do not know; I know that I am in pain, I perceive my pain in this way...; I would like this pain to stop; I am ready to go through a surgery if this means not feeling pain anymore; I would rather accept pains as long as I can keep leading a certain life, for example, keeping my actual job etc.* (Aisha, for example, may prefer pain and disability than surgery, but other people with the same symptoms would opt out for an operation); *I want to take drugs; I am not willing to follow the therapy if this impacts too much my mental health or relationships with my significant others; my point is to survive at any cost; my objective is to live the time I have left with the least pharmacologically impactful solutions.* There is a potentially endless array of intended meanings and goals in the stories told, and more than one of them may be conveyed at the same time.

Comprehension and construing of the source text (the illness story/stories told and listened to).

- How clear and understandable to the physician are the expressive means and strategies used by the patient to convey the state of illness? How familiar is the doctor with these means, and how trained is he to interpret them? This is the stage at which narrative knowledge comes into play, and “provides one person with a rich, resonant grasp of another person’s situation” (Charon, 2006, p. 9). Narrative competencies can be taught, acquired and developed.

This means that they are not natural gifts physicians are casually endowed with, though some are more naturally prone to use them than others, but can be learnt through study and practice. As Pellegrino, before Charon, argued in illustrating the role of the arts in medicine discussed in Chapter 1, “Art [as a constitutive part of medicine as much as science] is not synonymous with mysterious intuitive personal endowments peculiar to some and not others” (1979, p. 50).

- Keeping the parallelism between translation and sharing stories, a new target text or target story is produced, in which the original intentions and expectations may have changed. Aisha was recommended by the previous doctor and her children to have surgery; Faisal was supposed to speak with her doctor; the doctor in Launer's story still wanted to try something else with his patient: their stories have a different end. The doctors, too, have made decisions different from the ones expected (the doctor gives up the consultation or postpones it, is silent, or still, waiting for their patient to speak - as Aisha did - or not speak - as Faisal did). The function, the goal, that is making the right decision in that patient's interest in that moment, as Pellegrino would say, has been preserved.

Conclusions

In this chapter, I have analysed uncertainty in Medicine from different angles, comparing different sources on the topic. I highlighted that it is something common to medical sciences and narrative. Different narrative features and structures of medicine practice and knowledge were illustrated, providing and commenting on examples. The references offered were representative of broader research, but I suggested them based on their consistency with the theme of uncertainty.

Lastly, the potential and limits of the stories were critically considered, and an analogy between meaning construction in NM and the translation process was suggested.

Chapter 4

Endometriosis or Living with Uncertainty

In this chapter, I outline the main features of endometriosis, which is the pathology and illness experience of the case study I present soon after.

The overview of this multifaceted disease is obviously not as clinical as the one that a gynaecologist may offer, although it is based on clinical research and scientific literature. I actually highlight the uncertainty that surrounds this disease and how this is verbally conveyed in medical communication.

Definitions

Among the many definitions available for Endometriosis, I chose that of the European Society of Human Reproduction and Embryology (ESHRE, 2022a) and that of Agarwal (2019) for different reasons. As for ESHRE's definition, it calls into question the idea of uncertainty: I did not choose a definition provided by a specific clinician or researcher in a medical textbook, which would definitely grant for precision, reliability and authoritativeness among the scientific community. I rather opted for a "choral" definition filtered and mediated by an institution, hence based on different areas of expertise and diverse members' contributions. These were collected in online clinical *guidelines* (ESHRE, 2022a) and aim to:

improve the quality of healthcare delivery within the European field of human reproduction and embryology. [...] *In the absence of scientific evidence on certain aspects*, a consensus between the relevant ESHRE stakeholders has been obtained. The aim of clinical practice guidelines is to *aid* healthcare professionals in *everyday clinical decisions* about appropriate and effective care of their patients. However, adherence to these clinical practice guidelines [...] *does [not] establish a standard of care*. [...] Ultimately, healthcare professionals must make their own clinical decisions *on a case-by-case basis*, using their clinical judgment, knowledge, and expertise, and taking into account the condition, circumstances, and *wishes*

of the *individual patient, in consultation with that patient and/or the guardian or carer*. (p. 2 emphasis added)

This passage is part of the default disclaimer included in the aforementioned guidelines, and as such, it may contain statements that are common in every relatable document, but my use of italics in the above citations recalls many aspects discussed in this thesis: the awareness of knowledge gaps and uncertainty in the study and care for endometriosis (“In the absence of scientific evidence on certain aspects”); the reference to the “stakeholders”, a word that, semantically and morphologically (as a plural), implies a minimum degree of diversity and inclusiveness of interests in the issue, as confirmed by the presence of “consensus” in the co-text; the criticalities of daily medical decision-making and the supporting function (“aid”) that the guidelines may serve in this processes; recognizing the *epistemological and deontological limitations* of the guidelines and the importance of a personalized (“on a case-by-case basis”) and co-participated approach (“taking into account the wishes”, “in consultation with”) to patients and their surrounding network (“and/or the guardian or carer”).

On the theme of patients’ involvement, I would like to add that ESHRE provided the aforementioned guidelines in two issues; one designed for clinicians (specifically secondary and tertiary healthcare providers—specialists—although it is suggested that the primary ones could also find them helpful for first consultation and referral; in the references, this source is referred to as ESHRE, 2022a,); the other for patients.

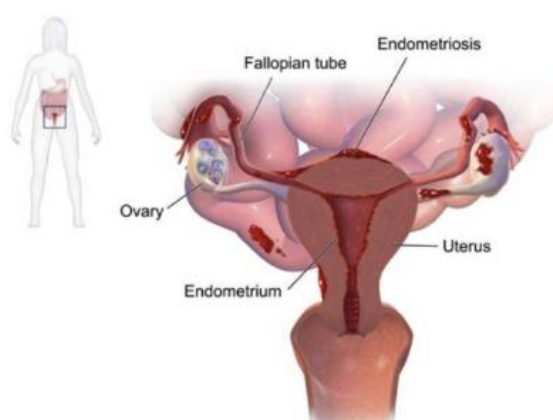
The two versions differ from each other in many respects: content (the former specifically suggesting good practices in treatment and diagnosis, the latter more explicative and featuring traits of scientific popularization such as simplification, summarization, pictorial references); text length, and language (more technical in the former, more accessible to laypeople in the latter, e.g. “outside the uterus” in place of “outside of endometrium and myometrium”).

Hence, the definition I suggest in this work results from combining the definitions provided in both documents, with which I intend to represent the clinicians’ and patients’ perspectives. So,

according to ESHRE, endometriosis is a chronic disease characterised by the presence of endometrium-like tissue outside the uterus, usually with an associated inflammatory process (ESHRE 2022a, ESHRE 2022b).

Figure 15

Information on endometriosis. Patient leaflet based on the ESHRE Guideline on Endometriosis (2022b, p. 3)



Notwithstanding the clinical facts and studies that inform such a definition, uncertainty underlies the endometriosis experience for several reasons.

First of all, the factors that cause the onset of this disease (aetiology) are still unclear, no cure is currently available for endometriosis and treatment aims at controlling symptoms (WHO, 2025). As I detail in the next sections, this knowledge gap is echoed in many of the patients' narratives participating in the NM project I carried out, where I tried to investigate and voice also the doctors' view on this matter, i.e. whether they, consciously or not, experience uncertainty about endometriosis and the related lack of cure for it and how they cope with these knowledge limitations, how they convey them to their patients.

In this chapter, instead, I investigate this aspect also in the ESHRE (2022a) guidelines for healthcare providers, which shortly state that the “cause of endometriosis is unknown” (p. 157). The only hypothesis taken in consideration for its aetiology is:

One of the risk factors for endometriosis seems to be having a first-degree family member with the disease, although the specific genetic origin of the association is still unknown. [This hypothesis is based generally on] the increased disease prevalence which has been found in first-degree relatives of women with endometriosis, [which in turn] results in questions from patients and family members on how they can prevent the development of endometriosis. (p. 157)

Interestingly, a further leaflet for patients seems to soften this claim, stating that the cause of endometriosis “is not fully understood”. The leaflet intended for educational purposes compares more possible hypotheses, without actually taking a stance: on the contrary, it consistently and frequently uses epistemic modal verbs and always reminds the reader of the unproven nature of all of them. I am quoting the following passage just to highlight this point through my italics (ESHRE, 2022c):

What happens is that during a period, cells from the womb *may* travel through the Fallopian tubes and implant on surfaces within the abdomen or other organs in the body. It *may* also be due to cells from the womb forming in the wrong place when the female baby is developing in the womb. There *could* also be a problem with the immune system that allows these cells to grow outside the womb. (p. 1, emphasis added)

In the guidelines intended for clinicians, despite the shortness of the section on endometriosis aetiology, more details are provided for its symptomatology through a list of medical terms, although, again, a certain degree of uncertainty is reflected in the linguistic choices made at a verbal and nominal phrase level marked by my use of italics (ESHRE, 2022a):

clinicians *should consider* the diagnosis of endometriosis in individuals presenting with the following cyclical and non-cyclical *signs* and *symptoms*: dysmenorrhea, deep dyspareunia,

dysuria, dyschezia, painful rectal bleeding or haematuria, shoulder tip pain, catamenial pneumothorax, cyclical cough/haemoptysis/ chest pain, cyclical scar swelling and pain, fatigue, and infertility. (p. 9)

The medical terms for the signs and symptoms in endometriosis are repeated and rephrased with a less technical vocabulary in the patient leaflet, as shown in the following figure:

Figure 16

Screenshot from *ESHRE leaflet, ESHRE 2022b*

The symptoms of endometriosis are:

- Painful menstrual periods (dysmenorrhea)
- Non-menstrual pelvic pain or pain occurring when a woman is not menstruating.
- Pain during or after sexual intercourse (dyspareunia)
- Pain emptying bladder/painful urination (dysuria)
- Pain emptying bowel (dyschezia)
- Painful rectal bleeding or the presence of blood in the urine (haematuria)
- Shoulder tip pain
- Cyclical lung problems (pneumothorax)
- Cyclical cough, chest pain, or coughing of blood (haemoptysis)
- Cyclical scar swelling and pain
- Fatigue
- Infertility
- Any other cyclical symptom



Cyclical symptoms are symptoms that develop a few days before a woman's menstruation and disappear a few days after her menstruation has stopped, or symptoms that occur only during the menstruation. The symptoms reappear the next month, following the woman's menstrual cycle.

A direct reference to the relation between signs and symptoms and to the uncertainty of endometriosis symptoms is expressed in the patient leaflet, where the process of basing the diagnosis on symptoms is framed as follows (ESHRE 2022b): “because the symptoms of endometriosis *are not very specific*, the diagnosis of endometriosis cannot be made by the symptoms alone. However, symptoms can give a doctor *a first hint* towards the diagnosis of endometriosis”. (p. 9)

Symptoms (patient's perspective) and signs (medical perspective) are fairly included in both documents examined here, but the patient leaflet seems to focus on the symptoms as a starting

(although not the only one) point to formulate a diagnostic hypothesis, aligning with the view of NM.

Yet, this also raises doubts about the scenes depicted in many illness accounts provided by women with endometriosis, which, in contrast, reveal a complete lack of medical trust in what patients say, i.e., in the symptoms they describe.

This calls for a reflection on the possible discrepancy between the institutional and the personal representation of the communicative experience in healthcare settings. In turn, this makes us wonder how representative data on endometriosis prevalence (a medical term for diffusion) are.

Moreover, I included in picture 14 also the passage clarifying the meaning of “cyclical” and non-cyclical, which presumably is assumed to be a concept known by clinicians, hence not better specified in their guidelines. I find this more important than a simple terminological matter, because it implicitly refers to another aspect of uncertainty, namely the unpredictability of endometriosis symptoms timing, which can be constant or random. Symptoms in endometriosis can vary not only across patients, but also in the same subject across time (Denny, 2009): the disease has been defined as “enigmatic” by Valle & Sciarra (2003, p. 229) and “the chameleon of endometriosis” by Brüggmann et al. (2016, p. 1).

In the definition I offered in this section, endometriosis is defined as chronic. Although scientific literature shows a tendency in relating endometriosis to women of reproductive-age (Agarwal et al., 2019; Drabble et al. 2021), the disease can actually last well into post-menopause, as reminded by ESHRE itself (2022) and World Health Organisation (WHO), which, on its official website (2025), adds: “symptoms often improve after menopause, but not always”.

Another mysterious aspect of endometriosis lies in the lack of correlation between the disease stage (whose classification was originally designed to address infertility issues) and the severity of symptoms: patients with the same stage of disease may have different disease forms, so a woman with a high disease stage may present with less or less painful symptoms than a woman with a lower stage, as well as some patients affected do not have any symptoms.

Lastly, although the pelvis is the most painful area in women affected due to the hormone-dependent nature of endometriosis, the disease has also been found in a minority of men and transgender males, for which at the moment insufficient data are available, also in Italy (Facchin, 2023).

In this section, after accounting for the choice of the scientific sources I drew upon, I provided and analysed a definition of endometriosis by describing the related inflammatory process and the signs and symptoms that may prompt a correct diagnosis. I also highlighted the uncertainty factors which characterize this disease, such as its unknown cause(s) and the current lack of cure, as well as the wide and diverse array of its symptoms, defined as “not very specific” in the institutional educational documents considered, as a point that makes the diagnosis more complex and difficult (WHO, 2025). In the next section, I offer a more in-depth discussion on the symptoms experienced by patients, their impact on their daily life, and how they are interpreted by clinicians.

Disorienting medical information

As shown in the definitions, infertility is among the endometriosis symptoms and is actually linked with another reason for the choice of ESHRE studies in defining endometriosis in this work. ESHRE is a scientific society concerned with human reproduction, hence also with other issues related to endometriosis, such as pregnancy, birth, parenthood, hereby placing the disease in a comprehensive framework. Fertility and sexual issues are other highly discussed topics in research on endometriosis.

I must specify that in this thesis the connection between endometriosis, general gynaecological issues, and motherhood does not imply that the disease should be managed prominently to improve pregnancy chances, as reported in many women’s accounts about their medical interviews, when one of the first questions asked is whether they want to have children. It seems that this is the main factor on which any symptom treatment or medical decision could be based, while patients ask to be attended to and treated, first and foremost, to improve their overall wellbeing and quality of life. Whether such wellbeing includes the wish for motherhood depends on

the priorities of the individual patient, who, in most cases, first of all wants and needs to get some relief from endometriosis-related pain and distress.

Furthermore, this tendency to prioritise fertility issues in endometriosis also relates to some oversimplifications and generalised, unproven assumptions, according to which pregnancy would fix the symptoms, a point for which there is no evidence at present, as stated by ESHRE itself (2022a):

Patients are being advised to become pregnant to cure their endometriosis, and the data clearly indicate that this advice is incorrect. [...] Patients should not be advised to become pregnant with the sole purpose of treating endometriosis, as pregnancy does not always lead to improvement of symptoms or reduction of disease progression (p. 107).

Construing pregnancy as the focus of healthcare delivery for endometriosis in doctor-patient communication means (once again) shifting the perspective on gender-related expectations, diminishing and biasing the patient's need. This idea is underpinned by some of the patients' accounts included in my project.

A study by Fauconnier et al. (2018) explained the process by which a consensus panel of clinicians and patients discussed, approved or rejected statements based *on the patients' perception* of painful symptoms, in order to identify those eligible for an endometriosis diagnosis.

As shown in Figure 17, throughout the discussion rounds, symptoms reported by patients are screened and reduced remarkably, but most of all, 12 items show a discrepancy between the opinions of the physicians and those of the patients (Figure 18).

For example, the items "different types of pain at the same time, several different pain symptoms" and "extreme fatigue, total exhaustion which interferes with daily life" were considered clear and valid for diagnosis by most of the patients participating in the consensus panel, but the physicians of the same panel did not agree on that. The item was eventually discarded. I am not implying that physicians arbitrarily ignore patients' complaints, but the patients' perception of

endometriosis symptoms is evidently filtered and often not totally represented in the diagnostic criteria.

Figure 17

Consensus Panel Round discussion: items selected and discarded (Fauconnier, 2018, p. 72)

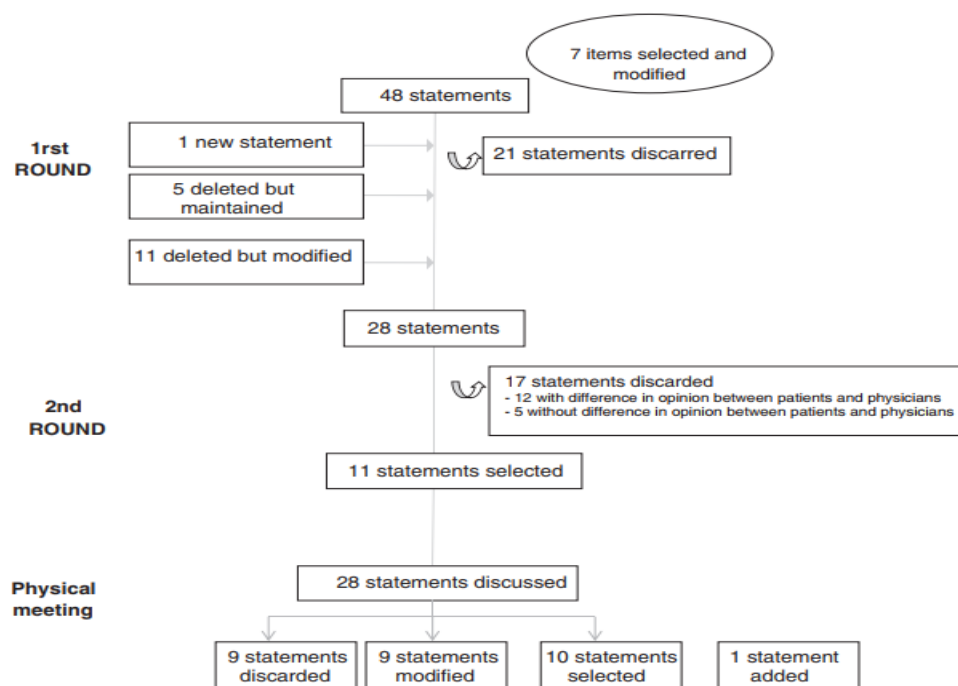


Figure 18

Discrepancies in the consensus panel (Fauconnier 2018, p. 76)

Statements	Diagnosis validity		Clarity		Status after 2nd round	Final status after discussion
	Median	% agreement (7-9)	Median	% agreement (7-9)		
18: pain spreads to the legs and hips	7	57.1	9	88.9	Discarded	Selected
Patients	8	76.5	9	100	Retained	
Physicians	6	38.9	8	78.9	Discarded	
19: different types of pain at the same time, several different pain symptoms	6	48.6	7	58.3	Discarded	Discarded
Patients	8	77.8	9	76.5	Retained	
Physicians	5	21.1	6	42.1	Discarded	
20: pain makes standing, walking or moving difficult if not impossible	7	55.6	9	88.6	Discarded	Selected
Patients	9	88.2	9	100	Retained	
Physicians	4	26.3	8	78.9	Discarded	
31: diarrhea during menstruation	8	70.3	9	97.1	Discarded	Retained but modified
Patients	8	82.3	9	93.7	Retained	
Physicians	7	60	8	100	Discarded	
34: bloating, bloated abdomen during menstruation	7	59.5	9	88.9	Discarded	Discarded
Patients	8	88.2	9	100	Retained	
Physicians	5	35	8	80	Discarded	
48: extreme fatigue, total exhaustion which interfere with daily life	7	51.4	9	86.1	Discarded	Discarded
Patients	9	88.2	9	100	Retained	
Physicians	6	20	8	75	Discarded	

Beyond symptoms

According to the WHO, 190 million women worldwide suffer from endometriosis. This number only tells part of the story, as in the US, for example, an estimated 6 of 10 endometriosis cases are undiagnosed, hence women may experience repercussions of endometriosis without the benefit of understanding the cause of their symptoms or appropriate management. As argued in the previous section, pain and infertility are two of the disease's more common symptoms. Yet, Agarwal notices (2019):

the real toll is even greater: women with endometriosis experience diminished quality of life, increased incidence of depression, adverse effects on intimate relationships, limitations on participation in daily activities, reduced social activity, loss of productivity and associated income, increased risk of chronic disease, and significant direct and indirect healthcare costs. (p. 354)

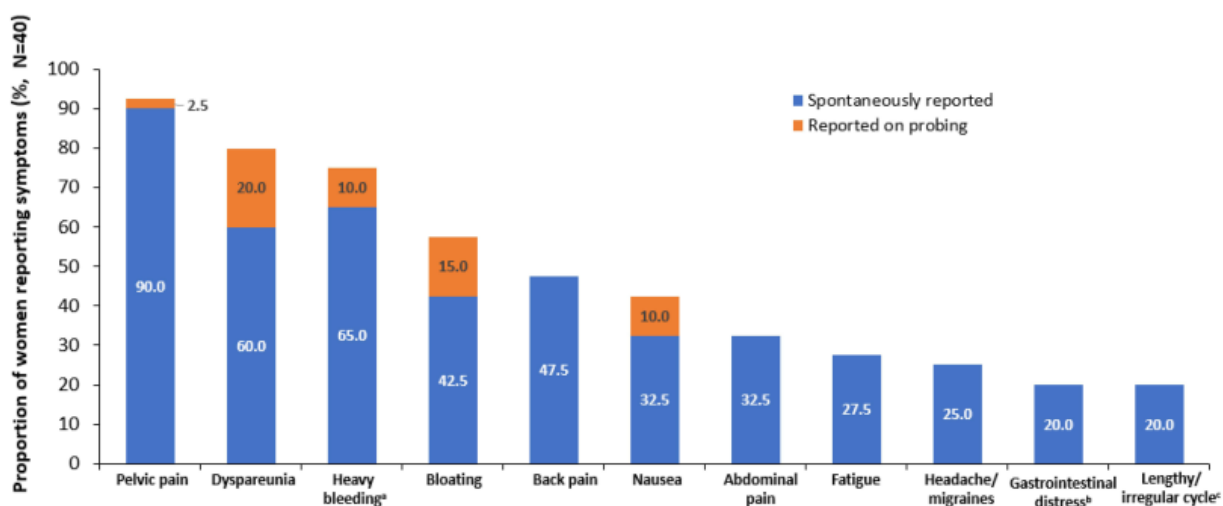
In a research contribution classified as “original research”, Hunsche et al. (2023) conducted an interview-based study in a sample of 40 US women with confirmed endometriosis.

These were asked to describe their symptoms and impacts on daily life *in their own words*.

Respondents reported both spontaneously and on probing, i.e., following further clarifying questions asked by the interviewer when deemed appropriate to obtain additional feedback. The answers displayed 18 different symptoms of endometriosis, with the first 11 most frequently reported represented in the following figure:

Figure 19

Symptoms of endometriosis, (Hunsche, 2023, p. 897)



The graphic is largely consistent with the symptoms listed in the ESHRE's documents discussed in the previous section, but at the same time it shows a significant and more detailed distinction between the pain perceived in the pelvic area and that in the abdominal area, between nausea, bloating and gastrointestinal distress.

This brings up a more detailed differentiation and different *mapping* of pain and distress, along with a special perception of specific body areas, which changes daily basic experiences concerning those areas, such as food intake and processing, and generally, the relationship with food, the biological and emotional dimension of eating, and the way it shapes the body, in turn connected with appearance and social/aesthetic acceptance.

The respondents' answers also include migraine/headache, which did not feature in the ESHRE's symptom description.

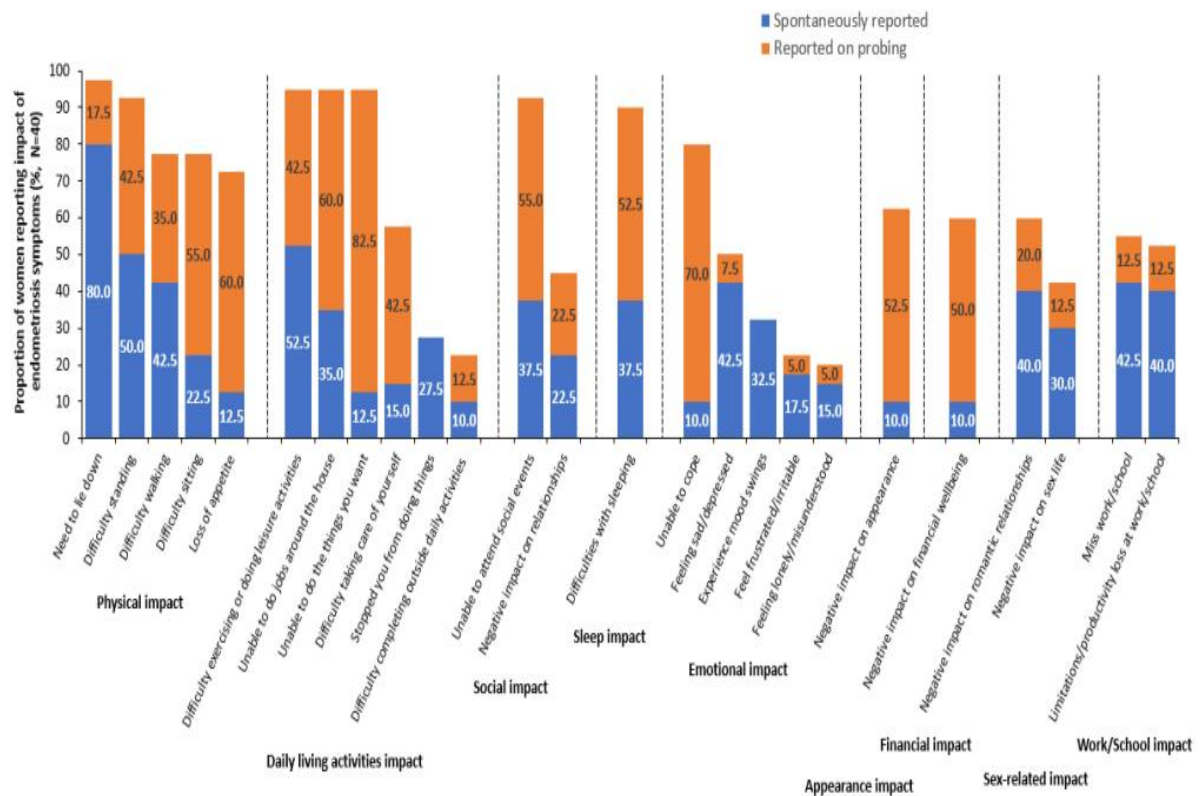
Furthermore, although not represented in the graphic, less than 20% of respondents reported anaemia, cramping (perceived in forms and body locations different from those of pelvic and/or abdominal pain), cysts, vaginal pain, acne, body temperature changes and leg pain. This last symptom is particularly interesting because it is among the statistically less frequently reported or rarely discussed symptoms (Facchin, 2023), such as reduced sleeping quality (Facchin et al., 2021), but it is mentioned also in Fauconnier et al.'s (2018) study concerning the difference between

clinical and non-clinical of endometriosis experience and the eligibility of some forms of distress to the status of endometriosis stress.

However, the relevance of Hunsche et al.’s study (2023) lies in its offering insight into the impacts of the reported symptoms on daily life, as if the patients’ perceptions were *translated* into the activities and experiences that they cannot perform or have to give up because of their endometriosis. These were subsumed in the conceptual categories of Figure 20: physical, activities of daily living, social, sleep, emotional, appearance, financial, sex-related, work/school-related, (plus fertility, and cognitive, the last two categories not represented in the graphic but meant as difficulty in conceiving and concentrating or remembering).

Figure 20

Impact of endometriosis symptoms (Hunsche et al., 2023, p. 900)



The highest impact of endometriosis symptoms is on physical activities, as reported by more than 70% of women, most of whom need to lie down (97.5%) or find it hard to stand (92.5%).

Another important score concerns social activities, for which “92.5% of respondents mentioned that they were unable to attend social events or had cancelled pre-existing plans due to endometriosis symptoms”, with easily predictable consequences on social relationships. Furthermore, the symptoms also heavily influenced sleeping (90%) and emotional well-being (80%). About the latter, most of the women reported spontaneously, so with no need for further clarifying questions or eliciting more information, that they feel sad or depressed.

Lower but significant impacts of endometriosis symptoms (60.0%) concerned the patients’ financial conditions, mainly due to expensive healthcare service, as well as romantic relationships (60.0%), including sexual intimacy (42.5%).

52.5% women reported loss of productivity at work/school, and 17.5% a lower ability to conceive.

Hunsche et al.’s findings on the impact of endometriosis on women’s daily lives illustrate that patients perceive a much broader burden than the commonly known symptoms with which the study aligns. This may help health professionals to include in their approach to medical consultations aspects of the disease that may not be readily discussed with patients: “Endometriosis burden arises not only from symptoms of the disease (e.g. pain) but also accumulatively from the consequences of these symptoms” (Hunsche et al., 2023, p. 902).

Clinical research does not overlook the uncertain nature of endometriosis either: Facchin (2023) admits that a comprehensive conceptualization of endometriosis is still a hard demand, given the unknown origins of the disease, and that despite the growing attention to the issue nowadays, cognition of endometriosis started only two decades ago, especially thanks to the advocacy activities of spontaneous associations of women affected by the disease and willing to support others who experienced the same in raising their voice. This also accounts for the diagnostic delay for this disease, which ranges between 8 and 12 years (Becker et al., 2022).

Facchin (2023) describes endometriosis as a complex and multidimensional pathology; Agarwal et al. (2019) introduced the term “systemic” for endometriosis, since the condition does

not affect only the pelvic area and the body, broadly speaking, but impacts the overall wellbeing of the patient. Facchin (2023) and Drabble (2021) agree on the point that endometriosis cannot be conceived only in terms of gynaecological conditions and treatments.

Such statements are paramount as they mark an important shift in the physicians' and medical researchers' attitude towards the matter. In Chapter 1, I have already discussed the implications of the dualism between body and mind and of the segmentation and hyper-specialisation in medicine as features of the biomedical model criticised by Engel.

In contrast, these authors recognise that confining endometriosis just to the uterus and hormones would be oversimplifying a more complex issue, and, broadly speaking, that a disease is not limited only to or even identifies itself with a specific part of the body or the whole body itself, but there is a human, non-physical dimension in health and illness.

This is per se an important acknowledgment, virtually applicable to any field in the approach to healthcare, but in the specific case of endometriosis, this reflection is even more meaningful, as historically the disease has received no due attention over a time which is difficult to quantify: Benagiano et al. (2015) notice that defining endometriosis as a "modern" disease is controversial, since "this adjective does not in any way imply that the condition did not exist in ancient times. On the contrary, it implies that only recently the scientific community began to untangle [its] complexity" (p. 237).

Now, instead, endometriosis is not only recognised, but also considered as part of a broader condition. The role of other related pathologies and symptoms (comorbidity) has also progressively affirmed itself in the approach to treatment and in research. As I detail in the next chapter, patients themselves highlight their wish for an integrated approach to treatment, involving different medical experts in their healthcare experience.

Chapter 5

The EndoNar Project

The topics discussed in the previous chapters provide the framework for the research project I present in this chapter, a project that I called EndoNar (from Endometriosis and Narrative).

Since the field of my PhD research is NM, and since the Tuscan healthcare system and the role of technologic advance are the requirements of the Tuscany Health Ecosystem programme, I searched for resources and tools that could match narrative research with digital applications.

So, after submitting the necessary requests to receive legal authorisation for data collection and processing from the hospital of Siena (Azienda ospedaliero-universitaria Senese: AouS), an agreement between my University (Università per Stranieri di Siena – Unistrasi) and AouS was signed in June 2024.

I could meet the AouS gynaecology team and present my research design to them. They welcomed the idea, and we had different meetings in which I shared with them my background studies on the NM approach. During these sessions, I asked them about any possible criticalities faced in communicating with their patients affected by endometriosis: chronicity, maternity and reticence in very young patients (especially if accompanied by their mothers) emerged as main topics of these discussions.

In the meantime, I had collected information through different online training sessions on NM provided by Columbia University's facilitators and different webinars offered by SIMEN (Società Italiana di Medicina Narrativa) until I learned about the activities of the Society for Digital Narrative Medicine (DNM). After sharing ideas on my research project with DNM, they decided to collaborate and offer free technological support for data collection and storage. DNM provides a digital platform which allows patients to share their stories with doctors and caregivers using a guided narrative path.

I could also rely on their past experience in Digital Narrative Medicine projects. Consulting both the anthropologist and the IT expert working at the DNM was particularly helpful for the

general set-up of the project and the collection of narratives. The advice of the society's CEO, the anthropologist Cristina Cenci, on the macro-phases of applied DNM was also enlightening to me: based on the experience she gained in the field and shared with me, I divided the project into three parts: narrative research, analysis and discussion of the collected narratives, and application of the derived results to the approach used in clinical practice. These steps, in my view, echo the sequence of attention, representation and affiliation put forward by Charon (2006), as shown in Chapter 3. The project, also reflects the Italian definition of NM since participants represent (at least intentionally, as I better detail later) all the stakeholders involved in the medical experience: doctors, patients and caregivers.

Research design and method

My research was carried out in a group consisting of 69 women aged 22-52, diagnosed with endometriosis and treated at AouS, their caregivers, and their gynaecologists. I refer to the women with endometriosis enrolled in this project as patients, participants, authors or writers. I refer to the three gynaecologists who took part in the project as G1, G2 (both men, with G1 teaching at AouS university and working as a surgeon) and G3 (woman, also teaching at AouS university).

The research questions I intend to answer in my project are whether and how uncertainty emerges from the digital narratives shared by patients, caregivers and doctors participating in our project, with a specific reference to the description and assessment of pain-related suffering.

Although I use mixed methods to analyse data, a qualitative approach informs my research. My project falls into the category of case studies, in that it observes and analyses a limited phenomenon in its real-life context, as defined by Yin (2014).

In line with the role of illness stories in medicine, the narrative form I chose for my data collection is the diary, in this specific case study, a digital diary.

This was set up on a digital platform provided by DNM, to which participants (gynaecologists, patients and caregivers) could easily access with personalized credentials. Doctors could view and read the patients' and caregivers' diaries: the goal of the project is to integrate NM

in the path of care of the participants, i.e. improve attention to the illness stories, absorb them (in Charon's understanding of the word), and moving back to the live medical encounter (and, broadly speaking, to care) with a new awareness (again, Charon's triad is recognizable in these goals). The diary is semi-structured: as I learnt at ISTUD, the diary frame leaves room to patients' total freedom in telling their story, in that, just like in a paper diary, patients could write their thoughts on their endometriosis experience whenever they wanted, in the form of free notes. So, they could choose the topic, the quantity, the frequency and the length of the notes they wanted to share. This allowed participants to write about what mattered to *them*, in the framework of a patient-centred perspective.

Before the writing process started, patients were asked if they were able to report everything they wanted to their doctors and if they found the diary helpful to keep track of their experience and to share it with doctors during medical interviews, gathering 75% of positive feedback.

At the same time, I had also prepared a set of 44 narrative prompts that could guide the patients' and caregivers' writing and elicit their narratives on particular features of their experience, so that a comprehensive overview of the could emerge. These prompts introduced in the diary a sort of guided plot. Here's the lists of prompts.

Table 1

List of narrative prompts for the patients

Prompt	Translation
1. Mi sono accorta che qualcosa nel mio corpo stava cambiando quando...	1. I noticed that something in my body was changing when...
2. Fuori dal contesto di cura, avevo sentito parlare per la prima volta di endometriosi da...	2. Outside the treatment setting, I had first heard about endometriosis from...
3. Prima che ai medici, ho raccontato per la prima volta i miei sintomi a...	3. Before meeting the doctors, I first reported my symptoms to...
4. La sua/loro reazione è stata...	4. Their reaction was...

5. L'episodio della mia esperienza di endometriosi che mi è rimasto più impresso è...	5. The episode of my endometriosis experience that has stuck with me the most is...
6. Prova a rappresentare il tuo presente con un disegno e allegane la foto, oppure a descriverlo con un brano, una frase, il ricordo di un luogo (o altro) che ti viene in mente...	6. Try to represent your present with a drawing and attach the picture, or describe it with a passage, sentence, memories of a place (or other) that comes to your mind...
7. La prima immagine che assocerei ai miei dolori è ...	7. The first image I would associate with my pains is ...
8. Senti che i test di valutazione/misurazione del dolore come quello qui sotto da endometriosi riescono a rappresentare efficacemente i tuoi dolori?	8. Do you think that pain assessment tests like the one below can effectively represent your pains?
9. In questo momento l'endometriosi influisce su questi aspetti della mia vita (lavoro, affetti, socialità, altro) perché...	9. At the moment, endometriosis affects these aspects of my life (work, relationships, social life, other) because...
10. Da quando ho l'endometriosi, quando aspetto il ciclo, il mio corpo/la mia vita...	10. Since I have had endometriosis, when I am waiting for my period, my body/my life...
11. Se penso alla frequenza e alla durata dei dolori mi viene in mente...	11. When I think about the frequency and duration of the pain, I think of...
12. La prima volta che i medici hanno dato un nome alla mia condizione, le loro parole mi sono suonate...	12. The first time the doctors gave my condition a name, their words sounded...
13. Mi sono sentita...	13. I felt...
14. La parte del corpo che solitamente mi fa più	14. The part of my body that usually hurts the

male somiglia per me a...	most reminds me of...
15. Cosa mi dà sollievo quando ho dolori	15. What gives me relief when I have pain is...
16. Da quando ho saputo di avere l'endometriosi, la cosa difficile da accettare per me è stata...	16. Ever since I was told I had endometriosis, the hardest thing for me to accept has been...
17. Durante i colloqui mi sento...	17. During medical interviews I feel...
18. La visita più impegnativa per me è stata...	18. The most challenging meeting with my doctors was/is...
19. Con i miei medici mi riesce facile...	19. With my doctors I find it easy to...
20. Durante i colloqui con i medici vorrei parlare anche di... ma mi risulta difficile perché...	20. During medical interviews I also want to talk about... but I find it difficult because...
21. Convivere quotidianamente con l'idea della cura ²⁷ significa per me...	21. Living with the idea of a daily treatment means to me...
22. Cosa mi aiuta a distrarmi	22. What helps me to distract myself is...
23. Il pensiero più ricorrente in questo percorso è...	23. The most recurring thought on this journey is...
24. Cosa mi dà più fiducia in questo percorso	24. What makes me feel confident on this journey is...
25. Cosa sto scoprendo/ho scoperto di me stessa in questo percorso	25. What I am discovering about myself on this journey is...
26. La mia esperienza può essere utile ai medici perché...	26. My experience can be useful to doctors because...
27. La mia esperienza può essere utile ad altre	27. My experience can be useful to other women because...

²⁷ The patients are aware and informed that “cura” (cure) here means just symptom management, a therapy to *control* symptoms. As shown in some excerpts later, the same word is used by patients themselves.

<p>donne perché...</p> <p>28. Dai medici sto imparando/ho imparato che...</p> <p>29. Senti che i test di valutazione/misurazione del dolore come quello qui sotto da endometriosi riescono a rappresentare efficacemente i tuoi dolori?</p> <p>30. In questo momento l'endometriosi influisce su questi aspetti della mia vita (lavoro, affetti, socialità, altro) perché...</p> <p>31. L'idea della maternità per me è...</p> <p>32. Prova a rappresentare il tuo presente con un disegno e allegane la foto, oppure a descriverlo con un brano, una frase, il ricordo di un luogo (o altro) che ti viene in mente...</p> <p>33. Quando penso al mio futuro...</p> <p>34. Durante i colloqui ora mi sento...</p> <p>35. Con i miei medici mi è riuscito facile fare/parlare di/sentirmi ...</p> <p>36. Con i miei medici mi è riuscito difficile/parlare di/sentirmi...</p> <p>37. La parola cronico per me significa...</p> <p>38. Quando sento la parola endometriosi oggi penso...</p> <p>39. In questo momento l'endometriosi influisce su questi aspetti della mia vita (lavoro, affetti,</p>	<p>28. From the doctors I am learning/learned that...</p> <p>29. Do you think that pain assessment tests like the one below can effectively represent your pains?</p> <p>30. At the moment, endometriosis affects these aspects of my life (work, relationships, social life, other) because...</p> <p>31. The idea of motherhood for me is...</p> <p>32. Try to represent your present with a drawing and attach the picture, or describe it with a passage, sentence, memories of a place (or other) that comes to your mind...</p> <p>33. When I think about my future...</p> <p>34. During consultations, I now feel...</p> <p>35. With my doctors, I found it easy to do/talk about/feel...</p> <p>36. With my doctors, I found it difficult to do/talk about/feel...</p> <p>37. The word chronic to me means ...</p> <p>38. When I hear the word endometriosis today, I think ...</p> <p>39. At the moment, endometriosis affects these aspects of my life (work, relationships, social</p>
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socialità, altro) perché...	life, other) because...
40. Fuori dal contesto di cura mi capita di parlare della mia esperienza di endometriosi con...	40. Outside the medical settings, I happen to talk about my experience of endometriosis with...
41. Parlarne mi fa sentire...	41. Talking about it makes me feel...
42. Sento che durante questo percorso di scrittura...	42. Do you feel that during this writing process...
43. L'immagine del mio corpo e di me stessa dopo questo percorso è...	43. The image of my body and myself now is...
44. Prova a rappresentare il tuo presente con un disegno e allegane la foto, oppure a descriverlo con un brano, una frase, il ricordo di un luogo (o altro) che ti viene in mente...	44. Try to represent your present with a drawing and attach the picture, or describe it with a passage, sentence, memories of a place (or other) that comes to your mind...

As the author of the narrative prompts, I based the drafting and the choice of the prompts on different criteria. I used Phillips et al.'s (2023) Comprehensive Clinical Model of Suffering (CCMS), described in Chapter 2, so that different domains and dimensions of pain-related suffering could be explored. Prompts 1, 7, 8, 11, 14, for example, focus on the physical dimension of suffering and on the domain of symptoms. As for the domain of functions, I did not suggest a specific prompt, but I implied it in prompt 9, as, for example, not being able to work relates both to functions one can no longer perform when ill and to roles and relationships (sociocultural dimension). Actually, references to functions emerged spontaneously in the narratives, even if they were not elicited (“dolori, tanti dolori, anche un semplice gesto come lavare i pavimenti”²⁸). The psycho-behavioural dimension was investigated through prompts related to thoughts, like in prompt 23, while the existential dimension was elicited through prompts 6 and 33, related to the perception

²⁸ Pain, so much pain, even a simple task like washing the floors

of the present and future (narrative and worldview). Other prompts specifically relate to the communication with clinicians—what works well and what does not—as in prompts 34, 35, 36. I shared the prompts with the AouS gynaecologists and asked for their review and feedback. Among the prompts, those on the perception of chronicity in endometriosis and on the idea of the pregnancy experience (real or desired) were specifically suggested by the gynaecologists during the preliminary meetings aforementioned. Based on the same meetings, it was agreed that no prompt would be submitted to gynaecologists: they were expected to read and reflect on the patients' diaries, and then share free comments and thoughts on those in the form of a parallel chart. A set of narrative prompts was also designed for the patients' caregivers.

Another feature orienting the choice of the prompts was the idea of coping, here not meant as in Illich's critical view, but as a set of resources to experience also the transformative function of the illness experience, which I tried to convey in prompts such as: *Cosa mi aiuta a distrarmi/Cosa mi dà più fiducia in questo percorso/Cosa sto scoprendo/ho scoperto di me stessa in questo percorso*. As I said, patients and caregivers can add free prompts or skip suggested prompts. This *skipping* can be casual, of course, but also indicative of topics they are more or less willing to write about.

Some of the prompts are repeated literally or slightly edited, but they stay similar at content level: the doctors involved in the project meet their patients every six months, so the goal of the repetition was to keep track of eventual shifts in the view, awareness of some topics or in the attitude towards pain and illness *across* the writing process, as in prompt 6, 8, 9 (on the perception of present, or on how the disease impacts the patient's life) or the prompt in which the patient remembers how the word endometriosis sounded to her the first time and how she feels now when she hears it.

One of these repeated prompts is the question on the adequacy of the pain assessment tools in use (prompt 6), which was administered along with the prompt on the patient's personal symbolic representation of pain (7). This match is due to the discrepancies between the clinical and

the patient's perception of pain, already discussed in Chapters 3 and 4 and on which I expand in the next section.

Prompts trace also an implicit narrative plot and a temporal path starting with prompt 1 on the symptom onset: this is the breaking biographical point, the beginning of the narrative of the wounded self, which unfolds through several prompts and opens up to the perspective on the present and the future.

It may be objected that the diary as a narrative form is far from the reality of medical life interactions.

Actually, the digital diary structure reflects aspects of oral communication, despite it deploying writing: any medical interview, as also described by Montgomery (1991), and theorised in the model by Philips (2023), consists of information that is partially shared spontaneously and partially elicited and guided by the doctors through questions.

The former corresponds to the free notes that the patients could leave, and the latter are reflected in the prompts that participants were invited to answer. A substantial difference connected to the medium lies in the lack of non-verbal communication, such as eye-contact, conversation rhythm and timing in turn-taking; shift in time and space of communication are also reflected in the use of deixis in the narratives.

The digital diary does not work as a replacement for live medical consultations and does not serve the functions of telemedicine, as specified in the privacy policy subscribed to by doctors and patients. Nevertheless, my goal was that the different dimensions of the illness experience and of pain-related suffering—especially in terms of uncertainty—could be explored also in the digital diary. The doctors meet these patients every six months. So it is true that they have an in-person medical relationship with them, but the range between clinical checks is pretty long. This also accounts for the number and the administration of narrative prompts distributed across a semester. In this way, the digital diary notes written by the patients were expected to ideally fill in the pause between a consultation and the following one.

I have highlighted how the patients' perception of time differs from that of their physicians and how temporality is one of the narrative features that Charon recognises in medicine. Time between medical conversations, which adds up to the feeling of betweenness, to the suspension caused by the ignorance of causes and cure for endometriosis, is not a vacuum: women affected keep living with a chronic and systemic disease which impacts their daily life, as discussed in the previous section. Ignoring or removing this part of the chronic illness experience means underrepresenting their suffering, and not reflecting the *Comprehensive Clinical Model of Suffering* (CCMS, 2023), as well as Cassel's idea of intactness of a person (1982), both illustrated in Chapter 2. The notes, whether free or guided, could fill this temporal void and create continuity in the path of care, reducing the burden of "biographical disruption" (Bury, 1991) already brought about by the illness onset.

One last observation on the choice of diaries as a data collection method: Becker et al. (2022) have researched the utility of *pain and symptom* diaries, thus focusing primarily on the physical dimension of the illness experience and stating that:

Although currently no evidence exists that a symptom diary/questionnaire/app reduces the time to diagnosis or earlier diagnosis, the GDG considers their potential benefit in complementing the traditional history-taking process, as it aids in objectifying pain and empowering women to demonstrate their symptoms. (Annexe, p. 8)

The need for demonstrating and documenting pain is examined in the next section, but I highlight here that the EndoNar diary is not designed to gain only clinical data, as also confirmed in the doctors' feedback collected at the end of the project, but the impact of symptoms and pain on the whole person affected, which is the novelty of NM, and the uncertainty surrounding the endometriosis experience.

As noticed in a recent study on the use of diaries (Bernal Marcos et al., 2024), these are definitely a personal and private space for thoughts, feelings, fears or hopes and as such they serve

an expressing function, but they help to “make sense of the experience of vulnerability, clarifying it, elaborating it, rethinking it” (p. 583).

As I show at the end of this chapter, sending narrative prompts to participants across six months can also show its drawbacks in terms of risks to make the writing task tiring. The access to the platform is something on which I would like to spend a few words because it is made possible not by me as a researcher, nor by the DNM IT-manager, but by the gynaecologists themselves. During the live medical consultation, the gynaecologist shortly describes the project to the patient, and if she wants to participate, the doctor enrolls her. By enrolling the patient, the gynaecologist engages actively in the story sharing, and by presenting the project implicitly says: *I want to know more about you, I want to read your story, I am not only treating you, but I am giving you attention.* This allows them to reset a connection that is easily lost or interrupted in the busy doctor’s agenda and conveys a clear, important message to the patient: *You are not just a clinical case, you are something more than the body I am about to examine:* Cassel’s idea of intactness is somehow at play here.

Moving back to the technical part of the process, the patient gives her contact details. The gynaecologists enter her data in the platform and invite her through email to access it, so that she can start writing or receiving the first prompts and answering.

Figure 21 shows the welcome descriptive message patients can view, followed by the first prompt.

Figure 21


*Welcome message with a short project description*²⁹

²⁹ English Translation: “EndoNar - Digital Narrative Medicine Approaches to Endometriosis” is a digital diary shared with your healthcare team that you can use to share your experience of the disease and your treatment journey. You will be given prompts to help you write. For the time being, you will receive one or two prompts each week. In addition, you can write about anything you consider important at any time by clicking on the “Add story” button. Some prompts may be more interesting to you than others. Please click on “Ignore” if there is a prompt that does not interest you, so that you can receive the next ones. An e-mail will notify you when a new prompt arrives. The team supporting you will read your diary and discuss it with you during face-to-face meetings, so that together you can define a programme that is tailored as closely as

Descrizione per i pazienti

EndoNar - Approcci di Medicina Narrativa Digitale all'Endometriosi è un diario digitale condiviso con il tuo team curante che puoi utilizzare per condividere la tua esperienza della malattia e del percorso di cura. Ti verranno proposti degli stimoli di riflessione che ti accompagneranno nella scrittura. Per il momento ne riceverai uno o due ogni settimana. Inoltre, in qualsiasi momento potrai raccontare tutto quello che ritieni importante con il tasto "Aggiungi storia". Alcuni spunti potrebbero risultarti più interessanti, altri meno. Ti chiediamo di cliccare su "Ignora" se c'è qualche stimolo che non ti interessa, in modo da poter ricevere i successivi. Una e-mail ti avviserà dell'arrivo di un nuovo stimolo. Il team che ti segue leggerà il tuo diario e ne parlerete durante gli incontri in presenza, per definire insieme un percorso il più possibile ritagliato sulle tue esigenze. *Attenzione: non utilizzare il diario per segnalare situazioni che richiedano un intervento immediato.*

#1

 **Mi sono accorta che qualcosa nel mio corpo stava cambiando quando...**

The narrative prompts are sent to patients once or twice a week, sometimes singularly, sometimes grouped if their content is related (e.g. prompt 2, 3 and 4 together or 5 and 6 together). Upon enrolment, the doctor also fills in a short questionnaire, entering basic information on the patient, as Figure 22 shows.

Figure 22

Questionnaire template

Endometriosi: questionario preliminare

Endometriosi: questionario preliminare 09/03/2025

Domanda	Risposta
Quando hai manifestato i primi sintomi? (indicare l'anno se si ricorda)	2012
Quando li hai riportati? (indicare l'anno e il mese se si ricorda)	2012
In quanto tempo hai ricevuto la diagnosi?	circa 60giorni
Da quanto tempo stai seguendo il percorso terapeutico?	13 anni
Durante i colloqui clinici riesci spesso a riportare al personale medico-sanitario quello che vorresti (per esempio ti capita di ricordare solo dopo cose che non ti sono venute in mente durante il colloquio, ma che ti sembrano importanti da chiarire)?	cerco di appuntarmi tutto su un foglio per poi chiedere in sede di visita
Pensi che annotare percezioni legate ai dolori e all'esperienza di endometriosi nella vita quotidiana potrebbe aiutarti a riportarli nei colloqui clinici?	anche
Hai mai scritto un diario sulla tua esperienza di endometriosi?	No
Di solito vai alle visite accompagnata da qualcuno?	No
Che ruolo ha il tuo accompagnatore/la tua accompagnatrice?	
Vorresti essere accompagnata da qualcuno/a?	No

+

In this section, I also analyse the data collected through the questionnaire, with a special focus on the time between the onset of symptoms and their verbalisation in medical interviews, as well as on the patients' attitude towards writing and live communication with clinicians. This

possible to your needs. Please note: do not use the diary to report situations that require immediate intervention.

information provides helpful extra background to the patients' stories and introduces some issues addressed later in the notes. The following two tables are related.

Table 2

Preliminary Questionnaire (1)

Question	Translation
Quando hai manifestato i primi sintomi? (indicare l'anno se si ricorda)	When did you first experience symptoms? (indicate the year if you remember)
Response	Translation
Sono asintomatica	I am asymptomatic
Non ricordo	I don't remember
Prima volta che ho avuto il ciclo	The first time I had my period
2009	2009
2023	2023
Non ho avuto sintomi particolari	I did not have any particular symptoms.
2015	2015
2000	2000
1995	1995
A 13 anni. Due anni dopo il menarca	At 13 years old. Two years after menarche.
2017	2017
Da sempre ho avuto mestruazioni molto dolorose	I have always had very painful periods
1996	1996
2014	2014
Nel 2017, anche se in realtà i primi sintomi sono iniziati intorno ai 13, 14 anni.	In 2017, although the first symptoms actually began around the age of 13 or 14
1986	1986

2007	2007
2012	2012
2020	2020
2021	2021

Table 3*Preliminary Questionnaire (2)*

Question	Translation
Quando hai riportato i primi sintomi? (indicare l'anno e il mese se si ricorda)	When did you report the first symptoms to the doctors?
Response	Translation
non ricordo	I can't remember
2018	2018
2009-2010	2009-2010
Maggio 2023	May 2023
Luglio 2008 anno di intervento	July 2008 Year of my surgery
2016/2017	2016/2017
2003/2004	2003/2004
2020	2020
2012	2012
2017	2017
1989	1989
1998	1998
2015	2015
Settembre 2017	September 2017

1990	1990
giugno 2017	June 2017
2012	2012
2020	2020
Credo di avere parte di una cartella del primo ginecologo. Prima visita a 16/17 anni, il documento potrebbe essere successivo sui 20 anni.	I think I have part of a file from my first gynaecologist. First visit at 16/17 years old, the document could be from when I was around 20.
1989	1989

Comparing the data in the first two tables with other information contained in the diaries, there appears to be an average time span of 7 years between the onset of the symptoms and the moment when they are reported. Furthermore, no direct correlation between this data and profession can be inferred: for instance, patient FB582774D451, C12370EAD9B2, 9E192F9666A5, and 261E60E61929, respectively, a neurophysiopathology technician, two nurses, and a social and health care worker, score different values even if they are all employed in healthcare (respectively 21, 1, 4, and 1 year). The same applies to the two unemployed patients.

Table 4

Preliminary Questionnaire (3)

Question	Translation
In quanto tempo hai ricevuto la diagnosi?	How long did it take to receive the diagnosis?
Response	Translation
È stata una diagnosi incidentale, occorsa durante una normale visita di controllo	It was an incidental diagnosis, made during a routine check-up
2 anni circa	Approximately 2 years

5 anni	5 years
Diagnosticata da subito ma non proposta di operarla fino ad adesso	Diagnosed immediately, but no surgery was proposed until now
Immediatamente, a maggio 2023, durante la visita annuale di controllo prenotata a seguito di un dolore mai avvertito prima	Immediately, in May 2023, during the annual check-up, which was scheduled after a pain never experienced before
1 mese	1 month
5 anni	5 years
6 anni	6 years
Dopo diversi anni in quanto il mio ginecologo non aveva riconosciuto la patologia.	After several years, because my gynaecologist had not recognised the condition.
Dopo 9 anni	After 9 years
1 anno	1 year
32 anni	32 years
Dopo 10 anni	After 10 years
Appena ricoverata in ospedale febbraio 2015	As soon as I was admitted to the hospital, in February 2015
2 anni	2 years
1995	1995
molto velocemente	Very quickly
circa 60 giorni	About 60 days
3 anni	3 years
2014	2014

The average time to diagnosis is 5.7 years. Given the presence of extreme values (like the case of 32 years), the median value calculated is 3 years, which represents the central tendency in this case study.

Table 5

Preliminary Questionnaire (4)

Question	Translation
Da quanto tempo stai seguendo il percorso terapeutico?	How long have you been following your treatment plan?
Response	Translation
Non sto effettuando percorsi terapeutici	I am not following any treatment plan
Da maggio 2024	Since May 2024
7 anni	7 years
5 anni, dal 2019 al 2024	5 years, from 2019 to 2024
1 anno, da gennaio 2024	1 year, since January 2024
17 anni	17 years
2 anni	2 years
12 anni	12 years
5 anni	5 years
5 anni	5 years
4 anni, dal 2019 al 2023	4 years, from 2019 to 2023
2 anni	2 years
1 anno e 1/2	1 year and a half
9 anni, dal 2015 al 2024 anno in cui sono entrata in menopausa	9 years, from 2015 to 2024, the year I entered menopause
6 anni	6 years

16 anni	16 years
8 anni	8 years
13 anni	13 years
3 anni	3 years
Credo dall'anno scorso quando ho fatto la prima visita a Siena presso il vostro centro endometriosi	I believe since last year, when I had my first visit to your endometriosis centre in Siena

Table 6.*Preliminary Questionnaire (5)*

Question	Translation
Durante i colloqui clinici riesci spesso a riportare al personale medico-sanitario quello che vorresti (per esempio ti capita di ricordare solo dopo cose che non ti sono venute in mente durante il colloquio, ma che ti sembrano importanti da chiarire)?	During clinical interviews, are you often able to tell the medical staff what you want to say (for example, do you sometimes remember things after the interview that did not occur to you during the interview, but which you feel are important to clarify)?
Response	Translation
Sì, sono sempre tutti molto gentili.	Yes, they are always very kind.
Non riesco a riportare tutto perché non me lo chiedono e avevo anche l'ansia e la paura che mi dicessero che la malattia è peggiorata.	I can't report everything because they don't ask me and I was also anxious and afraid that they would tell me that the disease had worsened.
No, penso di aver detto sempre tutti i sintomi o dolori riportati.	No, I think I always reported all the symptoms or pains I experienced.
Dipende, certe volte capita di ricordare delle	It depends, sometimes I only remember things

cose solo dopo che il colloquio è terminato.	after the interview is over.
No.	No.
Non sempre, spesso mi vengono in mente dopo il colloquio.	I am not always able to report the symptoms, and they often come to mind after the consultation.
Sì, riesco a riportare di solito tutto.	Yes, I am usually able to report everything.
Sì.	Yes.
In genere riesco a essere abbastanza dettagliata.	I am usually able to be quite detailed.
Sì riesco perfettamente.	Yes, I can do so perfectly.
No, non sempre.	No, not always.
Alcune volte non riesco a riportare tutto ed a fare le domande che vorrei.	Sometimes I am unable to report everything and ask the questions I would like to.
No.	No.
Sì, riesco sempre a chiedere tutto quello che vorrei, perché prima della consulenza mi segno tutto ciò che secondo me è importante dire o sapere (sintomi nuovi, terapie in corso, etc.).	Yes, I am always able to ask everything I would like to, because before the consultation I write down everything that I think is important to say or know (new symptoms, ongoing treatments, etc.).
No più delle volte non riesco a finire il discorso.	No, most of the time I can't finish what I want to say.
Sì, cerco sempre di riportare tutto quello che ritengo importante.	Yes, I always try to report everything I think is important.
Cerco di appuntarmi tutto su un foglio per poi chiedere in sede di visita.	I try to write everything down on a piece of paper and then ask during the consultation.
Ho riportato ma non mi hanno ascoltato.	I reported it, but they didn't listen to me.

Raramente.	Rarely.
Certo! Tantissime cose le do per scontate perché per me sono normali, è difficile capire che non lo sono, figuriamoci spiegarle o pensare che magari sono importanti da dire.	Of course! I take many things for granted because they are normal for me. It's difficult to understand that they are not, let alone explain them or think that they might be important to mention.

45% of respondents stated that they usually convey what they want to their doctors, perhaps with the help of notes where they write down questions to ask before the medical interview (22%). The remaining respondents (55%) stated that they do not ask everything they want to during the medical consultation, or at least not always. The reasons mentioned are: remembering questions only after the consultation has ended (18%), being unable to finish what they want to say, or not being listened to (18% each). Two other meaningful answers concern the emotional state of patients before the medical interview: their fear of discovering that the condition has worsened and the fact that doctors do not ask them questions. So the patient does not ask questions, but she actually expects to be asked. One last comment is that the inability to distinguish what is *normal* from what is not in endometriosis makes it difficult to choose relevant questions and ask them.

Table 7

Preliminary Questionnaire (6)

Question	Translation
Pensi che annotare percezioni legate ai dolori e all'esperienza di endometriosi nella vita quotidiana potrebbe aiutarti a riportarli nei colloqui clinici?	Do you think that writing down your perceptions of pain and your experience of endometriosis in everyday life could help you to bring them up in clinical consultations?
Response	Translation

Fortunatamente non soffro di dolori	Fortunately, I don't suffer from pain
Sì certo	Yes, of course
Penso di sì	I think so
Certamente	Certainly
Sì	Yes
Sì	Yes
Sì	Yes
Assolutamente sì	Absolutely yes
Sì	Yes
No	No
Forse	Maybe
Assolutamente sì	Absolutely yes
Sì	Yes
Sicuramente	Definitely
Nella mia esperienza annotare la percezione dei dolori non mi ha aiutato nei colloqui clinici	In my experience, noting down my perception of pain has not helped me in clinical interviews
Sì, potrebbe essere d'aiuto	Yes, it could be helpful
Anche	Also
I medici non ci vogliono ascoltare	Doctors do not want to listen to us.
Certo, lo trovo utile	Of course, I find it useful.
Credo di sì, penso a me e a come non mi sono resa conto che tutto quello che per me era normale, non lo era, non vedevo la patologia perché avevo smesso di ascoltare qualunque	I think so. I think about myself and how I did not realise that everything normal for me was not normal. I did not see the pathology because I had stopped listening to any symptoms. It was easier

sintomo. Era più facile ignorare che affrontare. Considerando il fatto che non mi è mai stata consigliata una cura solo per l'endometriosi. Operazione per la cisti: sì. Farmaci per l'infertilità: sì. Percorso di fecondazione: sì. Ma anche lì una vera cura per l'endometriosi: no.	to ignore than to face Considering the fact that I was never recommended a specific treatment for endometriosis. Surgery for cysts: yes. Infertility drugs: yes. Fertility treatment: yes. But even then, a real treatment for endometriosis: no
---	--

75% of participants believe that keeping a diary on the perceptions of pain and on the personal experience of endometriosis in everyday life can be useful for clinical interviews. Two answers confirm the lack of a listening attitude by doctors and the fact that the diary could help to recognise to what extent pain experienced is *normal*, a topic on which I expand in the next sections based on the frequent reference to normality in the patients' notes.

Table 8

Preliminary Questionnaire (7)

Question	Translation
Hai mai scritto un diario sulla tua esperienza di endometriosi?	Have you ever written a diary about your experience with endometriosis?
Response	Translation
Sì (8%)	Yes (8%)
No (92 %)	No (92 %)
Question	Translation
Di solito vai alle visite accompagnata da qualcuno?	Do you usually go to appointments accompanied by someone?
Response	Translation

Si (35%)	Yes (35%)
No (65%)	No (65%)
Question	Translation
Che ruolo ha il tuo accompagnatore/la tua accompagnatrice	What role does your companion have?
Response	Translation
Parente (44%)	A relative (44%)
Qualcuno/a che ti assiste quando non stai bene (22%)	Someone who looks after you when you are unwell (22%)
Marito (11%)	My husband (11 %)
Mi accompagna mio marito ma per una questione pratica, tipo guidare, cosa che a volte mi dà fastidio dopo una visita, lo fa sentire utile. Sennò preferirei stare sola.	My husband accompanies me, but for practical reasons, such as driving, which sometimes bothers me after a visit, but it makes him feel useful. Otherwise, I would prefer to be alone.
Question	Translation
Would you like someone to accompany you?	Would you like someone to accompany you?
Response	Translation
Si (18%)	Yes (18%)
No (82%)	No (82%)

To conclude the section on the questionnaire, the last three questions concern the role of the caregiver. Patients prefer to go alone to medical interviews, and when they are accompanied by someone, this is their partner, sometimes just for practical reasons, or a relative, or someone who takes just cares of them when they are unwell. Most participants have never written a diary about their experience of endometriosis. 69 patients were enrolled in the project, 294 prompts were sent to them, 249 of these prompts were viewed, 222 were answered, and 39 free notes were written. 23

patients actively wrote notes on the platform. Two patients responded to all the prompts administered.

I collected the patients' and doctors' narratives in a corpus of 17,728 words and 22 stories (see Annexe). I analysed the patients' stories through the narrative method applied by Rita Charon to clinical practice (2006), already illustrated in the subsection "Columbia's approach" (Chapter 3).

In Chapter 3, I have already provided sources for the definition of NM as a method according to Charon (2012) and the Italian official guidelines (ISS, 2014).

The first moment of the triad is attention, consisting of reaching the patient (Charon, 2001), reading their story with open-mindedness and care for details. The methodological tool to achieve attention is the close reading drill (described in Chapter 3) that Charon carries out to train the narrative competence in her students and colleagues. This aims at identifying frame, form, time, plot, and desire, the five narrative features to be considered when approaching an (illness) story. Hence, these categories support me in analysing the stories collected in the EndoNar project. The definition of textual analysis by Alan McKee (2003) is particularly meaningful in this respect, since it echoes the gist of the narrative method discussed so far, the need to search for meanings in illness stories and the idea that a story offers a *wide* range of possible interpretations.:

a way for researchers to gather information about how human beings make sense of the world. [...] When we perform textual analysis on a text, we make an educated guess at *some of the most likely interpretations* that might be made of that text [...]. (p. 1, emphasis added)

Among the narrative elements of close reading, in this analysis, I focus particularly on the form, since, according to Charon (2006), the way a story is recounted matters as much as what is recounted:

I listen not only for the content of his narrative but also for its form—its temporal course, its images, its associated subplots, its silences, where he chooses to begin in telling of himself, how he sequences symptoms with other life events. (p. 177)

The analysis carried out in this chapter will also be enriched by quantitative data obtained by processing electronically the EndoNar corpus through the software Sketch Engine. More precisely, these additional data inform on the frequency and co-occurrences of specific words and structures related to knowledge, fear, and normality in the endometriosis experiences as expressed in the stories of my corpus. Despite the relatively small size of the EndoNar corpus, this information aims to support the qualitative analysis with quantitative evidence that, in line with Brookes and Collins's claims, is also easily accepted in "the scientific evidence-based world of medicine" (2023: 21).

As much as their gynaecologists, I am only *one* of the readers of the participants' stories; the way I close-read them reflects my reception and interpretation, my choice does not claim to represent the self these women wanted to bring into their diaries. In this respect, the concept of intersubjectivity illustrated in Chapter 3 finds now its application: textuality is the foundation of the relation between the writers and me as well as between the writers and their clinicians. In the latter case, the relation is nurtured by words but also enriched through the live face-to-face connection and the other aspects of medical interactions (physical examinations, non-verbal language and so on) that I cannot investigate in this project. It follows that my interpretation of these stories will differ from that of their doctors.

The doctors were not specifically trained in NM courses, as it happens at Columbia University: I seized every possible chance to make them familiar with Charon's narrative approach through online and in-person meetings, along with the anthropologist from DNM, who also brought examples of DNM projects already carried out in other medical centres and healthcare institutions. Nevertheless, this cannot equal a systematic educational approach that could be introduced at an academic level³⁰. On the other hand, Charon says (2006):

³⁰ I conducted a survey and wrote an article (currently under review) on NM teaching at the University of Siena. The results show the value of including NM as a *mandatory* discipline in academic education and training, based on the benefits it offers to both doctors and patients.

I am not trying to train literary scholars, and I am not trying to train doctors or nurses or medical students to provide psychological care to troubled patients. Instead, I am trying to strengthen those cognitive and imaginative abilities that are required for one person to take in and appreciate the representation—and therefore the reality—of another. (p. 113)

In the same way, the essence of this project is also to improve the narrative competence of clinicians in grasping the patients' experience of uncertainty brought about by endometriosis and also representing their own medical uncertainty (if any) in treating these women.

I analyse most of the notes in the same order in which participants answered the prompts. Yet, since writing, especially when autobiographic, often follows its own path regardless of thematic consistency, in some cases, I may also cite and discuss the notes for their relevance in terms of concepts and style rather than their correspondence to a prompt. The original corpus in Italian is available in Annexe 1 to this thesis, whereas here I present excerpts of the texts with their translation into English. The English translations available in the tables were provided by DeepL software and post-edited by me. In the excerpts in Italian I presented in the tables of this chapter, I corrected spelling, punctuation and spacing errors related to digital writing. I deliberately omitted full stops at the end of the Italian excerpts just for graphic consistency, since punctuation was very irregular in the original text, available in Annexe 1. In order to facilitate reading of the analysis, references to the excerpts in the body of the text are only in Italian, while the translation in English is already available in the tables. Participants in this project are identified by a code for privacy reasons.

Analysis of the EndoNar corpus

The changing body. In this subsection, I analyse the patients' answers to the first prompt, concerning the onset of symptoms, as shown in Table 9. Although the perception of pain is a topic that informs the whole corpus and is also covered in the responses to other prompts, I found it meaningful to focus on the beginning of the endometriosis experience.

Table 9

Memories

Prompt	Mi sono accorta che qualcosa nel mio corpo stava cambiando quando...	I noticed that something in my body was changing when...
Participant	Excerpt	Translation
FF49204B9548	<p>Oddio non so proprio da dove cominciare...</p> <p>LA PRIMA VOLTA</p> <p>Ricordo di essere andata, stata portata a una visita, il Dottore era un Ginecologo.</p> <p>Mi ricordo l'ecografia, l'unica cosa che poteva fare essendo ancora vergine.</p> <p>Ricordo che ero andata per un problema di pelle. Acne. Quando hai 16 o 17 anni è un problema veramente importante!</p>	<p>Oh my God, I don't even know where to start...</p> <p>THE FIRST TIME</p> <p>I remember going, being taken to an appointment, the doctor was a Gynaecologist.</p> <p>I remember the ultrasound scan, the only thing he could do as I was still a virgin.</p> <p>I remember I went because of a skin problem. Acne. When you're 16 or 17, it's a really big problem!</p>
ED1AECDDDB82A	<p>Il primo giorno che ho avuto il ciclo da ragazzina ho avuto dolori fortissimi, duravano almeno i 3 primi giorni del ciclo. Ogni mese mi dovevano fare un'iniezione per addormentarmi, e questa fase è durata fino al 2018. Prima andavo in</p>	<p>The first day I had my period as a teenager, I had severe pain that lasted at least the first three days of my cycle. Every month, I had to have an injection to put me to sleep, and this phase lasted until 2018. I used to go to the hospital because of these pelvic</p>

ospedale per via di questi dolori	pains, but the doctors couldn't see
pelvici ma i dottori non vedevano	anything. I started going to the
niente, ho iniziato ad andare in	hospital in 2015 and 2016, but it
ospedale nel 2015-2016, è solo nel	wasn't until 2018 that I was
2018 che mi hanno diagnosticata e	diagnosed and operated on for
operata di endometriosi, ed era troppo	endometriosis. By then, it was too
tardi perché le tube erano già state	late because my fallopian tubes had
infettate, hanno dovuto levarle.	already become infected and had to
<i>Ancora non riesco a parlarne</i> , perché	be removed. <i>I still can't talk about it</i>
a tutto questo si è aggiunto il	because, on top of all this, there was
problema di infertilità.	the problem of infertility.

The first note in the table (FF49204B9548) opens up with: “Oddio, non so proprio da dove cominciare...”. This incipit is quite emblematic and rich at a semantic and stylistic level, since it includes a divine invocation and an epistemic verb in a negative form, all within an idiom. Although in current Italian it is no longer typical of the religious domain and has become part of standard language, the expression “Oddio” can unconsciously recognise the inability to face something with limited human means, and retains the sense of disorientation and fear in front of a doubt or an unexpected situation (online UTET Dictionary, 2025, n. d.).

This interjection points out to something that shakes our certainties, while the idiom “non so proprio da dove cominciare” is also typical of situations in which there are too many thoughts or events to deal with, for example when one has to reorder, rearrange or simply tidy up a room or start a challenging task: it’s the reaction to apparently unmanageable chaos. Chaos is also one of the features of illness stories in Frank’s view, outlined in Chapter 3. In this patient’s diary, chaos and quest follow each other periodically throughout the notes.

Paradoxically, “cominciare” marks also a punctual event in the patient’s temporal perception: the onset of the symptoms is the end of the old, known self and life and the beginning of a new puzzling phase. The narration dates back to the patient’s youth, so her endometriosis experience starts at a very young age, when her worries included, among others, a healthy-looking complexion. She gets to know about her endometriosis casually.

In patient ED1AECDDDB82A’s memories, the onset of her endometriosis symptoms dates back to her puberty, too. The first sentence of this note is emblematic of the meaning of periods for women with endometriosis. Generally speaking, the first menstruation, marking a shift in the female body and its ability to conceive and give birth, is per se a delicate and ambivalent moment (Deutsch, 1944; De Beauvoir, 2011). It opens up a new life chapter, but it also challenges the woman’s self-perception and self-image, especially at a physical level: the body changes in terms of look, of biological processes and symbolic meanings of renewal: curiously, just as snakes shed their skins, patient FF49204B9548 found out about her endometriosis because of dermatological problems arising in her teenage years. At the same time, the menstrual experience is often accompanied, when not made hateful, by pain and its impact on the psycho-physical balance. Given the increasing severity of endometriosis pain during periods, as mentioned in Chapter 4, it is hardly surprising that in women affected, femininity and pain unfold on parallel paths. For this patient, the beginning of her youth clashed with the beginning of such unbearable pains that she needed to go to the hospital and be sedated there. Only three years later, she was diagnosed with endometriosis and had an operation. Although this note is just the answer to the first narrative prompt available on the digital diary, she condensed here most of her whole experience from symptoms through diagnosis to surgery, shifting in a few lines from the first day of her entrance to a new stage in life to the day when it was too late. The gradual transition from the Italian *Passato Prossimo* (Present Perfect) to the *Imperfetto* (relatable to the Past Simple) mirrors that from the sudden and puzzling first episodes (“*Il primo giorno che ho avuto il ciclo*”) to the immanence and

immutability of the post-surgery consequences (“era troppo tardi”). Once again, all these events are not easy to put into words (“Ancora non riesco a parlarne”, emphasis added in Table 9).

As shown in Table 9, the early beginning of endometriosis and its coincidence with the first menstruation are also frequently documented by other participants.

Table 10

The beginning

Prompt	Mi sono accorta che qualcosa nel mio corpo stava cambiando quando...	I noticed that something in my body was changing when...
Participant	Excerpt	Translation
9E192F9666A5	Dal momento che ho avuto il ciclo mestruale, la mia vita è cambiata, [...] passavo da 4 a 6 giorni a letto ripiegata dai dolori	Since I started my period, my life has changed. [...] I spent four to six days in bed, doubled over in pain.
9F88481FF3BC	Ho fatto la mia prima visita ginecologica nel luglio 2015 (all'età di 14 anni) per cicli abbondanti e per familiarità di endometriosi	I had my first gynaecological examination in July 2015 (at the age of 14) due to heavy periods and a family history of endometriosis.
B60252BCF5B1	Dopo il menarca, progressivamente i dolori erano più intensi. A 15 anni prendevo un Moment ³¹ , a 16 anni 6 Moment.	After my first period, the pain gradually became more intense. At 15, I was taking one Moment tablet, and at 16, I was taking six.
	Ricordo che almeno dai 14 anni ho	I remember that from the age of 14 at

³¹ Italian name of a common painkiller.

	iniziato ad avere dolori fortissimi durante le mestruazioni	least, I started to experience severe pain during my period.
5CB9848575B2	Quando avevo solo 13 anni, mi ricordo come il dolore durante il ciclo mestruale diventasse per me, e solo per me, invalidante	When I was only 13 years old, I remember how the pain during my period became debilitating for me, just for me.
C76DBBDB968C	Ho iniziato ad avere problemi intorno ai 18 anni	I started having problems when I was around 18 years old.
C12370EAD9B2	Durante il turno di notte in ospedale ebbi un forte dolore al fianco destro	During a night shift at the hospital, I had severe pain in my right side.
CD1D49DBA94A	Ero arrivata ad avere dolori da ciclo fortissimi per circa 22 giorni al mese	I ended up having extremely severe period pain that lasted for about 22 days a month.

Participants tend to choose a wide range of verb tenses to recall their past, showing a preference both for present perfect, with which they stress the long duration of their discomfort (“Dal momento che ho avuto il ciclo mestruale, la mia vita è cambiata”), and for the Italian Imperfetto, used for regular actions in the past, like in the English form “I used to do something”, which renders the pain relentlessness or escalation (“passavo da 4 a 6 giorni a letto”, “progressivamente i dolori erano più intensi. A 15 anni prendevo un Moment, a 16 anni 6 Moment.”). Patients also tend to set a specific starting point with temporal deitics (“dai 14 anni, nel luglio 2015”, etc.), but this is not always the case: in “Durante il turno di notte in ospedale ebbi un forte dolore al fianco destro”, for example, the punctual aspect of the action conveyed by the Italian Passato Remoto represents a breaking and turning point in an unspecified moment in time, just

during a generic night work shift (the writer is a nurse herself). The lack of temporal references is not uncommon in medical interviews: in his pivotal 1986 study, Mishler writes about a doctor who finds out about the considerable alcohol intake of a woman patient with abdominal pain, and their dialogue unfolds as follows: “How long have you been drinking so heavily?” - “Since my husband died.” - “How long ago was that?” (1984, p. 85). The closer medical investigation emerging from the doctor’s second question shows that while the he wants to place the patient’s symptoms in chronological order, perhaps to fit them into a temporal biological reasoning, the patient answers just according to the events that marked her life, trying in turn, to make *her personal* sense out of them.

While the notes analysed so far seem to suggest a temporal pattern in the onset and severity of pain, other participants do not report any symptoms and are diagnosed just incidentally.

Table 11.

Silent endometriosis

Prompt	Mi sono accorta che qualcosa nel mio corpo stava cambiando quando...	I noticed that something in my body was changing when...
Participant	Excerpt	Translation
9364262644F5	La mia è stata una diagnosi incidentale, durante una normale visita di controllo. Non sono mai stata sintomatica	My diagnosis was incidental, during a routine check-up. I have never had any symptoms
BC650EA37D16	Non ho avuto segnali di cambiamento. Ad aprile 2008 mi fa male la schiena e da lì tramite ricovero PS (pronto soccorso) per sospetta colica renale [...] si riscontra una massa all’utero e [...] mi diagnosticano un’endometriosi	I had no signs of change. In April 2008, I had back pain and was admitted to A&E with suspected renal colic [...] where a mass was found in my uterus and [...] I was diagnosed with stage- 4

	al 4° stadio	endometriosis
C3699250CB72	In realtà non mi sono mai accorta di avere qualcosa di diverso, mai sentito dolore o flussi particolari. Non sapevo di avere l'endometriosi fin quando non restavo incinta dopo diversi mesi di tentativi. Non avevo sintomi inizialmente [...]	In reality, I never realised that I had anything different; I never felt any pain or had any unusual bleeding. I didn't know I had endometriosis until I got pregnant after several months of trying. I didn't have any symptoms at first [...]
A4D91660344E	Dubbio della ginecologa a seguito di una visita con eco di routine	A doubt raised by the gynaecologist following a routine ultrasound scan

These last notes provide a glimpse into the unpredictability and uncertainty of endometriosis: the *silent* form that it can take on, which spares patients painful symptoms but can leave them completely unaware of the disease by which they are affected, until this shows up after facing difficulty conceiving, as in C3699250CB72's note, or just unexpectedly and violently, as it happened to patient BC650EA37D16.

Table 12

The most memorable episode

Prompt	L'episodio della mia esperienza di endometriosi che mi è rimasto più impresso è...	The episode of my endometriosis experience that has stuck with me the most is...
Participant	Excerpt	Translation
1D89FB3AF555	Quando per quasi tre mesi ininterrottamente ho avuto il ciclo	When I had my period for almost three months straight, and no one, not even my

	<p>mestruale e nessuno, neanche il ginecologo, sapeva darmi una spiegazione del perché mi stesse succedendo ciò</p>	<p>gynaecologist, could give me an explanation as to why this was happening to me.</p>
A55769E5659F	<p>La prima volta ho provato un dolore lancinante, non riuscivo a respirare, né a stare in piedi eretta. Pensavo di svenire da un momento all'altro e mi sono trascinata sui gomiti sul piano della cucina per arrivare a prendere un bicchiere d'acqua per prendere un antidolorifico</p>	<p>The first time, I felt a sharp pain, I couldn't breathe or stand upright. I thought I was going to faint at any moment, so I dragged myself on my elbows across the kitchen floor to get a glass of water and take a painkiller</p>
ED1AECDDDB82A	<p>Quando ho iniziato avere perdite di sangue, cioè perdevo sangue dopo e prima il ciclo, avevo allergie alle dita ogni volta che si avvicina il giorno del ciclo, avevo anche sempre la febbre alta ero sempre bollente</p>	<p>When I started having blood loss, that is, I was bleeding before, and after my period. I had allergies on my fingers every time my period was approaching. I also always had a high fever and I was always burning up.</p>
9E80F99DA04A	<p>Il periodo dopo il primo intervento dove feci per tre mesi iniezioni di Enantone e nonostante fosse inverno dormivo spesso con le finestre aperte, ricordo benissimo</p>	<p>The period after the first operation, when I had Enantone injections for three months and, even though it was winter, I often slept with the windows open. I remember very well the hot flushes that would come</p>

<p>le vampate che mi prendevano all'improvviso, mentre ero a lavoro a contatto con il pubblico ed ero costretta a nascondermi, ricordo il sudore che mi gocciolava dalla fronte, ecco, essendo abituata ad una malattia nascosta, con quella cura fu piuttosto evidente a chi frequentavo quotidianamente che avessi un problema, ricordo che mi sentivo spesso in imbarazzo per questi episodi</p>	<p>on suddenly while I was at work in contact with the public, and I was forced to hide. I remember the sweat dripping from my forehead. You see, being used to a hidden illness, with that treatment, it was quite obvious to those I met every day that I had a problem. I remember often feeling embarrassed about these episodes.</p>
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<p>B60252BCF5B1 La prima colica diffusa all'addome... Ero al mare e stavo parlando con una vicina di bungalow, il mio cane era accucciato dietro ai miei piedi. Distrattamente pestai la sua coda ed il suo guaito mi fece sobbalzare... Improvvisamente ed in modo molto violento si diffusero dolori in tutto l'addome con una concentrazione al ventre e allo stomaco. Del tutto inaspettati, arrivarono i dolori da ciclo e</p>	<p>The first widespread abdominal pain... I was at the seaside talking to a neighbour in the bungalow next door, and my dog was crouched behind my feet. I absent-mindedly stepped on his tail, and his yelp made me jump... Suddenly and very violently, pain spread throughout my abdomen, concentrated in my belly and stomach. Completely unexpectedly, I had period pains and very heavy menstruation... If I hadn't been in a state of constant irregularity, I would have thought it was a haemorrhage, but being used to</p>
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<p>mestruazioni molto abbondanti...</p> <p>Se non fossi in uno stato di costante irregolarità avrei pensato ad un'emorragia, ma essendo abituata a dolori più intensi, pensai all'influenza del caldo, di un mese "storto" o della sfiga e cercai di gestirla con la mia farmacia personale. Due giorni a letto... Non riuscivo ad alzarmi... quando riuscii a mettermi in piedi, per non rovinare la vacanza a tutti, cercai di fare con calma una vita normale...ma non ci riuscii, era come se avessi costantemente un sassolino nello stomaco, ad ogni passo lo sentivo rimbalzare... se lo ignoravo, peggiorava e sentivo che ritornavano i dolori ai fianchi e reni... Schiena addome...</p>	<p>more intense pain, I thought it was the influence of the heat, a "bad" month or bad luck, and I tried to manage it with my personal medicine cabinet. Two days in bed... I couldn't get up... when I managed to stand up, so as not to ruin everyone's holiday, I tried to calmly go about my normal life... but I couldn't. It was as if I constantly had a rock in my stomach, and with every step...I felt it bouncing... If I ignored it, it got worse, and I felt the pain returning in my hips and kidneys... Back, abdomen...</p>
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 FB582774D451

<p>Ricordo, però, un giorno in particolare: ...ero in preda alle paranoie, disperata... mi sentivo sola, più di sempre. Decisi di scrivere ad alcune ragazze toscane</p>	<p>I remember one day in particular: I was feeling paranoid and desperate... I felt more alone than ever. I decided to write to some girls from Tuscany I had got in touch with, intending to create a</p>
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con cui ero entrata in contatto, con l'obiettivo di creare un gruppo WhatsApp tutto per noi. Doveva essere il nostro “diario segreto”, dove potevamo scambiarci informazioni utili, ma anche confidenze e sfoghi. Dove sentirsi meno sole. Dalle risposte immediate alla mia richiesta, ho capito che anche loro cercavano quello che io stessa stavo cercando: aiuto, comprensione, condivisione, supporto e, perché no, anche un po' di leggerezza! [...] Le ragazze sono meravigliose ed uniche, tutte con storie così simili e diverse tra loro allo stesso tempo. [...] Quando si condividono problemi e delusioni, tutto diventa più sopportabile. Le ragazze si sentono libere di parlare di tutto, in uno spazio nostro e “intimo”. Sono orgogliosa di loro e di quello che abbiamo costruito insieme!

WhatsApp group just for us. It was to be our “secret diary”, where we could exchange useful information, but also confidences and vent our feelings. Where we could feel less alone. From the immediate responses to my request, I realised that they were also looking for what I was looking for: help, understanding, sharing, support and, why not, even a little light-heartedness! [...] The girls are wonderful and unique, all with stories that are so similar and yet so different at the same time. [...] When you share your problems and disappointments, everything becomes more bearable. The girls feel free to talk about anything in our own “intimate” space. I am proud of them and what we have built together!

BC650EA37D16	<p>L'episodio che mi è rimasto impresso è quando mi hanno detto che a causa dell'intervento dove mi hanno diagnosticato l'endometriosi ero andata in menopausa e non avrei potuto avere figli, e che non avrei potuto neanche con fecondazione assistita</p>	<p>The episode that stuck with me was when they told me that because of the surgery where I was diagnosed with endometriosis, I had gone into menopause and would not be able to have children, not even with assisted fertilisation.</p>
C3699250CB72	<p>Non aver avuto figli e un aborto dopo Fivet³²</p>	<p>Not having children and an abortion after IVF³³</p>
70CB0C5D018D	<p>Sicuramente il momento in cui mi hanno detto che sarei andata in "menopausa forzata" prendendo la pillola continuativa. Non avere il ciclo mi alleggerisce perché non ho più emorragie, ma mi preoccupa un po' per eventuali ripercussioni sulla mia salute. Mi dà sempre la sensazione di essere come sterile non avere più il ciclo e di non poter avere bambini o bambine in futuro</p>	<p>Definitely when they told me I would go into "forced menopause" by taking the continuous pill. Not having my period makes me feel better because I no longer have heavy bleeding, but I am a little worried about the possible repercussions on my health. Not having my period always makes me feel like I'm infertile and won't be able to have children in the future</p>

³² In vitro fertilisation.

³³ In vitro fertilisation.

In the narration of the events that most marked the participants' memories, two different narrative features can be identified.

On the one hand, writers provide detailed and vivid descriptions of physical processes (“si diffusero dolori in tutto l'addome con una concentrazione al ventre e allo stomaco”) and contexts (“ero al mare e stavo parlando”). For one of these patients (9E80F99DA04A), memories date back to the moment in which her disease could no longer be concealed in her social and professional environment, causing her embarrassment and distress (“essendo abituata a una malattia nascosta fu piuttosto evidente a chi frequentavo quotidianamente che avessi un problema, ricordo che mi sentivo spesso in imbarazzo per questi episodi”): the close placement of the adjective “nascosta” to “evidente” marks this shift and the unplanned revelation.

These narratives feature a parallel description of physiological processes (“le vampate”, “il sudore che mi gocciolava dalla fronte”) and feelings (“imbarazzo”), confirming how pain and distress, in this case related to the effects of the pharmacological treatment, always involve both body and mind, acting at more than one level, as *pain related suffering* (Chapter 2). Among these relatively long notes, one stands out for the positive and constructive reaction to the feeling of helplessness and loneliness: patient FB582774D451 creates a chat for women with endometriosis, where common experiences, but not necessarily related to the condition, could be shared. This allows members to support each other in a safe space (“in uno spazio nostro e ‘intimo’”) and creates a sense of commonality (Aglen et al., 2011) that seems to relieve them from rumination, desperation and extreme loneliness (“ero in preda alle paranoie, disperata... mi sentivo sola, più di sempre...”). A deep sense of loneliness characterizes the illness experience, that marks distance and isolation from the others' healthy life (Sontag, 1978). It also underlies the corpus stories as proved by the 14 occurrences of the adjective “solo” (lonely). In this context the adjective suggests also a lack of answers, as if loneliness were intensified by the ignorance of the causes of endometriosis. In the doctor-patient relationship, when diagnosis and the course of the disease are known and predictable, doctors are viewed as a source of certainty deriving from their expertise. In more complex cases,

when the cause and development of the disease are not clear nor under control, medical epistemic authority falters, and both the patient and the doctor are alone in facing the unknown. If the doctor does not trust the patient, neither acknowledges, nor “honours” (Charon, 2006) their stories, the sufferer’s feeling of loneliness is even deeper. In this respect the self-help group provides the emotional support and mutual listening missing in the medical encounter and allows its members to share the diverse dimensions of illness that seem to find little room in the medical interview (“mariti che scappano, amiche che non capiscono, datori di lavoro che ti licenziano per i troppi certificati di assenza”).

Unlike the group of notes just described, other patients use a more concise narrative style, in which a more reflective attitude prevails over the physical dimension of illness. The most emblematic events of their illness experience date back to the first correct diagnosis, when they realized the potential impact of endometriosis on their future, first of all on their fertility. In contrast, in patient 1D89FB3AF555’s note, it is the *lack* of a diagnosis despite worrying symptoms to be recalled as the most traumatizing moment: “nessuno, neanche il ginecologo, sapeva darmi una spiegazione del perché mi stesse succedendo ciò”. Through a meaningful use of negative pronouns and adverbs (“nessuno, neanche il ginecologo”) and verbal collocations related to the field of investigation and explanations (“darmi una spiegazione del perché”), this brief note is quite emblematic of the angst in which uncertainty can turn. By specifying “neanche il ginecologo”, the patient singles out the role and expectations linked to the medical profession, showing that in some respects doctors are subject to the same limits of laypeople’s knowledge. In all the notes, the temporal adverbs highlight the unpredictability and irregularity of symptoms, oscillating between “ininterrottamente” and “da un momento all’altro”, “prima e dopo il ciclo”, “ogni volta che si avvicinava il ciclo”, “all’improvviso”, “improvvisamente ed in modo molto violento”, “del tutto inaspettati”. The oxymoron “costante irregolarità” in the protasis “se non fossi in uno stato di costante irregolarità” summarizes the difficulty to cope with so many variable symptoms.

Disinformation. This section addresses social awareness of endometriosis among laypeople, the way these talk or *do not* talk about the disease. Responses to this prompt offer insight into the *uncertain* way in which women affected hear about endometriosis before medical consultation. The picture emerging from the analysis is marked by TV programmes or celebrities that become official sources (a dancer and top model and activist are mentioned). Also casual acquaintances and cases in the same family are the options, unless the topic is totally undiscussed.

Table 13

A little-known disease

Prompt	Fuori dal contesto di cura, avevo sentito parlare per la prima volta di endometriosi da...	Outside the treatment setting, I had first heard about endometriosis from...
Participant	Excerpt	Translation
A55769E5659F	Ricordo di non averne mai sentito parlare prima	I remember never having heard of it before
9364262644F5	Amiche che ne soffrivano e durante l'università	Friends who suffered from it and during university
1D89FB3AF555	Ho sentito parlare di endometriosi nel momento in cui mi hanno diagnosticato la patologia	I heard about endometriosis just when I was diagnosed with the condition
BC650EA37D16	Non avevo mai sentito parlare di endometriosi prima che al PS il ginecologo mi dicesse che poteva essere endometriosi	I had never heard of endometriosis before the ER gynaecologist told me it could be endometriosis
C3699250CB72	Da nessuno, non conoscevo la malattia	No one had ever mentioned it to me; I didn't know about the disease

ED1AECDDDB82A	Da un dottore in Francia	From a doctor in France
B60252BCF5B1	In TV, ma non sapevo cosa fosse, qualche cenno qua e là...	On TV, but I didn't know what it was, just a few hints here and there...
FB582774D451	Da un'amica carissima. Quella sera le stavo raccontando che ormai da mesi non riuscivo più a gestire i dolori e le emorragie da ciclo e che nonostante decine di ecografie e visite non era mai saltato fuori niente. [...] Lei, a quel punto, mi disse che ad una sua collega era stata diagnosticata l'endometriosi e che, secondo lei, non era da escludere. [...] Più o meno avevamo gli stessi sintomi. Mi resi conto che la storia di quella ragazza era molto simile alla mia. Avevamo un sacco di cose in comune.	From a dear friend. That evening, I was telling her that for months I had been unable to manage the pain and bleeding from my period and that despite dozens of ultrasounds and examinations, nothing had ever been found. [...] At that point, she told me that a colleague of hers had been diagnosed with endometriosis and that, in her opinion, it was a possibility. [...] We had more or less the same symptoms. I realised that that girl's story was very similar to mine. We had a lot in common
C76DBBDB968C	Ne ho sentito parlare dalla mia mamma che ne soffriva, anche da altre amiche	I heard about it from my mum, who suffered from it, and also from other friends
C12370EAD9B2	La prima volta che sentii parlare di endometriosi ero in servizio in ospedale e venne una ragazza che aveva subito un intervento	The first time I heard about endometriosis was when I was working at the hospital and a girl came in who had undergone a radical operation.

	demolitivo e da lì iniziai a informarmi	That's when I started to find out more about it
70CB0C5D018D	Su Instagram, da una ragazza, (Giorgia Soleri) che ne soffre e ne ha sofferto molto	On Instagram, from a girl (Giorgia Soleri) who suffers and has suffered greatly from it
B60252BCF5B1	Nessuno per ben 14/15 anni aveva usato quel nome [...] Nessuno mai mi ha parlato o ha preso in considerazione quel nome	No one had used that name for 14/15 years [...] No one ever mentioned it to me or considered it
9E80F99DA04A	Prima che mi venisse diagnosticata, avevo sentito parlare di endometriosi in programmi televisivi medico/scientifici, da tutto ciò che avevo appreso in questa modalità avevo subito sospettato di poterne soffrire, è una cosa che ho sentito dentro, quasi visceralmente. Prima di allora né il medico di famiglia né durante le prime visite ginecologiche avevo sentito parlare di tale malattia	Before I was diagnosed, I had heard about endometriosis on medical/scientific television programmes, and from everything I had learned in this way, I immediately suspected that I might be suffering from it. It was something I felt inside, almost viscerally. Before that time, neither my family doctor nor my first gynaecological examinations had mentioned this disease
FF49204B9548	Anni 90 Rossella Brescia Bellissima Famosissima Niente figli per problemi di	The 1990s Rossella Brescia Beautiful Very famous No children due to endometriosis

endometriosi	problems
Ho pensato, voleva continuare la sua carriera...	I thought she wanted to continue her career...
Come siamo bravi a raccontarci le novelle da soli	How good we are at telling ourselves stories

The last three excerpts in the table offer insight into the lived experience of uncertainty of these patients and exemplify the possible ambivalence in the reader/listener's reception of a story. Patient B60252BCF5B1's note emphasizes the ignorance on the disease through the anaphoric repetition of both the pronoun "nessuno" and of the nominal phrase "quel nome". The latter, in turn, through a cohesive strategy of substitution, replaces the medical term "endometriosis", as if the disease, had become unnameable just as much as it was unknown. The frequent use of negative correlative conjunctions ("né il medico di famiglia né durante le prime visite ginecologiche") in 9E80F99DA04A's note, along with negative adverbs ("non, mai") and pronouns ("nessuno") seems to confirm at stylistic level the long-term denial, the non-validation of the pain that patients have undergone, not only in the clinical context but also in their family. Surrounded by total uncertainty, pervasive mistrust made them doubt about themselves or, on the contrary, let them trust just themselves, as the participant 9E80F99DA04A wrote: "avevo subito sospettato di poterne soffrire, è una cosa che ho sentito dentro, quasi visceralmente". With these words, the patient realizes how she privately anticipated the diagnosis, how she felt and sensed it thanks to her body before the doctor named it. The modal adverb "visceralmente" here takes on a literal and metaphorical meaning, as its meaning refers to the abdomen, the main pain location in endometriosis. This recalls the embodied space of the patients' psycho-physical distress: "viscerale" in Italian hints figuratively at something unfiltered by rationality (online UTET Dictionary, 2025). That part of the body where endometriosis pain is usually perceived by patients but unrecognized by doctors turns paradoxically into the reliable source of the diagnosis, into its messenger.

The last note in the table reveals the social imagery revolving around endometriosis, recalling the concept of Kleinman's sickness. The patient herself admits that, before she knew about the famous dancer's endometriosis, she had interpreted her child-free life as a personal choice. In her eyes, chasing career and professional success prevailed over having children in the dancer's life.

After the dancer's news on her disease, the picture is completely different. The last sentence in this patient's note "Come siamo bravi a raccontarci le novelle da soli", shows the bitter awareness gained by a woman who had misinterpreted another woman's life story and now is facing the same social stigma attached to child-free women. The sentence is a metaphorical expression per se, but it can also be considered as a meta-narrative reflection, in that it shows how meanings construed through stories (the missed pregnancy appeared intentional at the beginning) can change completely if the story is retold: what we say shapes our thought, and once again the meaning depends on the relation between the teller and the listener.

Table 14

Social reactions

Prompt	Prima che ai medici, ho raccontato per la prima volta i miei sintomi a... La sua/loro reazione è stata...	Before meeting the doctors, I first reported my symptoms to... Their reaction was...
Participant	Excerpt	Translation
1D89FB3AF555	Ai miei familiari, cosa purtroppo non compresa in quanto nessuno di noi, me compresa, aveva dato un nome a questa patologia. Non comprensione dei miei	To my family members. Unfortunately, they did not understand, as none of us, myself included, had given a name to this condition. Lack of understanding of my symptoms

	disturbi e del mio stato emotivo	and emotional state
9E80F99DA04A	<p>Ho sempre raccontato del mio malessere in famiglia, principalmente le prime risposte sono sempre state: "tutte le donne soffrono di dolori mestruali", "può capitare anche il vomito", "devi reagire ai dolori", ecc. Nonostante questo mia madre si rivolgeva al medico di famiglia con me per i forti dolori [...]. I miei genitori pensavano che tali sintomi potessero essere la "normalità", pertanto più che rivolgersi al medico di famiglia o inizialmente in farmacia per farmaci per i dolori non pensavano potesse servire altro</p>	<p>I always talked about my discomfort with my family, but their initial responses were always: "all women suffer from menstrual pain", "vomiting can also happen", "you have to react to the pain", etc. Despite this, my mother took me to see our family doctor because of the severe pain [...]. My parents thought that these symptoms were "normal", so rather than going to the family doctor or initially to the chemist for painkillers, they didn't think anything else would help</p>
A55769E5659F	<p>Ai miei familiari.</p> <p>Non sapevano cosa dirmi, perché per loro, come per tutti quelli che avevo sentito fino ad allora, era normale avere il mal di pancia durante e nei giorni vicini al ciclo</p>	<p>To my family.</p> <p>They didn't know what to say to me because, for them, as for everyone I had heard up to that point, it was normal to have stomachache during and around the time of your period</p>
B60252BCF5B1	Mia mamma, le mie amiche.... In	My mum, my friends... In both cases,

	entrambi i casi la risposta era che anche loro stavano male... Ma in effetti col passare del tempo anche loro si accorgevano che non era lo stesso malessere. Tutto comunque passato al setaccio che stai peggio di me ma è normale	the answer was that they also felt unwell... But in fact, as time went by, they too realised that it wasn't the same discomfort. However, it was established with certainty that I was worse off than the others, but it was normal
C76DBBDB968C	Mia madre Dobbiamo prendere provvedimenti	My mother We have to do something
FF49204B9548	Non credo di aver mai parlato con nessuno del “MIO PROBLEMA”. La questione veniva fuori quando non riuscivo ad alzarmi [...] e all'improvviso stavo male Quando tornavo a casa bastava continuare col silenzio e le omissioni giusto per non vedere la pena negli occhi di mia madre o se mi chiedeva qualcosa rispondevo con il codice di guerra “SEMPRE LO STESSO”, perché in realtà mi ammalo di rado, quindi il motivo era quello, come sempre, il solito stramaledetto	I don't think I ever talked to anyone about “MY PROBLEM”. The issue came up when I couldn't get up [...] and suddenly felt ill When I came home, I just kept quiet and avoided the subject so as not to see the pain in my mother's eyes, or if she asked me anything, I responded with a war-like code “ALWAYS THE SAME STORY”, because in reality, I rarely get sick, so the reason was, as always, the same old damn cycle. The initial reaction is one of great sorrow and concern. [...] Then comes the justification: “Just like

<p>ciclo. La reazione è in principio di grande pena e preoccupazione. [...]</p> <p>Poi giustificazione: “Proprio come tua sorella, ma anch'io da piccina, non mi mandavano neanche a scuola e mi ricordo una volta mi fecero una puntura.”</p> <p>L'impossibilità di aiuto lasciava lo spazio solo alla compassione.</p> <p>Quindi anche le persone più vicine dove non si mette in dubbio l'affetto pian piano si abituano alla tua condizione e anche se sempre affrante tendono a non farci più troppo caso</p>	<p>your sister, but when I was a little girl, they didn't even send me to school, and I remember once they gave me an injection.” The impossibility of helping left room only for compassion. So even the people closest to you, whose affection is unquestionable, gradually get used to your condition and, although they are still heartbroken, they tend not to pay too much attention to it anymore</p>
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FB582774D451	<p>Alla mia mamma.</p> <p>Lei sapeva che stavo male, anzi lo vedeva. Ma anche per lei era normale. La mamma aveva avuto più o meno gli stessi problemi che avevo io: un menarca precoce e delle mestruazioni molto abbondanti. Mi diceva che dopo la gravidanza [...] i sintomi erano</p>	<p>To my mum.</p> <p>She knew I was unwell; in fact, she could see it. But even for her it was normal. My mum had had more or less the same problems as me: early menarche and very heavy periods. She told me that after pregnancy [...] the symptoms had improved. It would be the same for me one day. I would have</p>
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	<p>migliorati. Sarebbe stato così anche per me un giorno. Avrei dovuto sopportare, alla fine era solo una mestruazione. Era il prezzo da pagare per essere Donna. [...] Sì, si tormenta per non aver capito prima. Ma anche lei non sapeva cosa fosse l'endometriosi. E per affrontarla, devi conoscerla</p>	<p>to put up with it; in the end, it was just a period. It was the price to pay for being a woman. [...] Yes, she torments herself for not understanding sooner. But she didn't know what endometriosis was either. And to deal with it, you have to know about it</p>
BC650EA37D16	<p>Quando il mio compagno lo ha saputo mi è stato sempre vicino e mi ha supportato</p>	<p>When my partner found out, he was always there for me and supported me</p>
70CB0C5D018D	<p>A mia madre e al mio partner dell'epoca.</p> <p>Mia madre ha avuto a 40 anni circa, per miomi all'utero e ovaia destra, un'isterectomia... ed io, sin da piccola, ho capito che qualcosa non andava nemmeno in me. Mi ha aiutata, ed insieme abbiamo preso in tempo sin dai primi sintomi i miei problemi con il ciclo e la mia salute in generale. Il mio ex partner mi ha sempre</p>	<p>To my mother and my partner at the time.</p> <p>My mother had a hysterectomy at around 40 years of age due to fibroids in her uterus and right ovary... and I realised from an early age that something was wrong with me too. She helped me, and together we addressed my period problems and my general health as soon as the first symptoms appeared. My ex-partner always supported and understood me</p>

appoggiata e capita

ED1AECDDDB82A	<p>Io raccontavo i miei sintomi a tutti perché cercavo una cura ma dicevano tutti che è normale avere dolori durante il ciclo che ho solo il ciclo doloroso.</p> <p>La loro reazione era la reazione di una persona che non sa di cosa si tratta esattamente, cioè per loro sto esagerando, i dolori non sono così forti, ho mia sorella che anche lei ha dolori durante il ciclo ma non fa tutte queste storie, mi dicevano cose così</p>	<p>I told everyone about my symptoms because I was looking for a cure, but they all said that it was normal to have pain during your period and that I just had a painful period.</p> <p>Their reaction was the reaction of people who didn't know exactly what it was, i.e. they thought I was exaggerating, that the pain wasn't that bad, that my sister also had pain during her period but didn't make such a fuss about it. They said things like that to me</p>
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The notes reveal that mothers and family members are the first subjects with which patients share their problems, causing concern and sorrow. In patient A55769E5659F and ED1AECDDDB82A, the key verb “sapere” in the negative sentences shows that uncertainty affects also family, since they clearly do not know what to say or what is going on: “Non sapevano cosa dirti”, “era la reazione di una persona che non sa di cosa si tratta esattamente”. Yet, helplessness seems not so much related to unclear or unknown diagnosis, but rather to the idea that the pain of their beloved is normal. Accepting the natural origin and existence of pain as part of the female being is confirmed by the fact that the other relatable experiences mentioned by the caregivers are lived by mothers, sisters and girlfriends, hence other women. Curiously, in the last excerpt of this table, the theme of stories and their power to describe or mystify reality, depending on how they are told and who tells them, comes back in another Italian idiom: “fare storie”, in “ho mia sorella che

anche lei ha dolori durante il ciclo ma non fa tutte queste storie, mi dicevano cose così” (B60252BCF5B1), where “fare storie” means to make a big deal out of something not really serious. This invites a new metanarrative reflection on the ambivalence in the relationship between the story producer, i.e. the poor patient, depicted as the one who makes stories up, and the story receiver, represented by the patient’s family and acquaintances. In reality, the truth is quite the opposite: family is misconstruing the meaning of the patient’s complaints, implicitly accusing her of overreacting. I discuss later how this surreptitious dynamic recurs in medical interviews as well. Objectively, the severity of pain is evidently above the average, as the patient B60252BCF5B1 notices (“stai *peggio* di me ma è normale”); caregivers seem to minimize the pain severity by saying “Avrei dovuto sopportare, alla fine era solo una mestruazione”, although, as analysed in the next sections, pain is mostly but not only limited to the menstruation time and, in addition to the abdomen, it can involve muscles, knees and so on, all areas that can also turn painful in men. Yet the alleged ineluctability of female pain as such seems to discourage even the patients’ parents from further medical investigation. Patient FB582774D451 lucidly recognises that one must know the disease to do something about that, and her mother is not to be blamed, since she was unaware and unconsciously functional to pre-existing beliefs. The deontic function of the modal verb “dovere” (must) in “devi reagire” or “Avrei dovuto sopportare” (should) makes the patient responsible for her own pain management and expresses the social expectations linked to femininity, underlined through the metaphor “era il prezzo da pagare per essere donna”. In a response to a different prompt (FF49204B9548), the alleged patient’s responsibility turns into real blaming: “ma ti stai curando? è anche colpa tua eeeh!!! Non fai nulla per stare meglio!!!” (But are you getting treatment? It's your fault too!!! You're not doing anything to get better!!!). These linguistic features mark the legitimization of a “discourse” *of* and *on* endometriosis that justifies pain and disregards complaints. The patients’ notes analysed here depict the context, Charon’s “frame”, the community and the cultural system in which the writers live. The repetition of the word “normale” already occurred in four of these notes of table 12 is the focus of the next section.

What is normal? Among the most frequent adjectives in the patient narratives, “normale” (normal) qualifies the endometriosis experience (29 occurrences were found in the corpus), especially menstrual pain, leaving patients disoriented, as I am citing here. I also included the occurrences of the related noun “normalità” (normality) in the following table.

Table 15

Normality

Participant	Excerpt	Translation
5CB9848575B2	Ogni mese era un incubo, ciclo abbondante e dolori lancinanti. Ma per tutti era <i>normale</i> , ed io esagerata. Con le mestruazioni si sta male.	Every month was a nightmare, with heavy periods and excruciating pain. But everyone thought it was normal, and that I was exaggerating. Periods simply make you feel ill
5CB9848575B2	Oramai a 18 anni mi ero convinta che fosse <i>normale</i> , cicli abbondanti e dolore invalidante, <i>normale</i> fino a quando non iniziai a finire in ospedale una, due, tre volte ma nessun medico mi ha mai parlato di endometriosi in quelle circostanze	By the age of 18, I had convinced myself that heavy periods and debilitating pain were normal, until I ended up in hospital once, twice, three times, but no doctor ever mentioned endometriosis in those circumstances
9E192F9666A5	Dal momento che ho avuto il ciclo mestruale, la mia vita è cambiata, il ginecologo diceva che era <i>normale</i> che non fosse regolare che passavo da quattro a sei giorni a letto ripiegata dai	From the moment I started menstruating, my life changed. The gynaecologist said it was normal for my periods to be irregular and for me to spend four to six days in bed doubled over in pain

dolori

B60252BCF5B1	Io lavoravo e accudivo due figli con fatica e se un medico (benché mi lamentassi e citassi tutti i sintomi) se diceva che era <i>normale</i> , lo facevo diventare <i>normale</i>	I worked and looked after two children with difficulty, and if a doctor (even though I complained and mentioned all the symptoms) said it was <i>normal</i> , I made it <i>normal</i>
B60252BCF5B1	In entrambi i casi la risposta era che anche loro stavano male... Ma in effetti col passare del tempo anche loro si accorgevano che non era lo stesso malessere. Tutto comunque passato al setaccio che stai peggio di me ma è <i>normale</i> .	In both cases, the response was that they were also unwell... But in fact, as time went by, they too realised that it was not the same illness. Everything was sifted through, and you were worse off than me, but it was <i>normal</i>
B60252BCF5B1	Ho imparato a gestirmi e gestire la malattia da sola. Tutto è diventato <i>normale</i> ...	I learned to manage myself and my illness on my own. Everything became normal...
B60252BCF5B1	non riuscivo ad alzarmi...quando riuscii a mettermi in piedi, per non rovinare la vacanza a tutti, cercai di fare con calma una vita <i>normale</i> ...	I couldn't get up... when I managed to stand up, so as not to ruin everyone's holiday, I tried to calmly lead a normal life...
ED1AECDDDB82A	Io raccontavo i miei sintomi a tutti perché cercavo una cura ma dicevano tutti che è <i>normale</i> avere dolori durante il ciclo che ho solo il ciclo doloroso	I told everyone about my symptoms because I was looking for a cure, but they all said that it was normal to have pain during your period, that I

		just had painful periods
FF49204B9548	Posso ancora avere una vita <i>normale</i> ?	Can I still have a normal life?
FB582774D451	Mia mamma. La persona che per prima ha sempre saputo ogni cosa di me. Lei sapeva che stavo male, anzi lo vedeva. Ma anche per lei era <i>normale</i>	The person who always knew everything about me. She knew I was in pain, in fact she could see it. But even for her it was normal
A55769E5659F	Non sapevano cosa dirmi, perché per loro, come per tutti quelli che avevo sentito fino ad allora era <i>normale</i> avere il mal di pancia durante e nei giorni vicini al ciclo	They didn't know what to say to me because, for them, as for everyone I had heard up to that point, it was <i>normal</i> to have stomachache during and around the time of your period
FF49204B9548	(forse anche se <i>normale</i> potrei stare meglio [...])	(even if it was <i>normal</i> , I could feel better [...])
FF49204B9548	Con la nascita del primo figlio la cosa si dovrebbe risolvere o attenuare di parecchio. Questo discorso non aveva suscitato in me il minimo interesse. Ero <i>normale!!!</i>	With the birth of your first child, the problem should be resolved or greatly reduced. This argument did not interest me in the slightest. I was <i>normal!!!!</i>
FF49204B9548	Non essere considerata <i>normale</i> perché non ho figli (roba da medioevo ma è così) Ho accettato che i medici trovassero il mio dolore fisico una cosa <i>normale</i>	Not being considered <i>normal</i> because I don't have children (something from the Middle Ages, but that's how it is) I accepted that doctors found my physical pain <i>normal</i>

FF49204B9548	<p>Credo cambi per una donna <i>normale</i>, cioè una donna non come me ma con un utero che non decide per lei. Diverso perché funziona al contrario: vuoi un figlio e concretizzi il tuo desiderio concependo oppure capita che non vuoi un figlio ma lo concepisci e dopo scopri che vuol dire essere madre o cos'è la maternità, questo è più o meno la mia idea di quello che succede a una donna "<i>normale</i>"</p>	<p>I think it changes for a <i>normal</i> woman, i.e. a woman who is not like me but has a uterus that does not decide for her. It is different because it works the other way round: you want a child, and you fulfil your desire by conceiving, or it happens that you do not want a child but you conceive, and then you discover what it means to be a mother or what motherhood is. That is more or less my idea of what happens to a "<i>normal</i>" woman</p>
C7BCF8D1B4DE	<p>Non ho mai pensato di avere qualcosa che non va. Le mestruazioni dolorose e abbondanti sono <i>normali</i> per tante donne</p>	<p>I never thought there was anything wrong with me. Painful and heavy periods are <i>normal</i> for many women</p>
FF49204B9548	<p>[...] ho scoperto tanti sintomi che credevo fossero <i>normali</i> per tutti.</p>	<p>[...] I discovered many symptoms that I thought were <i>normal</i> for everyone</p>
9E80F99DA04A	<p>I miei genitori pensavano che tali sintomi potessero essere la "<i>normalità</i>", pertanto più che rivolgersi al medico di famiglia o inizialmente in farmacia per farmaci per i dolori non</p>	<p>My parents thought that these symptoms were "<i>normal</i>", so rather than going to the family doctor or initially to the chemist for painkillers, they didn't think</p>

	pensavano potesse servire altro	anything else would help
B60252BCF5B1	Ormai era la mia <i>normalità</i> , usavo antidolorifici che ovviamente aumentavano...	By then, it was <i>normal</i> for me, I was using painkillers, which obviously increased...
B60252BCF5B1	Ed io arrancavo, faticavo ma mi ostinavo nelle mie nuove <i>normalità</i> ...	And I struggled, I struggled, but I persisted in my new <i>normality</i> ...
B60252BCF5B1	Quando si cresce con qualcosa che non va, lo ascolti solo nei momenti di picco, quando il confronto con gli altri evidenzia una indiscutibile differenza. Ma vivi la tua vita con assoluta <i>normalità</i> . Solo quando proprio non c'è la fai più capisci che c'è davvero qualcosa che non va	When you grow up with something wrong, you only notice it at peak moments, when comparison with others highlights an indisputable difference. But you live your life with absolute <i>normality</i> . Only when you really can't take it anymore do you realise that something is really wrong

On the one hand, there emerges from these statements that *normal* defines menstrual pain at a social level, that the normality of gynaecological pain is a conventionally accepted issue among laypeople, in that it is part of every woman's upbringing. Families are among the ones that share this assumption, as confirmed by Facchin (2023) and the EndoNar corpus (Chapter 5): “zero comprensione da parte dei familiari (“Classica frase: possibile che devi prendere tutti questi antidolorifici?”). On the other hand, given the fact that the word “normal” is used also by doctors, the scientific view seems to perpetuate and corroborate this understanding of menstrual pain: “Io lavoravo e accudivo due figli con fatica e se un medico (benché mi lamentassi e citassi tutti i sintomi) se diceva che era normale, lo facevo diventare normale”. This emblematic sentence is

emblematic of the ambiguous power of words: if language labels something as normal, that something becomes normal, no matter if it is true or not. So, endometriosis pain is not recognized as *extremely*, hence *differently* painful, but as something that simply must be endured.

This culture- and gender-based assumption makes the patients' complaints sound not legitimate: since it is normal, endometriosis pain is not validated. This is disorienting for patients, who question their pain perception and tolerance, hence themselves: "Ma per tutti era normale, ed io esagerata. Con le mestruazioni si sta male". The contraposition between everyone (tutti) and the patient (io) between "normale" and "esagerata" outlines a polarization of roles, followed by a homologation through the impersonal verbal form "*si sta male [con le mestruazioni]*". As highlighted in Chapter 2, according to Cassel (1982), not knowing the cause of one's distress, lack of recognition, chronicity, and incurability are all factors that amplify suffering. All these features apply to endometriosis and trigger a psycho-physical loop: the more my pain is not validated, the more I suffer; the more I complain about my suffering, the more I am told that my pain description is exaggerated, and so on.

As Nessa notices from a semiotic perspective (1996), non-validation of pain is inconsistent with the gist and goal of medicine. His words are particularly relevant for endometriosis:

All clinicians are familiar with history taking, listening to the patient's symptoms, which lead us to physical findings and give us a diagnosis. The ensuing treatment follows routine standards. A number of physical symptoms, however, such as *abdominal pain*, dyspepsia, headache, backache, joint pain, chest pain, palpitations and *fatigue* lack a satisfactory analytical term. *It makes no sense to say that these symptoms are not real. They are just as real as the patient is.* To accept utterances at face value is a prerequisite for all human communication. So also *in medicine*. (p. 374, emphasis added)

In contrast, in one of my corpus notes, a patient wrote that experiencing mistrust with doctors who downplayed her pain was even worse than endometriosis itself. In this case, too, she uses a provocative question, which I marked with italics:

Table 16

Mistrust

Participant	Excerpt	Translation
1D89FB3AF555	La cosa più brutta oltre l'aver l'endometriosi? Essere seguita per anni da un ginecologo che non ti riconosce la patologia stessa e minimizza i sintomi riferiti portandoti verso il IV stadio della malattia. Trascorri anni nel dolore fisico e mentale non riuscendo a vivere la vita che vorresti	The worst thing besides having endometriosis? Being treated for years by a gynaecologist who does not recognise the condition and minimises the symptoms you report, leading you to stage IV of the disease. You spend years in physical and mental pain, unable to live the life you want
9E192F9666A5	Per diversi anni, sono stata beffeggiata, insultata, dandomi della pazza, perché? Perché gli specialisti che mi visitavano mi dicevano ‘i sintomi che lei riporta sono tutti frutto della sua fantasia, forse è meglio che venga seguita da una psichiatra’, quali erano i miei sintomi? Dolori, tanti dolori anche un semplice gesto come lavare i pavimenti, stavo male, lasciamo stare	For several years, I was mocked, insulted, called crazy. Why? Because the specialists who examined me told me, ‘The symptoms you report are all figments of your imagination. Perhaps it would be best for you to see a psychiatrist.’ What were my symptoms? Pain, a lot of pain. Even a simple task like washing the floors made me feel ill, not to mention sex

poi il sesso

Normalization of pain leads to its psychologisation: since the symptoms reported are normal, what patients complain about is not real, it is all in their head. As in the dualistic view of human beings, medically unexplained symptoms are reduced to only psychological, as if they could not be both. My narrative analysis, aligning with scientific literature on the topic, confutes the argument of psychologisation. Patients' diaries reveal the wide range of experiences, plans, and dreams to which women have to give up, the feeling of constant fatigue, the reduced quality of life, in terms of social interactions, professional performance, infertility, and sexual pleasure, as quoted in the following excerpts.

Table 17

Impact of endometriosis on everyday life and wellbeing

Participant	Excerpt	Translation
5CB9848575B2	[...] a volte non riuscivo nemmeno ad andare a scuola	[...] sometimes I couldn't even go to school
B60252BCF5B1	Io ero piena di vita! Piena di attività che progressivamente faticavo a portare avanti... [...] Ed io arrancavo, faticavo ma mi ostinavo nelle mie nuove normalità...	I was full of life! Full of activities that I gradually found difficult to carry on with... [...] And I struggled, I struggled, but I persisted in my new normal...
70CB0C5D018D	[...] spesso mi sporcavo a lavoro e non potevo stare troppo tempo fuori o in un posto senza bagni con i miei amici	[...] I often got dirty at work and couldn't stay outside or in a place without a toilet with my friends for too long

B60252BCF5B1	[...] non riesco ad avere rapporti sessuali perché ho dolori, non riesco ad andare in giro o al ristorante perché mi fa sempre male qualcosa	[...] I can't have sexual intercourse because I'm in pain, and I can't go out or to restaurants because something always hurts
FF49204B9548	In quest'ultimo periodo ho constatato i danni emotivi. Nel tempo [l'endometriosi] mi ha reso fragile, insicura, molto più suscettibile	Recently, I've noticed the emotional damage. Over time, [endometriosis] has made me fragile, insecure, much more sensitive
FF49204B9548	[...] essere stanca e indisposta mi ha reso sola o non bella pimpante come tutti vorremmo essere	[...] Being tired and unwell has made me lonely and not as lively as we would all like to be
FF49204B9548	Quando vorresti le energie per uscire, un concerto, una serata, ma proprio non ce la fai...	When you want the energy to go out, to a concert, to a party, but you just can't do it
FF49204B9548	Stanchezza cronica Equilibrio emotivo Forte stress [..] non poter andare in bagno più volte a turno di lavoro e dover chiedere il permesso? Dolore nei rapporti col partner Non aver potuto avere un figlio Depressione Inadeguatezza [...] sei una donna e non hai figli...sei	Chronic fatigue Emotional balance Severe stress [..] not being able to go to the toilet several times during a shift and having to ask permission? Pain during intercourse with your partner Not being able to have a child Depression Inadequacy

già etichettata, non sei una vera donna.	[...] you are a woman and you don't
[..] Credo basti	have children...you are already
	labelled; you are not a real woman.
	[..] I think that's enough

An ironic sentence concludes the long list of the effects of endometriosis on patient FF49204B9548's life. The socio-cultural dimension (Kleinmann's "sickness") of the endometriosis experience and its impact on the psychophysical wellbeing that emerges from these excerpts determines what Hållstam et al. call "struggle for coherence" (2018, p. 99). The expression conveys effectively the complex picture emerging from the excerpts and the diverse challenges that patients have to face at more levels. It follows that the causal relationship between endometriosis and mental stress is that *endometriosis leads to vulnerability*. According to the opposite interpretation, the most socially accepted, patients would ask for validation of symptoms that they make up in their mind *just because* they are emotionally or mentally unstable: pain would be in her head. In her book, emblematically titled *All in your head: Making Sense of Paediatric Pain* (2015), Buchbinder investigates the factors that make it difficult to explain and understand pain. Although her book concerns children's and teenagers' (mental) health issues, it is interesting how the title is also one of the most frequent answers that women with endometriosis reportedly receive from their practitioners and gynaecologists (Facchin, 2023).

It is easy to notice that this all-in-your-head interpretation is attributed to two social groups that, due to age factors, gender-based assumptions and cultural constructions, are recognizably underrepresented in terms of decision making and power in society, and even in clinical research (Bierer et al., 2022). As Puechguirbal (2005) argues, even in the war context, the category women-

and-children includes both identities and confirms the model that sees women mainly as caring and nurturing beings, with children as their natural extension.

Moreover, Western culture conventionally associates these subjects with fragility and emotional complexity: as for adolescents, in particular, it is constantly questioned whether they “are to be treated as reliable narrators of their own embodied experience” (Buchbinder 2015, p. 12), whereas, Hoffman and Tarzian (2001) highlight that women are considered more inclined to express suffering through emotionalism and exaggeration.

While the gender bias is one but *not the only* focus of my discussion, through the reference to Buchbinder’s book title, I just want to highlight the relation between an allegedly unreal discomfort, made up in one’s head, and the paradigms of childhood and femininity, which confirms the dependence of medicine—despite its objectivity claims—on culture.

Communicating diagnosis. The two prompts quoted in Table were administered together, and it makes sense to analyse contextually the way the diagnosis was given and received.

Table 18

The diagnosis

Prompt	La prima volta che i medici hanno dato un nome alla mia condizione, le loro parole mi sono suonate... Mi sono sentita...	The first time the doctors gave my condition a name, their words sounded... I felt...
Participant	Excerpt	Translation
FF49204B9548	Il primo Medico che mi ha parlato di endometriosi è stato bravo, io avevo 16/17 anni ed era stata una diagnosi ottima, giusta, ma completamente sottovalutata, non considerata grave, non è stato preso in considerazione,	The first doctor who told me about endometriosis was good. I was 16/17 years old and it was an excellent diagnosis, correct but completely underestimated and not considered serious. No treatment or monitoring

	<p>una cura, un monitoraggio NULLA!</p> <p>Era considerato uno bravo e già il fatto che conoscesse la patologia negli anni 90 lo dimostrava, ma a che scopo?</p> <p>[...]</p> <p>Mi sono sentita distante (che deve fare? ma nulla, passerà col primo figlio) a 17 anni mi parli di figli? ma che mi frega? Ho 17 anni non ho neanche il fidanzato...</p> <p>Mi sono sentita usata</p> <p>Umiliata</p> <p>Triste</p> <p>Stanca</p>	<p>was considered, NOTHING! He was considered a good doctor and the fact that he knew about the condition in the 1990s proved it, but to what end?</p> <p>[...]</p> <p>I felt distant (what should you do? Nothing, it will pass with your first child). At 17, you're talking to me about children? What does that matter to me? I'm 17, I don't even have a boyfriend...</p> <p>I felt used</p> <p>Humiliated</p> <p>Sad</p> <p>Tired</p>
1D89FB3AF555	<p>Una totale liberazione perché finalmente la mia patologia, il mio stato di salute, aveva un nome</p>	<p>A total liberation because finally my condition, my state of health, had a name</p>
9E80F99DA04A	<p>[le loro parole mi sono suonate] familiari, avevo già sentito parlare di endometriosi in un programma televisivo scientifico e avevo già capito che era esattamente ciò che avevo, corrispondeva tutto, pertanto non ne fui affatto sorpresa, forse</p>	<p>[their words sounded] familiar to me, I had already heard about endometriosis on a science programme on television and I already understood that it was exactly what I had, everything matched, so I wasn't surprised at all,</p>

	sollevata che finalmente qualcuno avesse capito	perhaps relieved that someone had finally understood
A55769E5659F	[le loro parole mi sono suonate] sconosciute e preoccupanti, mi è stato detto che non me ne libererò più per tutta la vita. Mi sono sentita... affranta, preoccupata... non sapevo cosa aspettarmi	[their words sounded] unfamiliar and worrying to me, I was told that I would never be rid of it for the rest of my life I felt... heartbroken, worried... I didn't know what to expect
B60252BCF5B1	Non conoscevo la patologia... Direi che i concetti erano abbastanza chiari ma la cosa che mi rincuorò non fu detta o spiegata, fu sapere che c'era. C'era una cosa che invadeva ed era quello che sentivo ma che fino ad allora era negato. È per quello che molte di noi vanno in escandescenza o guardano al medico con scetticismo o polemica... Il nostro sentimento è quello di restituire il rifiuto che ci hanno costantemente servito...	I didn't know about the condition... I would say that the concepts were quite clear, but the thing that heartened me was not said or explained; it was knowing that it was there. There was something invading me, and it was what I felt but had been denied until then. That's why many of us get angry or look at the doctor with scepticism or controversy... Our feeling is to return the rejection that we have constantly been served...
70CB0C5D018D	A seguito del mio intervento non mi era stato detto che c'era un'ipotesi di	Following my surgery, I was not told that there was a possibility of

<p>endometriosi, mi era anche sfuggito anche se scritto in cartella "sospetta endometriosi". Mi è stato poi detto da una (penso) specializzanda durante uno dei miei controlli all'ospedale, non era presente nessun strutturato con lei durante quella visita, quindi mi è apparsa una novità scioccante , anche perché sapevo che fosse una "nuova malattia" ma non conoscevo bene tutte le sintomatologie e conseguenze</p>	<p>endometriosis. I also missed the fact that it was written in my medical records as ‘suspected endometriosis’. I was then told by a (I think) specialist trainee during one of my check-ups at the hospital. There was no senior doctor present with her during that visit, so it came as a shocking surprise to me, partly because I knew it was a “new disease” but I was not familiar with all the symptoms and consequences</p>
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<p>ED1AECDDDB82A Le loro parole mi sono suonate strane perché non sapevo cos'era questa malattia, non sapevo che era una cosa grave ma il momento in cui ha detto che mi devono operare, è lì che tutto cambiò</p>	<p>Their words sounded strange to me because I didn't know what this disease was, I didn't know it was serious, but the moment I was told I needed surgery, that's when everything changed.</p>
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<p>Mi sono sentita male, ogni giorno mi sento male</p>	<p>I felt ill, I feel ill every day</p>
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<p>C3699250CB72 Quando i medici hanno diagnosticato la malattia di endometriosi ho subito inteso che avrebbe portato a una difficoltà nel concepimento, cosa poi confermata da lì in avanti. Mi sono</p>	<p>When the doctors diagnosed me with endometriosis, I immediately understood that it would lead to difficulty conceiving, which was confirmed from then on. I felt</p>
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sentita diversa dalle altre donne,	different from other women, affected
colpita nella parte più intima	in the most intimate way,
psicologicamente parlando.	psychologically speaking

The excerpts of this table suggest a wide range of ways in which the diagnosis is communicated by doctors, and then processed by patients. Once again, words matter, but no special attention is paid to the way they are chosen. Patient B60252BCF5B1 and 9E80F99DA04A felt relieved and finally set free from the uncertainty about their symptoms. Some of these women (9E80F99DA04A) had already suspected their diagnosis and found the doctors' words familiar (“avevo già capito che era esattamente ciò che avevo, corrispondeva tutto, pertanto non ne fui affatto sorpresa, forse sollevata che finalmente qualcuno avesse capito”). Although these patients are told that they are affected by a chronic, incurable disease, the fact that their symptoms now have a name, an identity, has a relieving effect. The adverb “finalmente” confirms the long-awaited diagnosis. To other women endometriosis is a completely unknown word, but that name provides validation for their pain: “Non conoscevo la patologia... Direi che i concetti erano abbastanza chiari ma la cosa che mi rincuorò [...] fu sapere *che c'era*” (B60252BCF5B1). The same medical and social language that made patients' reports sound just as unfounded complaints now make these women's thoughts and pain real, offering bitter consolation but still recognising what had been denied for a long time.

Once again, in line with the concept of discourse, language not only influences but creates reality and meaning. The use of the name “endometriosis” makes it suddenly real, although patients affected had claimed its existence long before it was acknowledged.

For other patients, endometriosis was heard or read for the first time incidentally, from junior doctor assistants or just on the medical records, and not necessarily accompanied by more detailed information on its seriousness and possible monitoring measures: “era stata una diagnosi ottima, giusta, ma completamente sottovalutata, non considerata grave, non è stato preso in

considerazione, una cura, un monitoraggio NULLA!”. To those women, the diagnosis sounds unfamiliar and strange, shocking and worrying: understandable reactions, especially considering the form chosen to explain the chronicity of the disease as in patient A55769E5659F: “mi è stato detto che non me ne libererò più per tutta la vita”, implicitly associating the disease with a burden or a life-long prison. Such wording, while stating a matter of fact, intensifies the feeling of uncertainty in the patient, as confirmed by the last sentence “non sapevo cosa aspettarmi”. Moreover, these words focus just on the negative sides of the condition, since in her narrative the patient does not mention receiving from doctors further explanation on coping strategies, or symptom management, both complex and not always effective, but still possible in this benign disease. Chronicity is not the only aspect that gives rise to feelings of demoralisation. For patient C3699250CB72, the most impacting words of the diagnosis concern her fertility, which is enough to let her feel different from and inferior to other women, affecting her most intimate and fragile side, as well as her strongest hopes. In this case, she does not report the words used by her doctors, but it can be inferred that in the narrative process of diagnosis, besides the form and the content, the listener plays a role as determining as the teller, depending on which parts of the patient’s self are most sensitive to specific issues, such as motherhood for this woman. For instance, for patient FF49204B9548, on the contrary, pregnancy as an alleged *solution*, as her doctor put it, sounded like a completely irrelevant argument, given the young age at which she received her diagnosis. Data confirm the idea that meaning is co-created, but the co-creation process is complex since it is determined by a lot of variables, among which are the listener’s expectations. Listening to the patient’s priorities and expectations in medical encounters can help doctors arrange effectively the contents to be discussed and to choose the right form to do so.

Communicating patients’ expectations. In this section, I investigate the relation between uncertainty and communication in medical encounters. Since her first note, this patient always writes the word “Dottore, Dottoressa, Ginecologo, Chirurgo” (doctor, gynaecologist, surgeon) with

an initial capital letter, visually marking a difference, a distance, as if these clinicians were abstract, anonymous entities or they deserved some form of reverence.

This punctual attention cannot be casual, especially considering the taping mistakes occurring in digital writing. I hypothesise a link between this formal peculiarity and a more complex theme emerging in the patients' following notes. More specifically, the patient's note on the attitude she expects from her doctors (Table 19) raises an important issue about the roles, ideals and values associated with clinicians:

Table 19

The Patient's expectations

Participant	Excerpt	Translation
FF49204B9548	In tantissimi non comprendono come approcciare come comportarsi, cosa dire. Oddio, dopo tanti "trattori" umani ora vorrei un DOTTORE CON: Empatia Ascolto Conoscenze tecniche Conoscenza nella visione ecografica Tatto nell' applicare la teoria alla pratica Effettivamente pretendo tanto ma se avessi preteso tanto forse non avrei avuto tutte le conseguenze che ho vissuto.	Many people don't understand how to approach, how to behave, what to say. Oh dear, after so many human "tractors", now I would like a DOCTOR WITH: Empathy Listening skills Technical knowledge Knowledge of ultrasound imaging Tact in applying theory to practice Actually, I demand a lot, but if I hadn't demanded so much, perhaps I wouldn't have had all the consequences I experienced. I was looking for someone to trust, I'm

<p>Cercavo qualcuno a cui affidarmi, lo cerco ancora, ho imparato che la fiducia va guadagnata a volte, non bastano le specializzazioni. [...] Ed è difficile perché un paziente è sempre in un gradino inferiore rispetto al proprio medico. Vorrei affidarmi ed essere aiutata come un bambino si affida ad un adulto. Che succede quando gli "adulti" hanno ferito la bambina? L' hanno sminuita? L' hanno ferita? E magari dall'alto della sua conoscenza non se ne accorge neanche?</p>	<p>still looking for them, I've learned that trust has to be earned sometimes, specialisations are not enough. [...] And it's difficult because a patient is always on a lower level than their doctor. I would like to trust and be helped like a child trusts an adult. What happens when the "adults" have hurt the child? Have they belittled her? Have they hurt her? And perhaps, from the height of their knowledge, they don't even notice?</p>
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The patient has evidently experienced a lack of sensitivity in previous medical consultations, as the metaphor “trattoria umani” suggests. The idea of a massive vehicle contrasts with the delicacy required in terms of communication and physical contact during medical consultation, also due to the particular emotional fragility of the patient. The simile about the doctor-adult and the patient-child reflects the individual view of this writer, but it instantly recalls the relation of parents and children, which refers back conceptually and linguistically to paternalism in medicine. How does a doctor relate to epistemic authority in the treatment of a disease so unpredictable, with so many uncertainties? Which kind of attitude should they have towards patients? In the last part of the chapter, this topic is addressed from the doctors’ perspective.

But I would like to highlight two different steps in this analysis: one concerns the mental and cultural associations that can be triggered by the role of a doctor. These correlations evoked in

the patient's mind may be rooted in her past private life, awake memories of adults that may have hurt her as a child, or recall previous experiences of physicians' behaviours that may have disappointed her in other respects.

The verb "sminuire" (diminish) could refer to both cases, i.e. both to a family that does not acknowledge her value or does not support her and to doctors that downplay her suffering or the severity of her illness and pain. This last hypothesis seems to be supported by the following sentence, referring to an unequal level of knowledge, with the spatial deictic "dall'alto" (from the top, from the highness), used metaphorically to convey a hierarchical relation, but potentially representing the adults' physical size and authority perceived by children. Actually, this visual description of unbalanced knowing would apply also to parents'/adults' wider experience of life and world compared to that of a child, broadly speaking. These reflections are not an awkward and non-professional attempt to psychoanalyze the patient. They are a practical exercise of close reading of a story, especially of those words that seemingly have no direct, objective relation with the medical encounter. They are also indicative of the expectations placed on doctors, expectations that can turn into an emotional burden for doctors themselves, usually unaware of such deeper thoughts crossing their patients' minds. The sense of abandonment and betrayal emerging in this patient's note does not concern all patients or all doctors, but it deserves attention since it raises questions on the complex picture behind both general interactions in healthcare, and the more specific case of a disease with a remarkable diagnostic delay, no cure available and years of ignored or diminished symptom reports.

It also draws attention to how doctor and patient can build a trust-based relationship that does not necessarily mean *saving* someone from their personal traumas but allows doctors to *be with* patients, by their side during the care path, as Charon confirms in the following citation and I stress through my italics: "A medicine practiced with narrative competence will more ably [...] *accompany* patients and their families *through* the ordeals of illness" (2006, vii).

In any case, the patient's emotional fragility is unquestioned as expressed in the verb "ferire", "hurt", repeated twice ("hanno ferito la bambina? L'hanno sminuita? L'hanno ferita?"). Lack of recognition emerges as the apex of a painful process and adds frustration because the subject complaining feels ignored: "Mi sento ANCORA non ascoltata" (I feel that I am STILL not being listened to):

Table 20

A comprehensive approach to the disease

Participant	Excerpt	Translation
FF49204B9548	È molto difficile ora.	It's very difficult right now.
	Vorrei un percorso psicologico di sostegno perché per troppo tempo mi sono sentita colpevole perché stavo male o perché non riuscivo a fare tutte quelle cose che avrei voluto.	I would like psychological support because for too long I have felt guilty for feeling unwell or for not being able to do all the things I wanted to do.
	Vorrei riuscire a capire cosa mi dicono perché non capisco i termini tecnici.	I would like to be able to understand what they are telling me because I don't understand the technical terms.
	In fondo vorrei avere un percorso integrato.	Basically, I would like to have an integrated approach.
	Dove utero intestino stomaco vengano trattati e monitorati insieme. Quando dico che forse mi serve un gastroenterologo o un proctologo e mi viene detto che non è detto che sia un problema dovuto alla mia patologia, mi sento ANCORA non ascoltata. [...]	Where my uterus, intestines and stomach are treated and monitored together. When I say that I might need a gastroenterologist or a proctologist and I am told that it is not necessarily a problem due to my condition, I feel that I am STILL not being listened to. [...]

Dopo una faticosa e dolorosa ricerca di consapevolezza da parte mia? Dopo essermi informata sui termini e sui sintomi?	After a tiring and painful search for awareness on my part? After informing myself about the terms and symptoms?
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I would like to avoid possible (mis)interpretations of this passage, which I quoted and analysed, not because I want to stigmatize the role of doctors as insensitive beings making arbitrary decisions, and that of patients, as passive victims. Firstly, among the tenets of this thesis and of NM there is the idea of a tailor-made path of care, so generalizations find no room in this context. Secondly, I have no medical education and competence to provide arguments to counter the medical advice about a dubious relation between endometriosis and other comorbidities *in the patient's specific case*. The gynaecologists' feedback is grounded in clinical expertise and in the knowledge of this patient, whereas my textual analysis focuses on linguistic but indicative aspects of this woman's story, of the version of her experience that she provided. The note answers the prompt no. 20: "During medical interviews I also want to talk about... but I find it difficult because...". It is a prompt for investigating communication issues, particularly what patients would like to talk about and what stays unsaid.

The first topic that this patient mentions is that of fault: she blames herself for her illness, hence her need for professional psychological support. This feeling, as much as that of not being listened to, is related to an over-extended temporal framework, as the deictic markers "per troppo tempo" (too long) and "ANCORA" (still) underline. The latter is intentionally typed in capital letters, to stress a process of medical invisibility that has most probably started a long time ago, and that refers to the patient's whole endometriosis story, not necessarily to the gynaecologists that attend to her now³⁴.

³⁴ The patient herself clarifies in other notes that her actual experience at the AouS team is positive.

Limits of patient-centred care. Another reflection inspired by the close reading concerns the fragile balance between the patient's freedom on the one hand and the doctor's ethics and deontology on the other, an issue that actually transcends the specific case study I am presenting: I am talking more specifically about the issue of epistemic authority, the limits of empathy and the risks of paternalism.

I briefly discussed in Chapter 2 the patient-centred approach postulated by Balint (1969), stressing that, actually, in his methodology the focus is on the doctor's narrative perspective, in that doctors share their patient's stories with other doctors in order to reset or redefine their own clinical judgement and decision (especially for critical cases, like that of patient FF49204B9548), for example), to collect different points of view on the same issue, and eventually accept uncertainty as an endpoint where no other explanation or sense-making is possible.

In Chapter 2, it has also been recognised that power tends to shift towards doctors, in terms of their ability to determine specific courses of action in the patient's health and life, and that this tendency has been countered by new awareness of the right to a plain language, of concordance, and by the concept of health literacy.

I also supported with different sources the distinction between asymmetrical knowledge, as a factual condition in medical consultation, and epistemic authority, as a constantly and collaboratively negotiated result, based on cultural and social conventions shared by doctors and patients in each's assumed epistemic realm.

It seems that the balance in the doctor-patient relationship remains unresolved. But I provide a further argument in support of the claim of negotiation as a third realistic and rational way to manage medical interactions, and my argument is based on a particular patient's note, to exemplify that theoretical discussion.

Pilnick (2023) realises how some reviews have demonstrated increased patient satisfaction where patient-centred care (PCC) is practised, but wider research does not show a clear link between the adoption of PCC and improvement in health outcomes.

The sociologist tries to explain this discrepancy, considering that, historically, medical paternalism can be summarised as ‘doctor knows best’ and that, in contrast, PCC postulates a redistribution of control from doctor to patient. After recording healthcare interactions collected over 25 years in different settings in which PCC was adopted, she found a common trait.

Despite their claim of entitlement to knowledge, which emerges also in the patient’s note “Dopo essermi informata sui termini e sui sintomi?”, most patients consult with a healthcare professional in the first place “because they don't treat all sources of healthcare information as equal, and they lack the knowledge, or the ability to apply that knowledge, to solve their own problems” (Pilnick, 2023, p. 1787).

This ability is still considered a property of clinicians and makes them reliable, trustworthy, since they draw on medical knowledge, but they also have gained empirical experience with different patients in different contexts. It is not uncommon that patients ask questions such as “What do most people do?” (ibid). But there is more. If the pursuit of patient autonomy and freedom means that “medical decisions can become cast as purely private matters that patients must deal with alone, based on how they ‘feel’ about the options or how much they ‘worry’ about the alternatives” (ibid.), patients may feel abandoned. As they feel unqualified to make these decisions by themselves, they tend to expect anyway medical advice, asking indirect questions such as ‘What would you do in my situation?’. In this respect, epistemic authority, meant as a relationship based not only on knowledge but also on the ability of guiding and advising someone (as defined by Badino, 2022, see Chapter 2) is still, more or less willingly, expected and required by patients in medical consultations.

In the endometriosis treatment, this relationship is even more complex, as the patients, here represented on a smaller scale by the writers of our digital diary, have documented experience with professionals who did not trust their symptom records. Analysing the medical attitude in terms of competence and expertise, these doctors failed at diagnosing endometriosis, while in terms of epistemic authority, these doctors did not admit their inability to manage their patients’ conditions

or to treat their symptoms and misguided their patients by construing their pain as something just exaggerated.

So, once the right diagnosis was identified, the patients had to deal with different features of uncertainty, as they found out they suffer from a chronic disease, for which medical knowledge is still limited, symptoms are difficult to predict through patterns, no cause is known and no cure is available. This epistemic void makes it difficult for doctors, as well, to adopt a specific attitude in terms of epistemic authority. In the last section, I try to represent doctors' stance on this topic.

Communicating pain in endometriosis. I have already addressed in Chapter 2 the linguistic challenges related to the pain and illness discourse, comparing, among others, Charon's, Woolf's, Foucault's and Illich's perspectives on this topic. A close reading of the following notes can exemplify this communicative issue

Table 21

Uncertainty in the language of pain

Participant	Response	Translation
B60252BCF5B1	Non credo di riuscire a fare capire	I don't think I can explain it
FF49204B9548	Difficile comunicare cosa non va se non ti rendi conto di cosa non va. Difficile dire a un medico qual è il problema se non capisci cos'è normale e cosa no. Non sono mai stata in grado di spiegare che cosa volevo	It is difficult to communicate what is wrong if you do not realise what is wrong. Difficult to tell a doctor what the problem is if you do not understand what is normal and what is not. Every doctor inquires, according to their specific expertise, and suggest a possible solution. I was never able to explain what I

Firstly, patient B60252BCF5B1 expresses how difficult it is for her to explain herself: her note means “I am not sure that what I say makes sense, that what I feel can be understood at all.”

I found this incipit particularly representative of the deep uncertainty that informs the patient narratives.

In the second note, the inability of expressing one’s thoughts is even more clear and total: the repetition of negative adverbs, (“non, mai”, 7 occurrences in 3 sentences), of the adjective “difficile” (2 occurrences in two sentences) co-occurring with the verbs “comunicare” and “dire” are indicative of the inability to make sense of what the patient is experiencing *while* she is experiencing it and of the absolute lack of cognitive and linguistic references to do it. The ambiguity of the idea of “normality” contributes to this inability.

Now I aim to interpret the verbal challenge of expressing pain reported by our patient from Buchbinder’s viewpoint (2015). She considers Scarry’s view of pain as a private, intimate experience that “brings with it all the solitude of absolute privacy with none of its safety, all the self-exposure of the utterly public with none of its possibility for camaraderie or shared experience” (1985, p. 53).

“With none of its safety” here recalls the absolute absence of any certainty, even the comforting ones that privacy can offer. While in the analysis of the concept of pain-related suffering by Noe-Steinmüller et al. (2024) presented in chapter 2, the personal dimension emerged *alongside* the social and the other many different levels of the illness experience, Scarry (1985) seems to focus on the private, personal feature and to orient accordingly her view of the relation between suffering and language. According to Scarry, statements related to emotions and senses project us into the external world and beyond our body, as in utterances expressing states and processes like hearing *noises*, missing *a friend* and so on. On the contrary, the universal but subjective and private

condition of pain does not have objects to refer to. For Scarry, the pain experience cannot be verbally represented and shared because, as an inner state, it is hard to objectify.

David Morris (1991) suggested even a more extreme view, according to which the natural language of *chronic* pain would be silence: this idea recognises the intensity and incommensurability of pain. Yet, according to Cassel (1982), people stop talking about their chronic pain since they are not trusted: the social and interactional aspect plays a role in the verbal expression of pain.

I suggest that the argument of linguistic inefficacy can be countered by the iconic function of figurative language, which allows speakers to associate their feeling with something external and potentially material, as in the example “My pain is like a stab” or “The intense throbbing pain stabbed my stomach like a million knives”³⁵, in which the pain perceived is compared to an object from the outer tangible world.

Moreover, as Buchbinder (2015) contends, the pain experience can be also shared in ways other than linguistic objectification. Aligning with anthropologists such as Das (1997), Buchbinder sees pain as experienced not only in the individual body or in a vacuum, but within a cultural and social context, and saying “I am in pain” means “I need, I am asking for acknowledgement”, and does not only state a condition.

It follows that expressing pain through words acts on more levels, firstly a relational one, in that pain, despite its private dimension, requires “a social act to make it real to others, (and hence treatable)” (Buchbinder, 2015, p. 11): the patient writes namely “difficile dire al medico...” (it’s difficult to tell the doctor...), making explicit the subject she relates to, so assuming a relation.

Secondly, I argue, considering the statement “I am in pain” in a broader narrative context, for example including, among other information, what I was doing or what *I had to stop doing* on the symptom onset, how this impacted on my mood and on my caregivers, it is clear that the

³⁵ Pain description reported by a woman with endometriosis on the official website of the Endometriosis Foundation of America (2020, <https://www.endofound.org/meet-hailey-an-endo-patient-aspiring-endocrinologist>, last visited in July 2025).

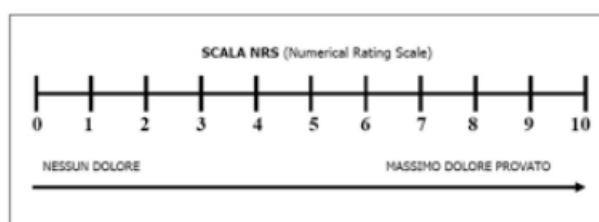
function of narratives, as means of self-reflection, representation and reordering of puzzling events, such as illness, links the personal dimension of suffering conveyed from the narrator's point of view with the relational meaning of pain language, and involves the receiver of my narrative from whom I expect acknowledgment. It is also in this sense that the narrative medicine is relation-centred. In the specific case of endometriosis, next to acknowledgment, women seek *validation*, as I argue further on.

This recalls the performative role of language, namely the idea that saying is also doing somehow. Declaring, saying, narrating is not only a subjective and relational but also a performative act, in that it recalls the performative role of particular utterances such as marriage vows, promises, legally binding declarations, that not only state or describe but also determine and cause actions (Austin, 1962). In this respect, NM first results (hopefully, in the endometriosis case) in an acknowledgement act and then it determines a specific course of action, a specific treatment and path of care, co-decided, co-participated, a concept echoed in Charon: “the narrating of the patient's story is a therapeutically central act” (2001, p. 1889) and in Charon & Montello (2002).

Uncertainty in the pain assessment. If talking about pain is difficult, assessing it can be even more difficult: the answers to the prompt on the assessment of endometriosis pain revealed very different stances on the method currently used, namely the NRS (Numerical Rating Scale).

Figure 23

NRS scale

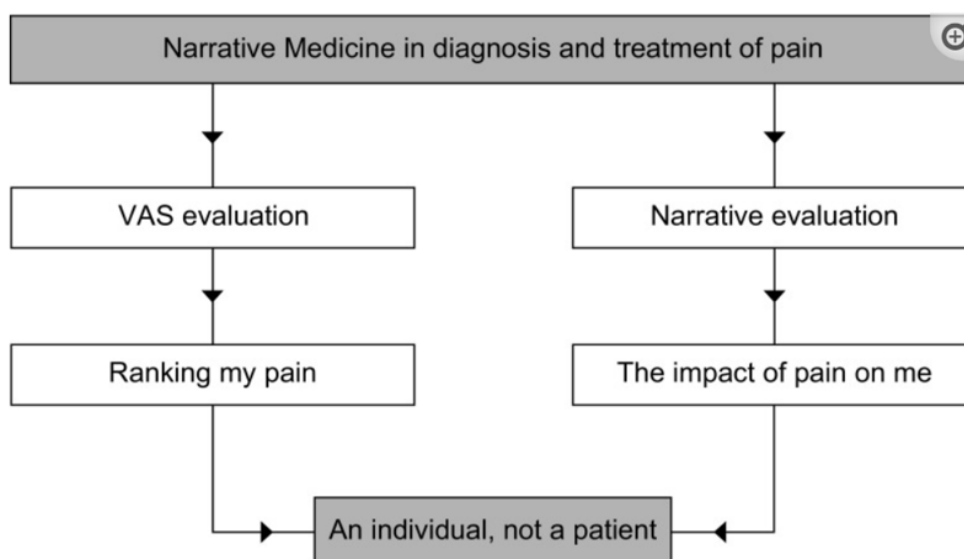


Patients are requested to assess the intensity of their pain by associating it with a number from 1 to 10. According to Drabble et al. (2021), the most common pain assessment tools respond

primarily to the need to produce data for clinical research rather than to facilitate communication between patients and doctors in the medical encounter. Moreover, they do not fully recognise the diversity of illness experiences, especially in such a chameleonic disease like endometriosis. While this system provides standardised results for healthcare professionals, it does not recognise the impact on the overall well-being of the patient, which is the focus of NM, as showed in this picture.

Figure 24

VAS evaluation versus Narrative Evaluation, Rosti, 2017



The NRS scale is based on numerical, quantitative standards, and does not leave much room for describing pains that are particularly changeable, unpredictable and difficult to relate to predefined patterns (like in endometriosis, Chapter 4).

Patients were asked to write if they found the NRS representative of their pain.

The diversity of responses to this prompt indicates that pain assessment is not simple and does not work in the same way for every patient.

Table 22

Pain assessment: a controversial issue (1)

Prompt	Senti che i test di	Do you think that pain
	valutazione/misurazione del dolore come quello qui sotto ³⁶ da endometriosi riescono a rappresentare efficacemente i tuoi dolori?	assessment tests like the one below ³⁷ can effectively represent your pains?
Participant	Excerpt	Translation
9E80F99DA04A	In verità no, un dolore simile penso non possa essere ridotto ad un mero numero, piuttosto è utile descrivere la tipologia del dolore stesso	Actually, no. I don't think pain like this can be reduced to a mere number. Rather, it is useful to describe the type of pain itself
A55769E5659F	Questa scala può valere per il picco del dolore, però ci sono i gonfiori addominali quotidiani, i dolori al basso ventre che a quel modo non sono ben rappresentati	This scale may be valid for peak pain, but there is also daily abdominal bloating and lower abdominal pain, which are not well represented in this way
1D89FB3AF555	Direi proprio di sì	Yes, definitively
FF49204B9548	Se si vuole semplificare la dismenorrea può essere utile ma la percezione del dolore cambia da persona a persona Dal momento, dalle ore o dal mese Delle volte può essere più a fitte o più diffuso. Malessere prolungato in intensità oppure	If you want to simplify dysmenorrhea, this system can be helpful, but pain perception varies from person to person. Depending on the moment, the time of the day, or the month. Sometimes it can be more

³⁶ The test referred to is represented in Figure 23

³⁷ The test referred to is represented in Figure 23

	<p>in durata</p> <p>Può prendere più la schiena o le gambe o lo stomaco o tutti insieme.</p> <p>Ci sono vari modi di percepire il dolore.</p> <p>Per non contare la possibilità di poter dormire o riposare.</p> <p>Da come ti svuota e ti fa sentire quando le parti acute sono passate.</p> <p>Lo si può considerare comunque dolore? L'efficacia dei farmaci.</p> <p>L'equilibrio emotivo.</p> <p>Io conosco solo il mio di dolore da ciclo.</p> <p>Ma non saprei classificarlo.</p> <p>Lo conosco talmente bene da averne paura. Come lo si può schematizzare?</p>	<p>stabbing, or more diffuse.</p> <p>The discomfort may be prolonged in intensity or in duration.</p> <p>It may affect the back more, or the legs, or the stomach, or all of them at once.</p> <p>There are many different ways of experiencing pain.</p> <p>Not to mention whether it's possible to sleep or rest.</p> <p>And the way it drains you and leaves you feeling once the acute phases have passed. Can you consider it pain, anyway?</p> <p>The effectiveness of medications.</p> <p>Emotional balance.</p> <p>I know just what my menstrual pain feels like. But I would not be able to classify it. I know it so well that I am afraid of it.</p> <p>How can it be put into a schematic form?</p>
ED1AECDDDB82A	<p>I dolori sono più forti perché una volta sono svenuta</p>	<p>The pain is worse because I fainted once</p>
C3699250CB72	<p>Sì, è un ottimo strumento per misurare e</p>	<p>Yes, it is an excellent tool for</p>

	valutare l'intensità del dolore	measuring and assessing pain intensity
BC650EA37D16	Sì	Yes
FB582774D451	<p>Si, penso che le scale siano fondamentali per dare una rapida indicazione quantitativa del dolore. Ovviamente da sole non bastano per inquadrare la situazione, ma possono essere utili anche nei follow-up successivi come termine di confronto per capire se con gli approcci terapeutici impiegati è cambiato qualcosa o no...</p>	<p>Yes, I think scales are essential for giving a quick quantitative indication of pain. Obviously, they are not enough on their own to assess the situation, but they can also be useful in future follow-ups as a basis for comparison to understand whether the therapeutic approaches used have changed anything or not...</p>
70CB0C5D018D	<p>Secondo me andrebbero descritte un minimo anche a livello di sintomatologia</p>	<p>In my opinion, they should also be described at least in terms of symptoms</p>

Some participants find the quantitative scale effective, some of them simplistic, for some women, pain can be even more severe than it could ever be represented by the scale. As this note reveals, uncertainty also underlies pain assessment and is expressed through the use of interrogative sentences (“come lo si può schematizzare?”) and of the negative modal that expresses the inability to classify pain (“Non saprei classificarlo”). Patient FF49204B9548 raises the issue of the variables included in the perception of pain and of the fear of the incoming pain, the anxiety that accompanies the pre-menstrual phase. She is not the only one to be scared by pain, and “paura” (fear) is cited 21 times in the corpus, in 10 of which it is related to pain. The following table shows the occurrences of paura, terrore, ansia. Most of the excerpts are from the patients’ responses to prompt 10 “Da

quando ho l'endometriosi, quando aspetto il ciclo, il mio corpo/la mia vita..." (Since I have had endometriosis, when I am waiting for my period, my body/my life...). While fear seems to precede the incoming period, in some notes, self-blame is the background feeling throughout the experience of endometriosis. Patient FF49204B9548 really thinks that something is wrong with her ("perché sei fatta male") and that she is somehow responsible for being affected by endometriosis ("perdonare i Medici che ho incontrato o/e me stessa per essere malata?").

Table 23

Fear and guilt

Participant	Excerpt	Translation
FF49204B9548	La condizione che vivo dai miei 11 a 48 anni è di una paura che è cresciuta nel tempo sempre più	The condition I have lived with from the age of 11 to 48 is a fear that has grown steadily over time
FF49204B9548	una parte di me ha paura dal momento stesso in cui ho preso l'appuntamento (dal medico)	Part of me has been afraid since the moment I made the appointment (with the doctor).
	La paura dei medici. La paura del dolore: lui arriva che tu lo voglia o no, lui arriva e la colpa è tua, perché sei fatta male.	Fear of doctors. Fear of pain: it comes whether you want it to or not, it comes and it's your fault, because you're broken.
(Responses to other prompts)	Paura che ti facciano male fisicamente e psicologicamente	Fear that they will hurt you physically and psychologically.
	Riuscirò mai a perdonare i Medici che ho incontrato o/e me stessa per essere malata? [...] È colpa mia? [...] per troppo tempo mi sono sentita	Will I ever be able to forgive the doctors I have encountered and/or myself for being ill? [...] Is it my fault?

	colpevole perché stavo male o perché non riuscivo a fare tutte quelle cose che avrei voluto.	
ED1AECDDDB82A	quando aspetto il ciclo già una settimana prima del ciclo mi prende un'ansia, una paura, una depressione quando penso al dolore che proverò, già con tutto questo sento dolori lievi di mestruazioni, il mio corpo mi dà segni che sto per provare dolori insopportabili	When I am expecting my period, a week before it arrives I feel anxious, fearful and depressed when I think about the pain I will experience. Even with all this, I already feel mild menstrual pain, and my body is giving me signs that I am about to experience unbearable pain
FF49204B9548	all'improvviso stavo male [...] andavo fuori per mettere più aria possibile nei polmoni per paura di svenire	Suddenly I felt ill [...] I went outside to get as much air as possible into my lungs for fear of fainting
5CB9848575B2	Ora attendo con terrore il mio prossimo ciclo.	Now I am dreading my next period.
ED1AECDDDB82A	una donna che non può mangiare quello che vuole per paura di sentirsi male	a woman who cannot eat what she wants for fear of feeling ill
	Quando aspetto il ciclo comincio ad avere paura	When I'm waiting for my period, I start to feel anxious
FF49204B9548	Lo [il dolore] conosco talmente bene da averne paura	I know [pain] so well that I am afraid of it
	Prima vivevo l'attesa del ciclo con l'ansia	I used to feel anxious while waiting for my period

The prompt was sent repeatedly throughout the project and patient FF49204B9548, one of the most active writers among the participants, shared two more notes on this topic. In her second response to the prompt, she also attached a picture (Figure 25) to the text cited in Table x:

Figure 25

*Pain assessment: a controversial issue*³⁸

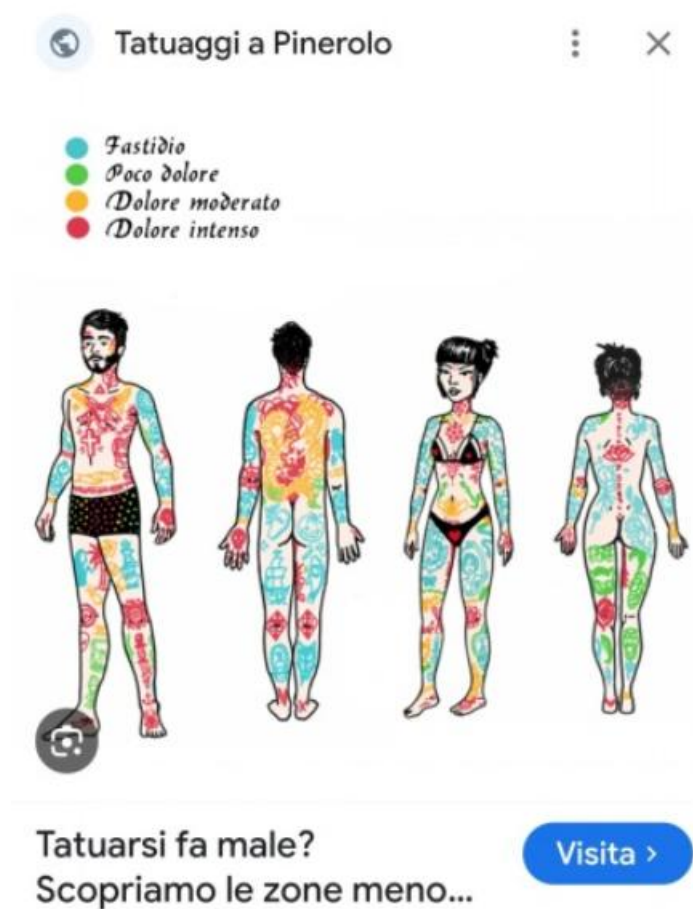


Table 24

Pain assessment: a controversial issue (2)

Prompt	Senti che i test di valutazione/misurazione	Do you think that pain assessment
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³⁸ “Tattoos in Pinerolo. Does getting a tattoo hurt? Let's find out which areas are less painful:”
Caption: Blue - Discomfort, Green - Slight pain, Yellow - Moderate pain, Red - Severe pain.

**del dolore come quello qui sotto da
endometriosi riescono a rappresentare
efficacemente i tuoi dolori?**

**tests like the one below can
effectively represent your pains?**

Participant	Excerpt	Translation
FF49204B9548	Non saprei.	I don't know.
	La maggioranza delle cose non si misura da 1 a 10.	Most things cannot be measured on a scale of 1 to 10.
	La vita.	Life.
	La felicità.	Happiness.
	La paura.	Fear.
	Il dolore? Quale dolore? Dove 1 è cosa? Dove 2 è cosa?	Pain? What kind of pain? What is 1?
	Deciso da chi?	What is 2?
	Quindi no, non mi pare una tabella adatta e mi sembra una soluzione semplice a un problema che non è semplice, questo apre una seconda riflessione:	Decided by whom? So no, I don't think it's a suitable table, and it seems to me to be a simple solution to a problem that is not simple. This leads to a second consideration:
	Perché una patologia di cui ancora si conosce poco, la causa, l'evoluzione, la cura, l'approccio, ma che è estesa a tantissime persone ha una tabella semplice quando altri argomenti no? (foto allegata è solo un esempio)	Why does a condition that is still poorly understood, whose cause, progression and treatment are unknown, but which affects so many people, have a simple table when other topics do not? (The

	attached photo is just an example).
MANCANZA DI INTERESSE?	LACK OF INTEREST?
Non credo affatto che tra visite specialistiche da più specialisti, ricerca, terapia, percorsi di fecondazione, integratori, diete, farmaci ci sia poco interesse o il problema è proprio questo?	I do not believe that there is little interest in specialist consultations, research, therapy, fertility treatments, supplements, diets and medication, or is that precisely the problem?

As it often happens in this patient's writing, 8 out of 10 utterances in the first note of the table above are questions, specifically non rhetorical questions, although her style is rhetorically refined, based on strategic repetitions of short and pregnant phrases with verbal ellipsis: "Il dolore? Quale dolore?" hints at the range and diversity of endometriosis related pain, so that it is difficult to homogenize the answer. The patient advances subtle arguments. A new sequence of questions with a parallel regular ("dove... è cosa?") structure makes the narrative rhythm compelling, "dove 1 è cosa? dove 2 è cosa? Deciso da chi?", before finally explicating the provocative meaning of her answer.

She adds a picture representing a classification of the pain caused by a tattoo, suggesting a comparison between two situations that do not have much in common: the tattoo, unlike endometriosis, is a choice, also linked to aesthetics. The pain experiences have two completely different meanings.

Irony arises also from the picture caption "Tatuaggi a Pinerolo" ("Tattoos in Pinerolo", a small and quiet Italian village), which has no logical connection with the disease and introduces an alienating perspective in the note. Irony intensifies the patient's stance on the inadequacy of the scale, which she finally expresses in the following comment: "mi sembra una soluzione semplice a un problema che non è semplice" i.e. it is a simple solution to a problem that is not simple at all.

The sentence arrangement, through the double placement of the adjective “semplice”, is functional to the paradox of the use of an oversimplifying method to a very complex health issue.

Another interrogative sentence stresses that a pain mapping related to the effects of a tattoo can be more detailed than the NRS used to assess endometriosis pain: “Perché una patologia di cui ancora si conosce poco, la causa, l'evoluzione, la cura, l'approccio, ma che è estesa a tantissime persone, ha una tabella semplice quando altri argomenti no?”

A second paradox follows: the scarce interest in endometriosis-related pain, foregrounded in capital letters (“MANCANZA DI INTERESSE?”), does not reflect the long list of specialists, diets and therapies that surround the disease. The note ends with one last question: “o il problema è proprio questo?”. The circle started with a sentence expressing uncertainty: “Non saprei” and ended with a new doubt. Uncertainty is the theme running through the note.

In her third note on this topic (Table 25), the patient uses again the repetition pattern: “Parte dallo 0 di cosa? Dove 3 è cosa? 7 è cosa?” and a hyperbole: “10 la morte?”

Table 25

Pain assessment: a controversial issue (3)

Prompt	Senti che i test di valutazione/misurazione del dolore come quello qui sotto da endometriosi riescono a rappresentare efficacemente i tuoi dolori?	Do you think that pain assessment tests like the one below can effectively represent your pains?
Participant	Excerpt	Translation
FF49204B9548	La scala è su cosa?	What is the scale based on?
	Parte dallo 0 di cosa?	What is the starting point of 0?
	Dove 3 è cosa?	Where is 3?
	7 è cosa?	Where is 7?
	10 la morte?	Is 10 for death?
	Un'unità di misura va bene perché capita di	A unit of measurement is fine, because

<p>avere un dottore che è uomo e allora che ne sa del dolore mestruale?</p> <p>E se poi è una donna? Che ne sa dei dolori endometriosi vs mestruazioni?</p> <p>Un'unità di misura ci vuole ma almeno colorati, in scala, che preveda dei parametri di tempo e spazio.</p>	<p>it can happen that your doctor is a man, but what if you have a male doctor who knows nothing about menstrual pain?</p> <p>And what if it's a female doctor? What does she know about endometriosis pain versus menstrual pain?</p> <p>A unit of measurement is needed, but at least it should be colour-coded, scaled, and include parameters of time and space.</p>
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This time, she interestingly suggests a relation between the assessment tool and the gender of the gynaecologist: it seems that the scale does not allow for a clear-cut assessment of the pain severity, since that specific pain has never been experienced by a male doctor. The same patient states in another note: “per una patologia che colpisce le donne servirebbe più dottori con un utero e un ciclo” (for a condition that affects women, we need more doctors with a uterus and a period). According to the patient, even if a female doctor has experienced menstrual pain, she may not have had endometriosis, hence she does not know how it acts. Once again, the concept of pain is surrounded by uncertainty: whether the doctor is a man or a woman, understanding and assessing pain is difficult because it is extremely subjective, and, in the case of endometriosis, very unruly and diverse. Yet, the diary note examined is constructive in its own way, since it suggests introducing parameters of time and space as more exhaustive criteria to represent the endometriosis pain. In scientific literature, this idea recalls Drabble et al.’s study on the “constellations of pain” (2021, p. 352).

Recognising that the diversity and complexity of women’s pain experiences are underrepresented in research, Drabble et al. (2021) classify endometriosis pains in different conceptual categories: type, pattern and intensity. These categories combine to create a complex

experience for each individual, defined as “constellations of pain” because each woman has a specific and unrepeatable complex set of pain categories, as in Figures 26 and 27.

Figure 26.

Elizabeth’s constellations of pain (Drabble et al., 2021, p. 352)

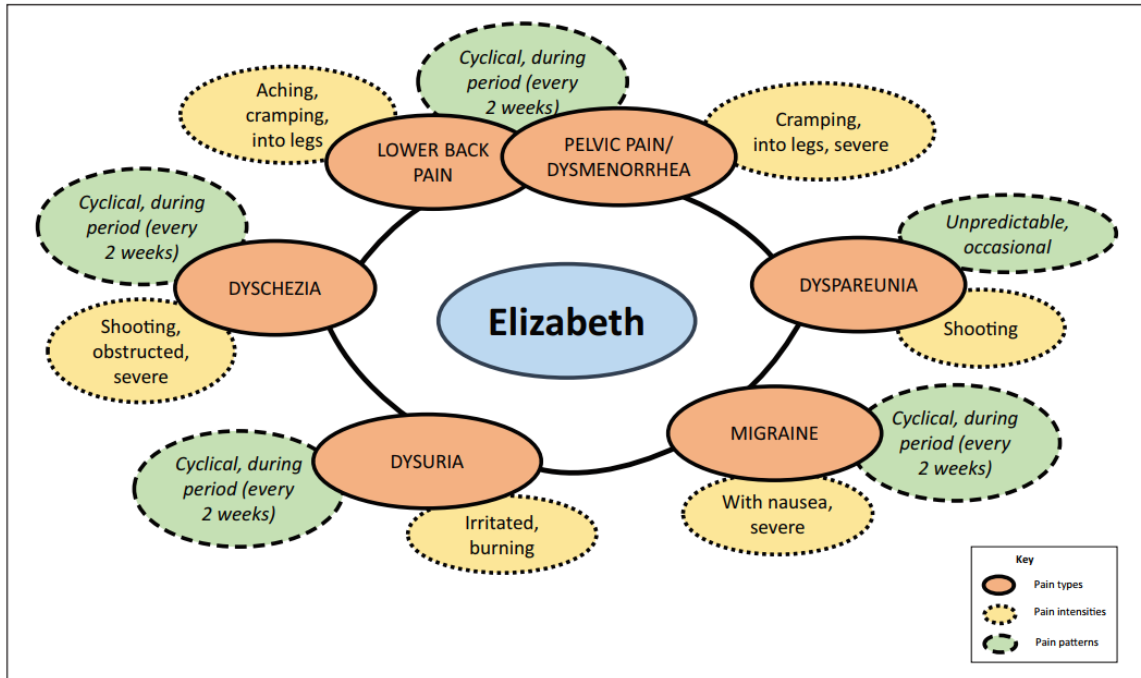
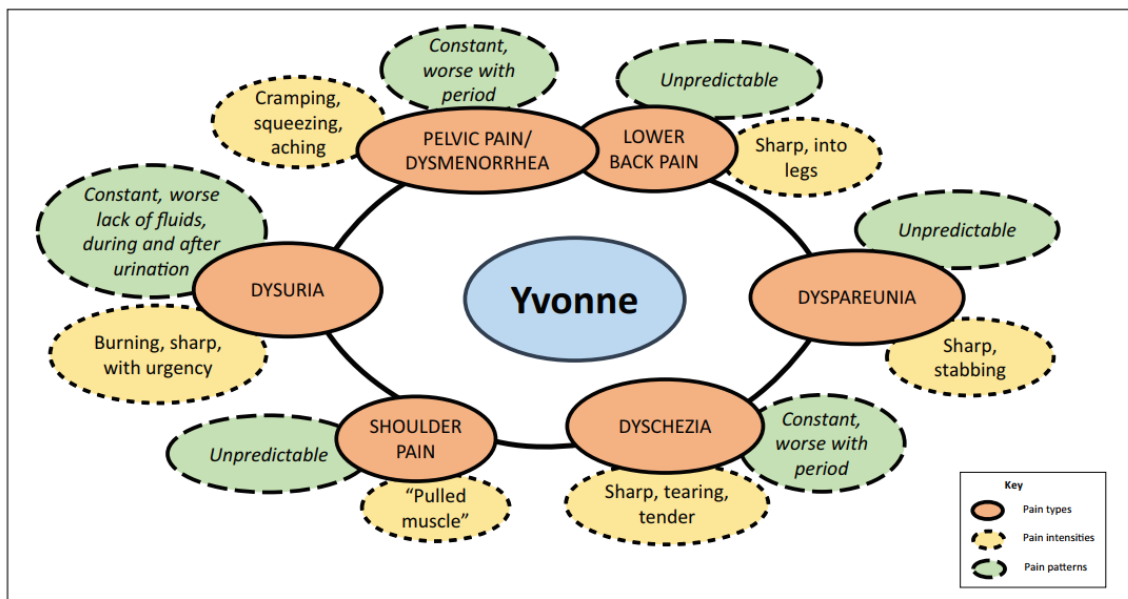


Figure 27

Yvonne’s constellations of pain (Drabble et al., 2021, p. 353)



As shown in these two pictures, the pain description covers aspects of pain such as type and time patterns, where the intensity is not expressed by numbers, but by adjectives, often through figurative language. On the topic of pain assessment, other patients agree with the comments just analysed although they use a different style or add more detailed alternative suggestions, as shown in the following table.

Table 26

Pain assessment: a controversial issue (4)

Prompt	Senti che i test di valutazione misurazione del dolore come quello qui sotto riescono a rappresentare efficacemente i tuoi dolori?	Do you think that pain assessment tests like the one below can effectively represent your pains?
Participant	Excerpt	Translation
B60252BCF5B1	<p>Ho sempre sostenuto che hanno senso i numeri...laddove ci sono riferimenti... Ma non ho mai portato stimare la differenza tra il 3 ed il 4... Tra il 6 ed il 7. Poi i dolori si dimenticano, cioè si fa fatica a collocare l'intensità quando si raccontano... Si dimenticano le sfumature e restano i sentimenti a loro collegati...il senso di smarrimento, la voglia di reagire...la confusione... Non ho mai apprezzato questo metodo di misurazione. Ma capisco la necessità di stimare il dolore. Ma ho pensato molto a come aiutare un medico per capire:</p>	<p>I have always maintained that numbers make sense where there are references... But I have never been able to estimate the difference between 3 and 4... Between 6 and 7. Then the pain is forgotten, that is, it is difficult to assess the intensity when recounting it... The nuances are forgotten and the feelings associated with them remain ... the feeling of being lost, the desire to react... the confusion... I have never appreciated this method of measurement. But I understand the need to estimate pain. However, I have thought a lot about how to help a doctor understand:</p>

1 - mi sono tagliata un'unghia troppo corta	1 - I cut my nail too short
2 - mi sono tagliata con un foglio un dito	2 - I cut my finger with a piece of paper
3 - mi sono bruciata il palato con il caffè	3 - I burned my palate with coffee
4 - mi sono schiacciata un dito in un cassetto	4 - I crushed my finger in a drawer
5 - un crampo	5 - a cramp
6 - una puntura antipatica	6 - an unpleasant injection
7 - una sciatalgia	7 - sciatica
8 - il blocco dell'ernia cervicale	8 - cervical hernia blockage
9 - travaglio da parto	9 - labour pains
10 - bruciare viva	10 - being burned alive
Il 10 non l'ho mai provato ma vado a fantasia	I have never experienced number 10, but I can imagine it

In this note, different linguistic features convey the sense of uncertainty surrounding the assessment of pain. In the excerpt “Si dimenticano le sfumature e restano i sentimenti a loro collegati...il senso di smarrimento, [...] la confusione...”, the nouns “sfumature” on one hand, and “sentimenti”, “smarrimento”, “confusione” on the other, are placed in a parallel sentence structure, where the order subject-verb is reversed: predicate-subject: “Si dimenticano le sfumature e restano i sentimenti [...]”. This focus strategy allows the readers to picture in their mind a sort of replacement, in which pain and its related feelings fade away (the previous sentence was “I dolori si dimenticano”), while confusion and disorientation come over and stay. At a graphic level, the sequence of ellipses, serving a metalinguistic function, especially in digital writing (Antonelli, 2008), underscores uncertainty and makes the reader closer to the emotional state of the writer (Testa, 1997). The ellipses make the reader imagine the patient while she simultaneously thinks, remembers and writes her diary, realising that old emotions disappear (“si dimenticano”), leaving room for new ones (“restano”), and ellipses represent the suspension between these shifts.

The previous note criticised the NRS as an oversimplifying method since it did not consider pain in terms of space and time. This one highlights the subjectivity and so the relativity of such a scale, too, but it includes in the assessment criteria memory (“I dolori si dimenticano, cioè si fa fatica a collocare l'intensità quando si raccontano...”), the context in which those pains were experienced, reactivity and confusion. This patient is unconsciously recalling Cassel's (1982) and Phillips' (2023) idea of suffering, illustrated in Chapter 2. Moreover, diaries as a genre offer a narrative self-questioning frame, in which one's memory is not always reliable, as Charon confirms (2006):

[...] autobiography makes one ask intimate questions about the truthfulness of one's memory, [...] Where is the self recoverable—if, indeed, there is a recoverable self—in memory, in external reality, in others, or in language? Is there a factual and objectively retrievable past, or is the past a construct of recollection and desire? How is memory related to experience, and how are they both related to imagination? (p. 70).

In the note analysed, the patient seems to be aware of the power and limits of memory and tries to suggest an alternative method to assess pain, mostly based on the association between pain and the external factors that cause it. This anticipates the figurative language used in pain description that I cover in the next section. To conclude this part, it is worth noting that despite their deep thoughts about pain, these women occasionally add humour and irony to their notes (“10 - bruciare viva. Il 10 non l'ho mai provato ma vado a fantasia”). This choice can reveal the need to tease someone, like in patient FF49204B9548's note, critically addressing the medical system and its practice, or can simply work as a coping strategy to manage critical situations like pain and its chronicity (as in this last note).

Images of pain. I decided to analyse the responses to prompts 6, 7, 10 and 11 in the same section, since they have two features in common: the pain/illness experience and its description through figurative language.

The choice of this section title, “Images of pain”, and the concept of figurative language that I consider in the following analysis are based on Wohlman’s (2022) research on metaphors in illness writing. Assuming that in figurative language words take on a meaning that departs from their standard one, and that metaphors allow people to understand and experience “one kind of thing in terms of another” (Lakoff & Johnson, 1980, p. 5), in this thesis I use the term “figurative language” as an umbrella term including “metaphors, similes, analogies, allegories, metonymies, synecdoches and idiomatic expressions³⁹” (Wohlman, 2022, p. 9). This also aligns with the relationship of synonymy between the terms “metaphorical images” and “figurative images” identified by Cipriani to indicate “language that goes beyond literal meaning” (2025, p. 33). To the array of figurative devices just listed, I would also add non-verbal language, such as the pictures with which some patients answered prompt 6 (“Try to represent your present with a drawing and attach the picture, or describe it with a passage, sentence, memories of a place (or other) that comes to your mind...”).

The addition of these elements was also inspired by Lévi-Strauss’s thought and its applicability to medicine. He contended that (1963):

The shaman provides the sick woman with a *language*, by means of which unexpressed, and otherwise inexpressible, psychic states can be immediately expressed. And it is the transition to this verbal expression — at the same time making it possible to undergo in an ordered and intelligible form a real experience that would otherwise be chaotic and inexpressible — which induces the release of the physiological process, that is, the re-organization, in a favourable direction, of the process to which the sick woman is subjected. (p. 193)

This reflection anticipates a similar understanding of metaphor by Jamison (2014), according to whom metaphors make bearable those things that would be unbearable if expressed directly and literally. For Wohlman (2022), metaphors and stories do share a common trait and

³⁹ We have already discussed some instances of idiomatic expressions and their metaphorical feature (“raccontarsi le novelle”, “Oddio” etc.) in 5.3.1.

function, in that they can conceal or help to create and reshape meaning, to find some sense in the inexplicable. Also in medical anthropology, Becker (1984) studies how metaphors can help people to find or re-establish meanings and connections after traumatic events in their lives.

Ricœur (2001, 2004) finds that metaphors also fill in an expressive shortage of words necessary to represent the complexity of reality and add energy and force to communication. All these research contributions align with the theme of the linguistic inadequacy in medical communication, already illustrated in Chapter 2: the complexity of the illness experience, especially for a disease that is chronic or hardly detectable through technical investigation⁴⁰, makes pain description hard and frustrating, causing communicative issues in clinical encounters. Yet, as Semino (2010) notices, the resort to metaphors:

may facilitate some form of internal embodied simulation of pain experiences on the part of listeners/readers, which may in turn provide the basis for an empathic response. [...] This tendency may be explained as an attempt to enable others to experience something akin to the sufferer's own sensations. (p. 2-3)

Although figurative language is used spontaneously throughout the corpus, in the prompts considered in this section, it is specifically elicited and encouraged at the lexical level, as words like “immaginare”, “associare”, “venire in mente” suggest. The following tables also include responses to prompts other than 6-7-10-11 that yet feature figurative language related to the body and pain.

These extra notes are marked in the table as “other prompt”.

Table 27.

Figurative language on pain

Prompt:	La prima immagine che assocerei ai miei dolori è ...	The first image I would associate with my pains is ...
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⁴⁰ The note excerpt “ho sempre effettuato controlli, dai quali non è mai emerso niente” (9F88481FF3BC) exemplifies how such investigation can fail.

Participant	Excerpt	Translation
ED1AECDDDB82A	L'immagine di una donna sola, incompresa, che soffre ogni giorno, che dorme e si sveglia con dolori, che nemmeno la notte dorme perché ha delle crisi, l'immagine di una donna sempre stanca, una donna che non può mangiare quello che vuole per paura di sentirsi male e infine una donna che non riesce a immaginare il suo futuro perché ha paura di un futuro senza figli 😞	The image of a lonely, misunderstood woman who suffers every day, who sleeps and wakes up in pain, who cannot even sleep at night because she has acute episodes, the image of a woman who is always tired, a woman who cannot eat what she wants for fear of feeling ill, and finally a woman who cannot imagine her future because she is afraid of a future without children
C3699250CB72	L'immagine associata è quella di me che non dormo di notte per i dolori fortissimi.	The associated image is one of me lying awake at night because of the intense pain.
BC650EA37D16	Non ho immagini da rappresentare perché non avevo dolore durante i cicli	I have no images to represent because I had no pain during my periods.
1D89FB3AF555	Adolescenza non vissuta, esperienze negate o fatte a metà. Non ho trascorso un solo giorno senza il mio fidato compagno al quale finalmente, nel 2020, ho dato un nome: endometriosi	Adolescence not lived, experiences denied or only half-lived. I have not spent a single day without my trusted companion, whom I finally gave a name to in 2020: endometriosis
A55769E5659F	Un fulmine a ciel sereno	A bolt from the blue

	poi resta quotidianamente un peso	then remains a daily burden
9E80F99DA04A	Tanti coltelli che mi penetrano	So many knives piercing me
1D89FB3AF555	Un pugnale	A dagger
B60252BCF5B1	Un bruco che mangia una foglia partendo da una crepa al centro	A caterpillar eating a leaf, starting from a crack in the centre

Table 28*Figurative language on the body*

Prompt:	La parte del corpo che solitamente mi fa più male somiglia per me a...	The part of my body that usually hurts the most reminds me of...
Participant	Excerpt	Translation
ED1AECDDDB82A	La parte del corpo che mi fa più male è il basso ventre. Sento dolori simili a coltellate, a volte come scariche elettriche. I dolori pelvici sono simili a contrazioni	The part of my body that hurts the most is my lower abdomen. I feel pains similar to stabbing, sometimes like electric shocks. The pelvic pains are similar to contractions
C3699250CB72	la parte del corpo che mi porta più sofferenza sono le ovaie di sinistra. quando sento dolore sembra che qualcuno ti stringa in modo molto forte la parte dolorosa come se volesse strappartela via	The part of my body that causes me the most pain is my left ovary. When I feel pain, it feels like someone is squeezing the painful area very tightly, as if they wanted to tear it off

9E192F9666A5	avevo la sensazione la notte che	I had the feeling that something was
Other prompt (1)	qualcosa si muovesse nella mia pancia, tipo una palla piena di acqua [...]scoprirono che era una ciste ovarica, come una bomba, era esplosa, frantumandomi l'ovaio destro	moving in my stomach, like a ball filled with water [...]the they discovered that it was an ovarian cyst, like a bomb, it had exploded, shattering my right ovary
B60252BCF5B1	Un sasso mi rimbalzava nello stomaco	A stone bounced around in my
Other prompt (11)	facendomi sentire le vibrazioni ad ogni passo	stomach, making me feel the vibrations with every step
1D89FB3AF555	Una immensa onda anomala	A huge rogue wave
Other prompt (11)		
B60252BCF5B1	È un pulsare... Con punture piuttosto forti che arrivavano dopo un crescendo sordo. Non credo di riuscire a fare capire. Il mal di testa è pulsante e si irradia ad altre zone annebbiando dei sensi, perché logora se lo tieni troppo addosso...no? Ecco, questo tipo di dolore ad ondate...quando aumentava l'intensità, mi veniva di strizzarmi e premere il ventre...come se dovessi fare uscire da me un qualcosa che invece resisteva e si aggrappava... Che pesava nelle viscere schiacciando e	It's a throbbing... With rather strong stings that came after a dull crescendo. I don't think I can explain it. The headache is throbbing and radiates to other areas, clouding the senses, because it wears you down if you hold it in too long... right? That's it, this kind of pain in waves... when it increased in intensity, I felt like squeezing and pressing my stomach... as if I had to get something out of me that was

<p>facendo pressione verso il basso. Un movimento dell'intestino era una fitta acuta, fare pipì era un acutizzare il dolore sonnolente... Perché quel dolore riposava ma non se ne andava nemmeno con gli antidolorifici. Sentivo dolori alla schiena, al basso ventre che a tratti salivano ed un vuoto alla bocca dello stomaco. Avevo in bocca un sapore cattivo ed a volte dolori ai reni...O verosimilmente alla loro collocazione...ho provato due parti, con due travagli molto diversi tra loro, conosco il dolore...Ma quando arrivava la vera colica gli assomigliava molto, in una sorprendente dinamica ad ondate... A volte, se mi sorprendevo mentre ero al lavoro, perdevo forza anche nella presa con le mani, tanto mi indeboliva.</p>	<p>resisting and clinging on... That weighed heavily in my guts, crushing and pressing downwards. A movement of the bowels was a sharp pain, peeing was an intensification of the drowsy pain... Because that pain subsided but did not go away even with painkillers. I felt pain in my back and lower abdomen that would come and go, as well as emptiness in the pit of my stomach. I had a bad taste in my mouth and sometimes pain in my kidneys... Or where I presume my kidneys were... I have given birth twice, with two very different labours, so I know pain... But when the real colic came, it was very similar, in a surprising wave-like dynamic... Sometimes, if it caught me while I was at work, I lost strength even in my grip, so much did it weaken me</p>
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The tables feature both descriptive/narrative notes and more iconic and evocative representations of pain.

In the former case (e.g., ED1AECDDDB82A, C3699250CB72), the patient focuses on her life quality: the frequent use of modal and semi-modal verbs in negative sentences (“non può, non riesce”) expresses the inability to satisfy some primary needs, such as eating what she wants and sleeping quietly (“una donna che non può mangiare quello che vuole, nemmeno la notte dorme”). The patient’s imagination seems to be locked, as she states herself, “una donna che *non riesce a immaginare* [il suo futuro]”: her thoughts are rooted in a world limited by pain and the *fear of pain* (“per paura di sentirsi male”, “ha paura di un futuro senza figli”). The temporal adverbs “ogni giorno”, “sempre”, “nemmeno la notte” make these limits sound eternal and seem to align with the chronicity of the disease. The anaphorical phrase “una donna”, repeated four times, suggests a feeling of alienation, of disconnection between the writer and herself, as if she were looking at herself from an outer perspective, as if she were a spectator of her own life, a metaphor recurring in another patient’s note (ED1AECDDDB82A: “è come se fossi una spettatrice della mia propria vita”), when she talks about how she feels during medical interviews. The use of the third person, (“che soffre ogni giorno, che dorme e si sveglia con dolori”) shifting the narrator’s perspective, makes this detachment more visible.

Figurative language is deployed more frequently in the other notes of the table. In one note (1D89FB3AF555), the disease is personified and identified with a name, throughout a process that relieves the patient from sharing a lifetime with something/somebody who is first unknown and then becomes trusted: “il mio fidato compagno”. This bitterly ironic relation to the friendship/partnership reflects resignation and acceptance. Unlike in this reluctantly accepted personification, pain is still recognised as something undefined, unknown (“come se [...] qualcuno, qualcosa”) that attacks the body (“si aggrappava, resisteva”). Other images offer a sensory insight into physical states and processes, caused by external objects, especially the act of cutting (“coltelli”, “coltellate”, “pugnale”, “scariche elettriche”, “puncture”, “bomba”). Other notes draw on the natural environment, where unexpected and violent atmospheric events (“fulmine”, “onda”, “ondate”, “palla piena di acqua”) disturb the quiet, leaving behind a feeling of oppressive heaviness

(“peso”). The image of water, used by two patients, is associated in both cases with a disruptive, overwhelming force. The vivid and unsettling image of the caterpillar eating the leaf from a central crack also evokes an animal, alien (non-human) presence that takes something away from the human body and consumes it.

In the studies on metaphors, sharp objects, tormenting animals, fire, alien attacks are the most dominant patterns identified by Kövecses’s (2008), and subsumed by Semino under the general label of “causes of physical damage” (2010: 3). According to a study conducted by Camerota and colleagues (2023), the quality of metaphors changes according to the intensity of chronic pain perceived by the subject: patients with tolerable pain depict it as a friend/partner who never leaves you but is tolerated (companion). Those suffering from severe pain tend to use more violent images, referring to foreign or dehumanizing elements, that might reflect a sense of detachment from the body, of aggression from the outside.

This finding seems to be confirmed by the analysis of the EndoNar corpus: most of the figurative language cited in the tables above refers to external sources of pain and is used by patients who in the notes on the symptomatology report very severe pains, as shown in this table, where pain description and severity are coupled to highlight this relation:

Table 29

Relationship between figurative language and severity of pain

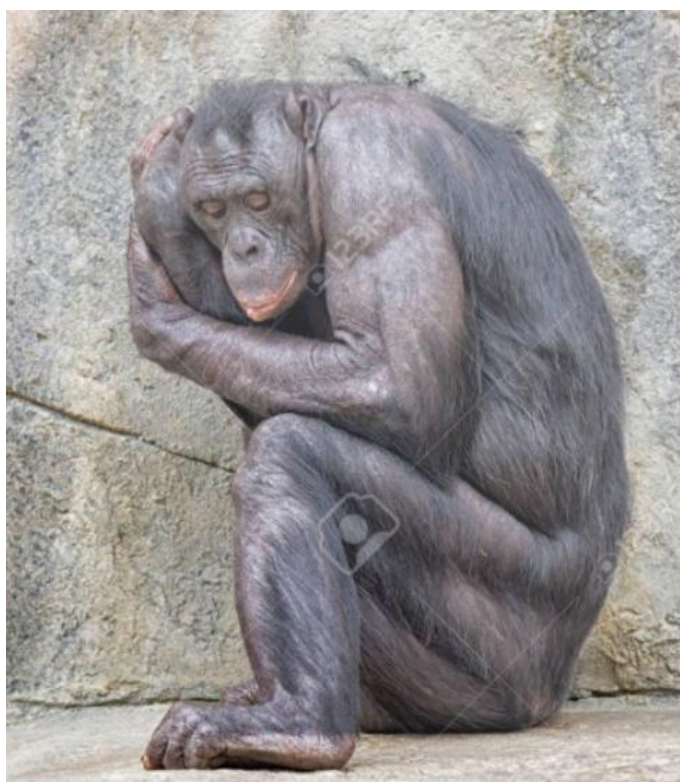
Image and pain description	Translation
Un bruco che mangia una foglia partendo da una crepa al centro	A caterpillar eating a leaf, starting from a crack in the centre
Improvvisamente e in modo molto violento si diffusero dolori in tutto l'addome [...] Poi arrivata a non riuscire a stare bene eretta, con coliche addominali un mese si ed uno no	Suddenly and very violently, pain spread throughout my abdomen. [...] Then I couldn't even stand upright, with abdominal cramps every other month.

Tanti coltelli che mi penetrano	So many knives piercing me
Non ho memoria di aver comunque mai avuto cicli con dolori sopportabili	I don't remember ever having periods with bearable pain.
Un fulmine a ciel sereno	A bolt from the blue
Ho provato un dolore lancinante, non riuscivo a respirare, né a stare in piedi eretta	I felt a sharp pain, I couldn't breathe or stand upright

Patient FF49204B9548 responded to this prompt by attaching the picture with which she associates her pain (Figure 28).

Figure 28.

Multimodal language of pain (1)



The patient used the chimpanzee picture to represent her endometriosis pain, drawing again on the domain of nature. Here, the female body loses its human shape and traits, although the animal chosen to represent pain is the most connected one to human beings in terms of evolutionary origin and behaviour. The animal in the picture curls up just like the patient describes herself when

she is in pain (Table 30). The inability to stand upright is also documented by other pictures of the corpus

Table 30

Relationship between image (Table 29) and description in the language of pain

Prompt	La prima immagine che assocerei ai miei dolori è ...	The first image I would associate with my pains is ...
Participant	Excerpt	Translation
FF49204B9548	Quando ero fuori il sabato sera e all'improvviso stavo male e mi mettevo rannicchiata in un angolo il più nascosta possibile. Mi sento molto stanca come se avessi camminato tantissimo e vorrei soltanto stare rannicchiata	When I was out on Saturday night and suddenly felt ill, I would curl up in a corner as hidden as possible. I feel very tired, as if I had walked a long way, and I just want to curl up

The distance of such natural images from the medical discourse seems to reset a connection with what is far from the social conventions, even from language, as proved by the fact that the patient did not use words, but a picture to respond to this prompt:

As Facchin notes, “L’essere immersi nel campo del linguaggio – dunque nel romanzo della propria vita, sin da prima della nascita, e nella cultura – smarca gli esseri umani dall’istinto che regola il comportamento animale” (2023, p. 46)⁴¹.

Moving to a different domain, the following notes refer metaphorically to a military environment and a defensive reaction to the disease:

⁴¹ Being immersed in the field of language – and therefore in the novel of one's own life, even before birth, and in culture – sets human beings apart from the instinct that governs animal behaviour.

Table 31*War imagery in healthcare*

Participant	Excerpt	Translation
B60252BCF5B1	C'era una cosa che <i>invadeva</i> ed era quello che sentivo ma che fino ad allora era negato	There was something <i>invading me</i> , and it was what I felt but had been denied until then
FF49204B9548	[...] se [mia madre] mi chiedeva qualcosa rispondevo con il <i>codice di guerra</i> SEMPRE LO STESSO, perché in realtà mi ammalò di rado, quindi il motivo era quello, come sempre, il solito stramaledetto ciclo	I responded with a <i>war-like code</i> “ALWAYS THE SAME STORY”, because in reality I rarely get sick, so the reason was, as always, the same old damn cycle

Excepted for these two cases, the corpus does not reveal a real tendency to use the well-known warfare or agonistic metaphor of the patient’s struggle against the enemy (i.e. the disease), which, on the contrary, has been identified in other corpus studies on the same disease, such as in the web-page discourse of organizations promoting endometriosis awareness in the United States. Specifically, on the Facebook webpage of MET (My Endometriosis Team), followers are often addressed as “Endowarriors”, are encouraged to stay strong, in control, and to battle endometriosis (Lecompte-Van Poucke, 2022). Based on the idea that our conceptual system is metaphorical in nature (Lakoff & Johnson, 1980), comparing patients to warriors means that there is something (the disease, the body) seen as an opponent, an enemy. So the reaction to the disease and the attitude to the body will reflect this metaphorical and conceptual structure: patients may fight against their own body. Semino (2017, 2018) and Bleakley (2017) have critically studied, among others, the metaphor of medicine as a war and that of illness as an enemy to be defeated.

They warn against the doctors' and health institutions' tendency to deploy it universally, i.e. with any patient, and they consider the ambiguous effect that such metaphors can have on patients in terms of attitude to the illness experience and to the therapy: on one hand the battle idea can sound engaging, empowering, motivating to react; on the other hand, it can create a sense of inadequacy and guilt in those who do not win the battle, as if they had not tried hard enough. At the same time, Semino (2017) highlights that the military metaphor is not inherently negative, and that, especially if it is used autonomously by a patient, it could just convey that specific patient's determination and optimism. So, the use of these metaphors is very context-dependent.

The Present. In this section, I analyse the perception of the present and future among participants (prompts 6, 32, 33, 45). Prompt 6 was sent to patients three times during the project admits a multimodal expression in the responses, since patients could use both drawings/pictures and texts.

Table 32

The perception of the present

Participant	Excerpt	Translation
Prompt	Prova a rappresentare il tuo presente con un disegno e allegane la foto, oppure a descriverlo con un brano, una frase, il ricordo di un luogo (o altro) che ti viene in mente...	Try to represent your present with a drawing and attach the picture, or describe it with a passage, sentence, memories of a place (or other) that comes to your mind...
ED1AECDDDB82A	Il mio presente è sempre pieno di dolore, per esempio oggi mi sono svegliata con dolori nonostante il fatto che abbia preso degli antidolorifici	My present is always full of pain. For example, today I woke up in pain despite taking painkillers
BC650EA37D16	Mi viene in mente la casa che avevamo	I remember the house we bought

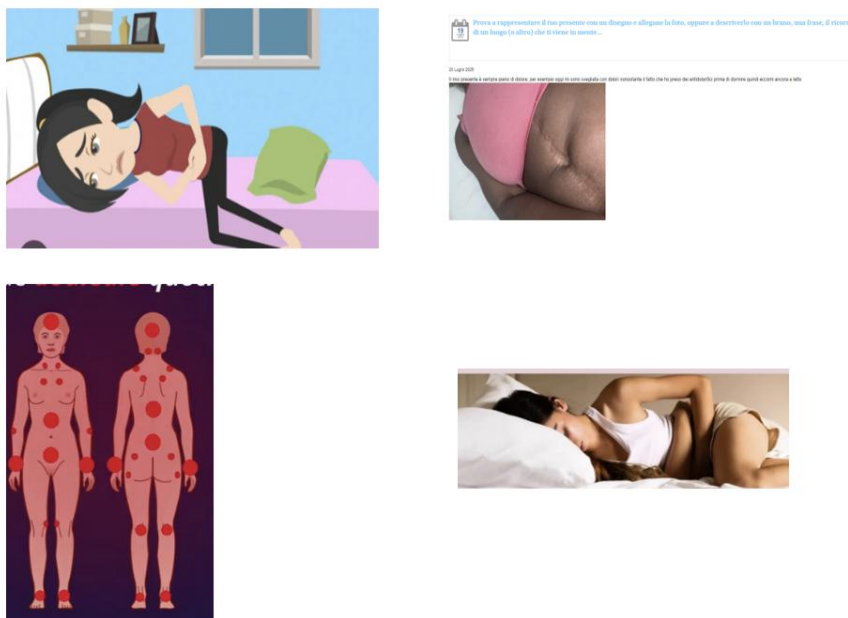
	comprato per crescere dei figli che non sono arrivati...	to raise children who never arrived...
9E80F99DA04A	Le fusa dei miei gattoni che rendono "famiglia" la vita di mio marito e me	The purring of my big cats that make my husband's and my life a "family"
1D89FB3AF555	"Never give up" sicuramente... diciamo che il mio disegno è una alternanza di nubi e sole	"Never give up" for sure... let's say that my drawing is an alternation of clouds and sunshine
B60252BCF5B1	La mia vita è nel qui e nell'ora. Ma voglio portare la mia esperienza per colei che non ne ha la forza. Il destino è stato gentile, mi ha dato nuove possibilità, non voglio sprecarle!	My life is in the here and now. But I want to share my experience with those who don't have the strength. Fate has been kind to me, giving me new opportunities, and I don't want to waste them!
C3699250CB72	non riesco a caricare l'immagine del disegno che ho riportato su di un foglio bianco. comunque ho disegnato un cerchio	I can't upload the image of the drawing I made on a blank sheet of paper. Anyway, I drew a circle
	"Mi sento male perché sento di non viverle, queste cazzo di giornate. Sento che le faccio passare, che faccio scorrere il tempo senza usarlo, senza prenderlo per il culo e magari farmi quattro risate e basta.	I feel bad because I feel like I'm not living these fucking days. I feel like I'm letting them pass, I am letting time flow by without using it, without messing with it and maybe just having a few laughs then, and that's it.

Non sto vivendo, io sto solo passando."	I'm not living, I'm just passing through."
Charles Bukowski ⁴²	Charles Bukowski ⁴³

Patient ED1AECDDDB82A attached to the text cited in the table the following pictures, here shown in chronological order, with which she wanted to represent her present.

Figure 29

Representing the Present in Patient ED1AECDDDB82A's Response



Pain is sadly constant in the pictures chosen by patient ED1AECDDDB82A, who offers a realistic representation of her current state, sharing even a photo of herself and the evident signs of surgery on her body. This has been visibly marked by the illness.

Patient FF49204B9548 responded to this prompt by attaching some pictures, too.

Figure 30

Representing the Present in Patient FF49204B9548's Response

⁴² Actually the poem is not among Bukowski's published works

⁴³ Actually the poem is not among Bukowski's published works



She did not add any verbal note on the pictures, so what can be inferred from the first image is that this time the domain is non-natural (unlike the chimpanzee in her previous picture), but *fictional*, mimetic: it is the marble sculpture by the Italian artist Gian Lorenzo Bernini “Apollo and Daphne”, (1622-25), representing the homonymous myth about the divinities of the classical mythology. This time, the sculptured subjects are human, at least in terms of shape and look: someone else’s hand is on the nymph’s abdomen. According to the mythological plot, Apollo chases Daphne, who tries to run away from him and asks her father to turn her body in a tree: although it is not possible to know exactly the reason for the choice of this sculpture, it represents the desperate request for a metamorphosis, a change, as well as the suffering related to the metamorphosis itself, and finally an attempt to escape something unwanted. The message the patient wants to share is the relationship between the disease and the myth described. The second picture is also consistent with this participant’s intertextual approach to writing, and seems to be explained in the last note of (Table 32), the poem incorrectly attributed to Bukowski: the man in the picture is far from the world, and looks at it from a privileged but passive perspective: again slightly curled, he seems to be the spectator of a life that he does not live to the full.

As for the other texts in the table, the theme of infertility unfolds through the image of an empty house with no children. But some notes also reveal resilience and new forms of motherhood (the *cat* family), new possibilities to rethink life, to find new meanings in the illness experience and support other sufferers. The image of a circle is pretty ambiguous, but among its possible meanings are that of continuity (of pain? of life?) as well as that of a cycle, which, semantically viewed, is a synonym for menstruation.

Accepting endometriosis. This section explores what aspects of the disease are the most difficult to accept, as well as how the patients found the diary writing experience.

Table 33

Acceptance

Prompt	Da quando ho saputo di avere l'endometriosi, la cosa difficile da accettare per me è stata...	Ever since I was told I had endometriosis, the hardest thing for me to accept has been...
Participant	Excerpt	Translation
C3699250CB72 49	[...] comprendere di non poter concepire naturalmente come tante donne, non fu facile. Il dopo fu invece un dramma, fatto di mille visite e diverse Fivet e scongelamenti, medicinali e un numero immenso di delusioni. Oggi vivo questa mia condizione con serenità dal punto di vista del mancato concepimento. Vivo molto peggio il dolore fisico e la perdita di sangue nei primi giorni di	[...] understanding that I couldn't conceive naturally like many women was not easy. What followed was a drama, consisting of a thousand visits and several IVF treatments and thaws, medications and countless disappointments. Today, I live with my condition serenely from the point of view of not being able to conceive. I find the physical pain and blood loss in the first few days of my cycle

	ciclo	much more difficult to deal with
ED1AECDDDB82A	Non posso avere figli naturalmente o potrei non averne affatto	I cannot have children naturally, or I may not have any at all
A55769E5659F	Che ci sarebbe sempre stata da quel momento in poi	That she would always be there from that moment on
FF49204B9548	Accettare è una parola difficile. Ho accettato che per gli altri il mio dolore fisico sia un fastidio. Ho accettato che i medici trovassero il mio dolore fisico una cosa normale. Ho accettato che se stavo male (difficoltà anche a stare in piedi) era un mio problema. Ho accettato che dietro alla fecondazione c'è un grande mercato. Ho accettato che se quelli che mi hanno operato mi avessero detto che il mio benessere era temporaneo, sarebbe stato meglio. Ho accettato che se la diagnosi a 16/17 anni fosse stata presa sul serio, la mia vita sarebbe molto diversa. Ho accettato che Dottori che sull'endometriosi basano la loro carriera in fondo ci capiscono poco,	Acceptance is a difficult word. I accepted that my physical pain was a nuisance to others. I accepted that doctors found my physical pain normal. I accepted that if I was in pain (even finding it difficult to stand up), it was my problem. I accepted that there is a huge market behind fertilisation. I have accepted that if those who operated on me had told me that my well-being was temporary, it would have been better. I have accepted that if the diagnosis at 16/17 had been taken seriously, my life would be very different. I have accepted that doctors who base their careers on endometriosis ultimately understand little about it,

più di me ma meno di quello che spererei.	more than I do but less than I would hope.
Ho accettato che nessuno in fondo mi può aiutare e che forse è solo una questione di tamponare i danni di testa corpo e cuore.	I have accepted that no one can really help me and that perhaps it is just a matter of patching up the damage to my mind, body and heart.

Infertility, chronicity and diagnostic delay seem to be the most unbearable aspects of endometriosis.

Also in these excerpts, figurative language makes bearable what is unbearable: the exhausting journey to conceive is compared to a drama or a market. In the notes, the inability to conceive is a recursive/obsessive thought connected to sadness and regret. The in vitro fertilization experience is often depicted as an exhausting process leading to disappointment. The patient seems involved in an endless, chaotic and disappointing quest. The notes covering this aspect are usually characterized by an asyndetic structure or by the total lack of punctuation, which represents the accumulation of targets to reach, of standards to meet and makes the narrative rhythm sound more compelling.

They also recall the process known as “medical shopping” or the “medical merry-go-round” (Cox et al., 2003; Bell, K., et al. (2019), that is, long sequences of tests, therapies, and referrals that do not substantially improve the patient’s condition.

Table 34

Between quest and medical shopping

Participant	Excerpt	Translation
FB582774D451	Visite, ecografie, risonanze, interventi...sentenze!	Visits, ultrasounds, MRIs, surgeries...verdicts!

	Viaggi e costi da sostenere.	Travel and costs to bear
FF49204B9548	Esami da fare	Tests to do
	Dopo un mese altro controllo	After a month, another check-up
	Visite, visite, visite!	Visits, visits, visits!
	Esami da fare	Tests to do
	Altri esami	More tests
	Altre visite	More visits
	Esami	Tests
	Rifare tutto	Do it all again
	Altre ricette dal medico di base, altri cambi e spostamenti [...]	

The last prompt of the EndoNar project represents how patients view their body at the very end of the writing experience. Neither of the two patients recognises her body as her own. The first one is even disappointed by her shape, but realizes that she is alive and grateful for the life she has. As for the second patient, the writing process has improved her self-awareness and helped her to process the impact of endometriosis on the overall wellbeing. Patients use the words “accettare, accettazione” at different stages of the process, but ambivalent feelings emerge: recognition that the diary was “la luce in fondo al tunnel” (the light at the end of a tunnel), a unique experience during a hard journey in which interest in the human side of the illness had hardly been shown to her before; resignation to the fact that the condition is incurable and painful, and at the same time helplessness because some core questions stay unanswered “Perché corpo mio mi tradisci così?”. A certain disconnection between body and mind informs these notes: the patient wants to reconcile herself with her body by addressing it as “mine”. The body, that is externalised and has a separate identity, is a traitor, in that it does not represent the woman: the patient clearly says “vedo un corpo che non dovrebbe essere il mio”: that one should not be her body. The patient had already represented the

uterus as endowed with agentivity, when she wrote about her idea of maternity: she does not feel like a normal woman, because, unlike the others, her uterus makes decisions for and in place of herself. The uterus has been personified and rules over the patient's life.

Table 35

Self-perception

Prompt	L'immagine del mio corpo e di me stessa dopo questo percorso è...	The image of my body and myself now is...
Participant	Excerpt	Translation
ED1AECDDDB82A	Sono delusa del mio corpo, non riesco più ad andare al mare, mi vergogno della mia pancia, i vestiti non mi vanno più bene ma alla fine della giornata mi dico che almeno sono ancora viva e vado avanti con la vita	I am disappointed with my body. I can no longer go to the beach. I am ashamed of my belly. My clothes no longer fit me. But at the end of the day, I tell myself that at least I am still alive, and I carry on with my life
FF49204B9548	Se per percorso si intende il diario, bene, una sorta di accettazione, devo accettare per il mio bene che anche se limitato questo è l'unico corpo che ho e che avrò, accettarlo e custodirlo è il regalo più grande che posso farmi. Capisco e accetto i limiti della malattia. In realtà cerco di capire e mi costringo ad accettare di non essere sana. Il problema è quello! Per nessuno sei	If by journey you mean the diary, it feels good, a sort of acceptance, I must accept for my own good that even if limited, this is the only body I have and will ever have, accepting and cherishing it is the greatest gift I can give myself. I understand and accept the limitations of the disease. In reality, I try to understand and force myself to accept that I am not healthy.

malata e tu stai lì a cercare di essere come gli altri ti vedono. Non malata. Invece meglio o peggio ma siamo tutte affette da qualcosa che ti modifica. Guardo e vedo un corpo che non dovrebbe essere il mio. Perché quella faccia coi brufoli e perennemente sbattuta? Perché quella pancia sempre gonfia ma mai con un feto all'interno? Perché quella postura sempre un po' piegata come se si aspettasse una bastonata in qualsiasi momento? Perché corpo mio mi tradisci così?	That's the problem! No one thinks you're ill, and you're there trying to be how others see you. Not ill. Instead, for better or worse, we are all affected by something that changes us. I look and see a body that shouldn't be mine. Why that face with pimples and perpetually battered? Why that belly always swollen but never with a foetus inside? Why that posture always a little bent as if expecting a blow at any moment? Why, my body, do you betray me like this?
Questo progetto mi sembra la luce in fondo al tunnel	This project looks like the light at the end of a tunnel
Estremamente utile!!!! Grazie per l'opportunità. Ho fatto chiarezza su che cosa sono. Ho imparato a capire alcuni dei miei meccanismi fisici e psicologici.	Extremely useful!!!! Thank you for the opportunity. I have clarified what I am. I have learned to understand some of my physical and psychological

Ho capito che la ricerca sta andando avanti.	mechanisms.
Purtroppo sono "vittima" se mi passate il termine, di ignoranza e interesse.	I understand that research is progressing.
La cosa più importante e per certi versi assurda è che ho capito che NON GUARIRÒ. Che devo accettare quello che sono, che è e sarà doloroso, sotto tutti gli aspetti, che non mi è permesso fare tutto, che non posso avere la vita che vorrei, ma per il mio bene devo anche smettere di provarci.	Unfortunately, I am a "victim", if you will pardon the term, of ignorance and interest.
Se poi lo accettassero anche gli altri sarebbe stupendo...	The most important and, in some ways, absurd thing is that I have realised that I WILL NOT BE CURED. That I have to accept who I am, that it is and will be painful in every way, that I am not allowed to do everything, that I cannot have the life I would like, but for my own good I must also stop trying.
Consapevolezza di una quasi 50enne affetta da endometriosi.	If others would accept it too, that would be wonderful...
Mi sento molto stupida.	The realisations of a woman in her late 40s suffering from endometriosis.
A 50 anni credevo di capirmi, di conoscermi, ma in realtà dagli 11 anni ho scrupolosamente imparato a nascondere, fingere, glissare, non ascoltare tutti i segnali.	I feel very stupid.
Lo faccio ancora a volte. Mettere nero su bianco aiuta. Forse questo è la cosa che mi ha aiutato di più. Forse siete i	At 50, I thought I understood myself, that I knew myself, but in reality, since the age of 11, I have scrupulously learned to hide,

Dottori che mi hanno aiutato di più.	pretend, gloss over and ignore all the
Anche se credo che nessuno legga	signs.
queste parole o almeno non tutte, ma	I still do it sometimes. Putting it
non importa. Le leggo io e questo	down on paper helps. Perhaps that is
aiuta, non salverò nessuno altra ma	what has helped me the most.
aiuta me.	Perhaps you are the doctors who
	have helped me the most. Even
	though I don't think anyone will read
	these words, or at least not all of
	them, it doesn't matter. I read them
	and that helps. I won't save anyone
	else, but it helps me.

Close reading as an insight into the participants' illness experience. In the previous sections of this chapter I performed the close reading of the patients' notes, based on the five elements put forward by Charon, focusing on the form. In this section I draw general conclusions from this analysis and, to this purpose, I make reference mainly (but not only) to patient B60252BCF5B's responses to different prompts. I chose them for this section because they exemplify and summarize the concept of uncertainty in many respects (Table 36). Few responses from other patients are also considered in the comments following the table.

As for Charon's category of frame, the close reading shows that the social and cultural environment in which patients grow up and live legitimates menstrual pain as normal, and labels those who cannot fit into this pattern as untrustworthy. The quantitative and qualitative analysis for the adjective "normale" best demonstrates this point.

With regard to time, given the chronic duration of the disease, living with endometriosis means to recognize a breaking point, usually adolescence, in which everything changes forever.

Table 36

Summary: A close-reading of Uncertainty in the Endometriosis Stories

Participant	Excerpt	Translation
FF49204B9548	il dolore da ciclo [...] molto forte non sembrava un problema, più un'eternità, da sempre [l'endometriosi] ci sarebbe stata da quel momento in poi Sai che il dolore arriverà! Che starai male.	The very severe period pain [...] didn't seem like a problem, more like an eternity, ever since [endometriosis] would be there from that moment on You know the pain will come! That you'll be in pain.
9E80F99DA04A	non ricordo molti giorni senza dolore	I don't remember many days without pain
B60252BCF5B	Il ciclo [...] Mai aspettato da calendario, poteva arrivare dopo 25 GG o saltare a piedi pari al mese successivo.	My period [...] I never waited for the calendar, it could arrive after 25 days or skip straight to the next month.
ED1AECDDDB82A	quando ho il ciclo la mia vita si mette in pausa almeno per un mese	When I have my period, my life is put on hold for at least a month.
B60252BCF5B1	voglio portare la mia esperienza per colei che non ne ha la forza.” (Table 32)	I want to share my experience with those who don't have the strength.
	essere di aiuto a donne che stanno affrontando sfide simili	help women who are facing similar challenges

Time is marked by menstrual cycles that are not always regular (“Mai aspettato da calendario, poteva saltare [...] al mese successivo”) or are too long (“quando ho il ciclo la mia vita

si mette in pausa almeno per un mese”) and change the perception of time as something eternal and suspended: “il dolore da ciclo [...] molto forte non sembrava un problema, più un'eternità, da sempre [...]”. Time is full of uncertainty, since possible symptoms make it hard or impossible to make plans: “difficile preventivare il tempo, il luogo”.

As for the form, uncertainty is conveyed through a wide range of linguistic features, some of which are marked with emphasis in this representative table:

Table 37

Endometriosis or Living with Uncertainty

Participant	Excerpt	Translation
B60252BCF5B1	<p><i>Non so cosa ci sia di imputabile all'endometriosi o ad altro... Non sono mai riuscita a stimare i sintomi. [...] sento che c'è qualcosa che non va... Ma cosa non saprei descriverlo! [...] A volte sento dolori inspiegabili [...] [...] non mi sento più sicura delle funzioni fisiologiche...a volte devo correre in bagno [...] rapporti sessuali da dopo l'intervento sono cessati, cancellati, rimossi... sempre indecisa ed un po' insicura sul da farsi. Costantemente precaria, [...] ho dovuto fare i conti con la precarietà, difficile preventivare il tempo, il luogo... A volte ho lasciato lavori molto</i></p>	<p>I don't know what can be attributed to endometriosis or something else... I've never been able to assess the symptoms. [...] I feel that something is wrong... But I can't describe it! [...] Sometimes I feel inexplicable pain [...] I no longer feel confident about my bodily functions... sometimes I have to rush to the toilet [...] sexual relations since the operation have ceased, been cancelled, removed [...] I was always undecided and a little unsure about what to do... Constantly precarious, [...] I had to deal with uncertainty, it was difficult to predict the time, the place... Sometimes I left very stimulating jobs</p>

stimolanti perché avuto <i>esperienze un po' umilianti e che mi rendevano</i>	because I had <i>experiences that were a little humiliating and made me feel</i>
<i>insicura. Un pantalone macchiato o un</i>	<i>insecure. A stained pair of trousers or a</i>
<i>odore che sentivo e che mi provocava</i>	<i>smell that I noticed and that made me</i>
<i>disagio... Insomma, ha condizionato</i>	<i>feel uncomfortable... In short, it had a</i>
<i>molto!</i>	<i>big impact!</i>

The negation “non” is the most frequent collocation for the verb “sapere”: 33 out of 68 occurrences of “sapere” meant as “to know” (and not as semi-modal meaning “can”) feature pronouns as “nessuno”, adverbs like non “non” and “neanche” in their co-text. This contrasts with the use of the same verb in affirmative sentences to express the certainty of pain: “Sai che il dolore arriverà! So che starò male”, as if patients had no other certainty than that of pain. Adjectives like “indecisa, insicura, precaria” convey uncertainty as an attitude towards life. The frequency of interrogative sentences and ellipsis is another element indicative of uncertainty: diaries are characterised by a strong introspection and work also as a space for dialogue with oneself (Bernal Marcos et al., 2024), which accounts for self-questions. But the corpus analysis yielded 115 interrogative sentences in the stories collected: this means that the patients’ notes are imbued with questions. Uncertainty and the search for meanings and answers underlie the narrative of endometriosis, and emerge in the question that every person falling ill asks themselves, as shown in the following table.

Table 38

Unanswered questions

Participant	Excerpt	Translation
FB582774D451	Perché io? Un senso di ingiustizia e di domanda sul perché sto vivendo questa	Why me? A sense of injustice and questioning why I am going through

	esperienza.	this experience.
FF49204B9548	Perché a me? Le domande ora sono: avrei potuto stare meglio se [il dottore] avesse detto o fatto qualcosa? Mi sarei risparmiata 35 anni di dolore di stanchezza? Sarei stata una persona diversa adesso? [...] Ora mi chiedo se il dolore non ci fosse stato? Che persona sarei ora? [...] chissà come sarebbe stato il sesso senza la malattia?	Why did this happen to me? The questions now are: could I have been better off if [the doctor] had said or done something? Would I have been spared 35 years of pain and fatigue? Would I be a different person now? [...] Now I wonder, if the pain hadn't been there, what kind of person would I be now? [...] Who knows what sex would have been like without the disease?

The first-person narration prevails in the digital diaries of the EndoNar project in line with the traits of autobiographic writing. Yet some notes, (especially by patient FF49204B9548) are mostly written by a second-person narrator as the following examples show:

Table 39

Uncertainty and Identity in the second-person Narration

Participant	Excerpt	Translation
1D89FB3AF555	Essere seguita per anni da un ginecologo che non ti riconosce la patologia stessa e minimizza i sintomi riferiti [...]	The worst thing besides having endometriosis? Being treated for years by a gynaecologist who does not recognise the condition and minimises the symptoms you report [...]

C3699250CB72	[...] ti senti di non essere in grado di lasciare una parte di te su questo mondo ma con l'andare avanti degli anni te ne fai una ragione.	[...] you feel unable to leave a part of yourself in this world, but as the years go by, you come to terms with it.
FF49204B9548	Trascuri i tuoi bisogni, smetti di ascoltare quei piccoli segnali, smetti di ascoltare tutto quello che il tuo corpo ti dice. Escludi le uscite [...] Vorresti, ma non ce la fai proprio. E dormi, dormi tanto [...] Tieni duro a lavoro, impari a mentire agli altri, poi a te stessa. [...] La rabbia ti resta dentro.	You neglect your needs, stop listening to those little signals, stop listening to everything your body tells you. You exclude going out [...] You would like to, but you just can't do it. And you sleep, sleep a lot [...] You hold on at work, you learn to lie to others, then to yourself. [...] The anger stays inside you.

Bal's (2017) and Bonheim's (1983) arguments on the second-person are extremely helpful to interpret the choice of this narrative perspective in the patients' stories. The implied "you" in the notes of Table 39 could act as an alternative to the impersonal pronoun "one", extending the pain experience to anybody affected by the same disease. On the contrary, the ideally addressed "you" might be a fictional reader who acts as a witness to the events described and is indirectly involved in the plot and to empathise with the patient. Alternatively, as Bal (2017) suggests, "The "you" is simply an "I" in disguise, a "first-person" narrator talking to himself" (p. 22), or, "becomes a reminder of the alienation, that recession of subjectivity, rather than a fulfilment of it" (p.23). This last hypothesis would align with the sense of alienation emerging from the description of pain (Table 27, patient ED1AECDDDB82A).

The plots emerging from the notes analysed offer insight into the daily life of patients and span across professional, medical and private contexts, showing the challenges that very simple acts

can represent in endometriosis (“non mi sento più sicura delle funzioni fisiologiche...a volte devo correre in bagno”) as well as the end of big plans such as having children, enjoying sexual life or the job environment due to embarrassing situations. Events are usually recounted following the order of the prompts, but, especially in patient FF49204B9548, this pre-set narrative flow is interspersed with digressions on the long IVF process, spontaneous reflections on how endometriosis impacted her relationship with her partner, and both positive and negative medical experiences.

As for Charon’s category of *desire* (2006), two hypotheses can be suggested: these women want to be *seen* through, listened to, and they want their pain to be recognized. In their notes, they often write about the invisibility of endometriosis in technical examinations and in medical consultation.

Table 40

Invisible endometriosis, unheard patients

Participant	Response	Translation
9F88481FF3BC	Annualmente ho sempre effettuato controlli, dai quali non è mai emerso niente	I have always carried out annual checks, which have never revealed anything.
ED1AECDDDB82A	Prima andavo in ospedale per via di questi dolori pelvici ma i dottori non vedevano niente	I used to go to the hospital because of these pelvic pains, but the doctors couldn't see anything.
FB582774D451	Anche i consulti con gli specialisti non avevano aiutato: non era emerso niente	Consultations with specialists had not helped either: nothing had emerged.
FB582774D451	[...] nonostante decine di ecografie e	[...] despite dozens of

visite non era mai saltato fuori niente	ultrasounds and examinations, nothing had ever come up.
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Despite the lack of visual evidence, patients have a lot to tell about living with endometriosis: the quantity of free notes for patient FF49204B9548, along with the length and richness of details of her writing, shows that she needs medical and human attention, she needs to share her story since she appears to be still wounded by the disease and by the previous experiences with doctors. The other hypothesis about the participants' desire is the idea of solidarity and reciprocal empowerment behind narratives: “voglio portare la mia esperienza per colei che non ne ha la forza”, “essere di aiuto a donne che stanno affrontando sfide simili”.

To conclude this analysis, in Table 41, I quote two meaningful notes that explicitly express uncertainty in the endometriosis experience, especially about symptoms, the unavailability of a cure, the limits of the current treatments and the doctors' competence.

Table 41

Between Uncertainty and Helplessness

Participant	Response	Translation
ED1AECDDDB82A	Convivere con l'endometriosi significa dover convivere con l'incertezza e la variabilità dei sintomi	Living with endometriosis means having to live with the uncertainty and variability of symptoms
FF49204B9548	Le mie poche certezze sono, non posso guarire o almeno non per ora, le cure funzionano fino a un certo punto, non posso far finta di nulla, i medici ci sono quelli bravi e quelli che lo sembrano e	My few certainties are that I cannot be cured, at least not for now, that treatments work only to a certain extent, that I cannot pretend nothing is wrong, and

 basta

 that there are good doctors and
 those who only appear to be
 good

Before moving to the representation stage of Charon's method (2006), the role of caregivers in this project calls for some reflection. They did not write any notes. When collecting opinions on the possible reasons for that, doctors said that they did invite caregivers, when present during medical interviews, but patients generally prefer not be accompanied (as stated in the preliminary questionnaire). Especially when patients are very young, doctors say, the presence of their mothers makes the interaction less spontaneous, so this could account for the unavailability of this type of participants. Of course, this removes an important voice from the project. Yet, the patients' notes are an indirect source on these participants, and inform implicitly how they live the endometriosis experience of their loved ones.

Table 42

The role of caregivers

Participant	Response	Translation
FB582774D451	Amiche che non capiscono, compagni o mariti che scappano, suocere invadenti, [...]	Friends who don't understand, partners or husbands who run away, intrusive mothers-in-law, [...]
FF49204B9548	Una persona che si avvicina deve sopportare tanto. Sia fisicamente che psicologicamente. E per sopportare intendo non scappare a gambe levate. [...] il dolore fisico è principalmente mio	A person who gets close has to endure a lot. Both physically and psychologically. And by endure, I mean not running away. [...] physical pain is

ma non solo e questo un compagno non lo sa. [...] la famiglia ti conosce, lo sa, ma è comunque infastidita dal fatto che non vai o non fai per loro, prendendola come una mancanza di affetto.

mainly mine, but not only mine, and a partner doesn't know that. [...] your family knows you, they know, but they are still annoyed that you don't go or do things for them, taking it as a lack of affection.

B60252BCF5B1 Mio marito ha appreso la notizia con disinteresse sulla patologia, ma allarmato dall'urgenza dell'intervento (non era chiara la natura della ciste all'ovaio destro). La sua tesi, una volta uscita dalla sala operatoria con la certezza che era endometriosi, era piuttosto spicciola! C'è una malattia, c'è una cura, sei guarita. Piuttosto disumano, piuttosto deludente! Non l'ho mai portato con me alle visite, era talmente abituato a vedermi rimbalzare da un medico all'altro in modo del tutto inconcludente che iniziava ad essere piuttosto indifferente e credere che ci sarebbe stato bisogno di una reazione energica da parte mia! Ho imparato a gestirmi e gestire la malattia da sola. Tutto è diventato normale... Ed io

My husband heard the news with indifference about the condition, but was alarmed by the urgency of the surgery (the nature of the cyst on my right ovary was unclear). Once I came out of the operating theatre with the certainty that it was endometriosis, his conclusion was rather blunt! There's a disease, there's a cure, you're cured. Rather inhuman, rather disappointing! I never took him with me to the appointments, he was so used to seeing me bounce from one doctor to another in a completely inconclusive way

affrontato da sola tutto, per non	that he was starting to be rather
preoccupare i miei e i ragazzi e perché	indifferent and believe that I
mio marito avrebbe giudicato e non	needed to react more
supportato...	energetically! I learned to
	manage myself and the illness
	on my own. Everything became
	normal... And I dealt with
	everything alone, so as not to
	worry my parents and children,
	and because my husband would
	have judged me and not
	supported me...

The notes reveal that husbands tend to simplify the complex impact of endometriosis on the patients and to downplay their suffering: for them, a diagnosis and a treatment are enough to manage the condition and they expect their partners to react vigorously. On the other hand, patients seem to expect or fear their husband's judgment, ("mio marito avrebbe giudicato") indifference ("iniziava ad essere piuttosto indifferente"), or abandonment, as the verb *scappare* ("run away") suggests ("mariti che scappano"). Friends and other family members seem to misunderstand or not to fully understand the seriousness of the patients' experience ("amiche che non capiscono"), which is perceived as annoying ("la famiglia [...] è infastidita dal fatto che non vai o non fai per loro"). In contrast, other relatives are depicted as intrusive ("suocere invadenti"). In general, the disease seems to compromise family relationships and harmony, as well as friendships, contributing to the patients' isolation. Moreover, the caregivers' reactions confirm how endometriosis is little understood.

The doctors' narratives

This section focuses on the “representation” stage of Charon’s triad (2006, p. 140), on the moment in which doctors “absorb” (Charon, 2001, p. 1897), i.e. process the patients’ stories and possibly share thoughts about those stories with other colleagues. Doctors wrote only four comments on the patients’ notes. Specifically, only G3, the same gynaecologist who enrolled all the participants, shared some ideas on the platform in response to the patient’s notes. Table 43 shows a reply to the patient’s note on the need for an integrative approach to endometriosis:

Table 43

Doctors’ comments on patients’ diaries (1)

Doctor’s note	Translation
Capisco la frustrazione.	I understand the frustration.
È frustrante anche per noi combattere tutti i giorni in carenza di personale, facendo salti mortali per coprire i turni e garantire le coperture lavorando giorni notti e festivi.	It is also frustrating for us to struggle every day with staff shortages, bending over backwards to cover shifts and ensure coverage by working days, nights and holidays. Having a multidisciplinary team that is always available would be wonderful.
Avere a disposizione il team multidisciplinare sempre disponibile sarebbe meraviglioso. Dobbiamo lavorare su percorsi condivisi preferenziali ma servirebbe anche attenzione da parte di chi a livello aziendale tende sempre a guardare ai numeri della produzione tralasciando o meglio non considerando e non potenziando attività specialistiche come l'endometriosi richiede. Se l'unico obiettivo dell'azienda sono le liste di attesa per le visite	We need to work on shared preferential pathways, but we also need attention from those at company level who tend to focus on production figures, neglecting or rather not considering and not enhancing specialist activities such as endometriosis requires. If the company's only objective is the waiting lists for gynaecological visits, obviously the dedicated clinic is reduced, resources are scarce and the delivery room and A&E cannot be closed. We’re stretched thin. It is

<p>ginecologiche, ovviamente l'ambulatorio dedicato si riduce, le risorse sono poche e le urgenze la sala parto e i PS non si possono chiudere. La coperta è corta. Per noi, per i gastroenterologi, per gli psicologi, i fisioterapisti.... ma cerchiamo sempre di indirizzare le donne a figure che conoscono il problema. È frustrante per le donne, ma credete è frustrante anche per me che amo il mio lavoro e che via via lo vedo sempre meno efficace ma che si scontra con muri che difficilmente si riescono ad abbattere</p>	<p>the same for us, for gastroenterologists, for psychologists, for physiotherapists... but we always try to refer women to professionals who are familiar with the problem.</p> <p>It is frustrating for women, but believe me, it is also frustrating for me. I love my job and I see it becoming less and less effective, banging my head against a brick wall that is difficult to break down</p>
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The first observation on this comment focuses on the use of the words “frustrazione”, “frustrante”, the latter repeated three times. The short incipit of the comment, “Capisco la frustrazione”, shows recognition, validation of the patient’s thoughts. Not only does the doctor understand, but she shares the patient’s frustration, since she experiences it in the daily work life: “È frustrante anche per noi”, “È frustrante per le donne, ma credete è frustrante anche per me”. The alternation between conditional and indicative forms indicates the difference between the ideal and necessary approach to illness and the real healthcare standards: “il team multidisciplinare sempre disponibile *sarebbe* meraviglioso” “*servirebbe* anche attenzione”, “l'ambulatorio dedicato *si riduce*, le risorse *sono* poche e le urgenze la sala parto e i PS *non si possono* chiudere”. Curiously, the doctor uses that figurative language related to the military domain that has hardly occurred in the patients’ notes (“combattere tutti i giorni in carenza di personale”) as well as idioms to indicate limited resources (“la coperta è corta”) and a system difficult to change (“si scontra con muri”).

G3 also commented on patient FF49204B9548's note about the experience of writing the digital diary.

Table 44

Doctors' comments on patients' diaries (2)

Doctor's note	Translation
Amara consapevolezza della malattia che forse ancora non è stata completamente accettata, ma questo si sa non è facile e il percorso è a ostacoli. E invece... i messaggi li leggiamo... grazie per la condivisione	The bitter awareness of the illness that perhaps has not yet been fully accepted, but we know that this is not easy and the path is fraught with obstacles. And yet... we do read the messages... thank you for sharing.

As the author of the prompts, I had no direct contact with the patients, although I monitored their diaries, nor could I reply to the notes. The note that G3 left is extremely important because she reassures the patients that their diaries were not just a creative exercise for its own sake, but that doctors are interested in what their patients have to say. And, last but not least, she thanks the patient, recognising the added value that her notes can offer in terms of improvement of communication practice in healthcare settings. G3's thanks were a confirmation for me too that the medical team had grasped the principles of NM and applied them when possible, despite no parallel chart being written.

Given the unavailability of parallel charts, the moment of representation was rearranged: I also asked the doctors if we could arrange a meeting to collect and share thoughts on the project, and they accepted. So I had a short semi-structured interview with them and I attached the clean transcription in Annexe 2 (Kvale & Brinkmann, 2015).

I asked doctors for their feedback on the diaries and on the project, in general, trying to direct as little as possible the doctors' answers, asking for their overall impression on the project, to

complete the few notes shared on the platform by G3 with some spontaneous oral comments. Yet I also tried to focus on the pain description patterns emerged in the patients' narratives and how doctors view it. In the interview, I am identified as R1, and the researcher from DNM as R2. In this analysis, I discuss the written notes and some interview excerpts in parallel.

Among the few free notes, there is one in which G3 replies to the patient who compared the scale used to assess post-tattoo pain with the endometriosis pain scale. The note is titled "Forse non funziona proprio per tutte" (Maybe it doesn't work for everyone).

Table 45

Doctors' comments on patients' diaries (3)

Doctor's note	Translation
La scala del dolore che noi usiamo per praticità e velocità forse necessita di una revisione includendo, per valutare l'intensità del dolore delle scale più strutturate, che comprendano più campi del vissuto oltre che semplicemente uno score numerico. Il problema è che il vissuto non è facilmente oggettivabile e quantificabile cosa che a volte in medicina serve. Oggi però penso che sia anche difficile a volte lavorare sentendosi sempre sotto accusa, come se non volessimo il bene del paziente	Perhaps it doesn't work for everyone. The pain scale we use for practicality and speed may need to be revised to include more structured scales that assess pain intensity and cover more areas of experience than just a numerical score. The problem is that experience is not easily objectified and quantified, which is sometimes necessary in medicine. Today, however, I think it is also difficult at times to work while always feeling under scrutiny, as if we did not have the patient's best interests at heart

The use of the modal adverb "forse" both in the title and in the first sentence introduces the theme of medical uncertainty, this time and for the first time, in the doctors' words. In her

qualitative study on diaries written by nurses for patients in intensive care units, Maagaard (2022) notices that the frequent use of the English adverb “maybe” (the Italian “forse”) is one of the modality markers through which nurses express a certain degree of uncertainty in advancing hypothesis on what critical patients feel when they are not able to communicate and interact.

Conversely, here the doctor reads a patient’s diary note that is pretty clear and explicit about the limits of the numeric pain assessment scale. Here, the use of “forse” does not serve only a hedging function: it not only softens but also questions the validity of a pain assessment tool that has always been regarded as reliable and applied systematically to clinical practice. The non-casual sequence of “forse” and “necessita” highlights at the lexical level the conceptual contrast between “il vissuto” and “l’oggettività”, the lived experience of the patient on one hand and the objectivity of quantifiable standards required in medicine (“che a volte in medicina serve”) on the other hand. The use of “a volte” also makes this needed objectivity less peremptory: the patients’ diaries have led to a gradual change in G3’s medical point of view, who admits (maybe realises?) that the use of numerical scales is mainly due to practical reasons and timing, but does not work for everyone.

It also emerges that, with human fragility and honesty, the gynaecologist in question feels under pressure and wants to stress that the final goal of care is the best outcome for the patient.

It must be recognised that training in close reading could help doctors to realise that patients’ notes are not always (or not only) emotionally loaded and connotative, but also very accurate and denotative in their descriptions, and they resort to numbers too, as shown in these excerpts (I have already analysed one of them in the previous sections but I resume it here again for reference).

Table 46

Combining qualitative and quantitative description of pain

Patient	Note	Translation
FF49204B9548 48	Attualmente la cosa che mi dà più fastidio è il fianco destro. [...] Se	Currently, the thing that bothers me most is my right side. [...] If I had to

<p>dovessi descrivere il dolore: sono indolenza dall'ombelico alla spina dorsale. Più forte e focalizzato nel punto preciso all'altezza dell'ovaio, il punto è circoscritto nel senso che ha la grandezza della punta del dito. Da quando si presenta il primo dolore, nel punto preciso parte subito con la stessa intensità, parte da tipo 4 e resta a 4 ma tutto intorno cresce da tipo 2 sale e si allarga a tutta la zona lombare alla gamba alla bocca dello stomaco. [...]</p>	<p>describe the pain, it is a dull ache from my navel to my spine. It is stronger and more focused at the exact point of the ovary, and the point is limited in the sense that it is the size of a fingertip. From the moment the first pain appears, it starts immediately with the same intensity at the exact point, starting at level 4 and remaining at 4, but all around it grows from level 2, rising and spreading to the entire lower back, leg and pit of the stomach. [...]</p>
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<p>B60252BCF5B1 È un pulsare... Con punture piuttosto forti che arrivavano dopo un crescendo sordo. Non credo di riuscire a fare capire. Il mal di testa è pulsante e si irradia ad altre zone annebbiando dei sensi, perché logora se lo tieni troppo addosso...no? Ecco, questo tipo di dolore ad ondate...quando aumentava l'intensità, mi veniva di strizzarmi e premere il ventre...come se dovessi fare uscire da me un qualcosa che invece resisteva e si aggrappava... Che pesava</p>	<p>It's a throbbing... With rather strong stings that came after a dull crescendo. I don't think I can explain it. The headache is throbbing and radiates to other areas, clouding the senses, because it wears you down if you hold it in too long... right? That's it, this kind of pain in waves... when it increased in intensity, I felt like squeezing and pressing my stomach... as if I had to get something out of me that was resisting and clinging on...</p>
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<p>nelle viscere schiacciando e facendo pressione verso il basso. Un movimento dell'intestino era una fitta acuta, fare pipì era un acutizzare il dolore sonnolente... Perché quel dolore riposava ma non se ne andava nemmeno con gli antidolorifici. Sentivo dolori alla schiena, al basso ventre che a tratti salivano ed un vuoto alla bocca dello stomaco. Avevo in bocca un sapore cattivo ed a volte dolori ai reni...O verosimilmente alla loro collocazione...ho provato due parti, con due travagli molto diversi tra loro, conosco il dolore...Ma quando arrivava la vera colica gli assomigliava molto, in una sorprendente dinamica ad ondate... A volte, se mi sorprendevo mentre ero al lavoro, perdevvo forza anche nella presa con le mani, tanto mi indeboliva.</p>	<p>That weighed heavily in my guts, crushing and pressing downwards. A movement of the bowels was a sharp pain, peeing was an intensification of the drowsy pain... Because that pain subsided but did not go away even with painkillers. I felt pain in my back and lower abdomen that would come and go, as well as emptiness in the pit of my stomach. I had a bad taste in my mouth and sometimes pain in my kidneys... Or where I presume my kidneys were... I have given birth twice, with two very different labours, so I know pain... But when the real colic came, it was very similar, in a surprising wave-like dynamic... Sometimes, if it caught me while I was at work, I lost strength even in my grip, so much did it weaken me.</p>
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Firstly, patient B60252BCF5B1 expresses how difficult it is for her to explain herself: “Non credo di riuscire a fare capire” means I am not sure that what I say makes sense, that what I feel can be understood at all. Nevertheless, her words show that a multidimensional description of pain, as a mix of physical sensations (“indolenza dall'ombelico alla spina dorsale”), impact on the general

wellbeing (“molto stanca”, “non so se è psicologico o fisico”) and numeric assessment (“cresce da tipo 2 sale e si allarga”) *is* actually possible.

Furthermore, I asked the doctors to comment on some of the figurative language and pictures that patients had shared on the platform to describe their pain. According to G2, reading descriptions that compare endometriosis pain to stabbing is more impactful than reading an eight-score on an NRS scale, since it involves the non-clinical dimension and addresses the emotional one. Such descriptions allow him to grasp better the idea of suffering, as in Table 47:

Table 47

The doctors' perception of patients' figurative language

Doctor's comment in the interview	Translation
[...] il valore VAS 5,6,7 mi dà meno sensazione di disagio rispetto a quello che scrivono in questo caso. [...] se io leggo questo, “un pugnale”, piuttosto che “tanti coltelli che mi penetrano”, mi dà un'immagine più forte di quella di una paziente a 8 NRS, francamente. Quindi è un linguaggio più emozionale, diciamo, che va a coltivare la parte non professionale, la parte indipendente dal ruolo. Mi rende più l'idea di sofferenza, nonostante conosca la scala e conosca come funziona	[...] the VAS value 5,6,7 gives me less discomfort than what they write in this case. [...] if I read this as “a dagger” rather than “many knives piercing me”, it gives me a stronger image than that of a patient scoring 8 on the VAS, frankly. So it's more emotional language, let's say, which cultivates the non-professional side, the side that is independent of the role. It gives me more of an idea of suffering, even though I know the scale and how it works

For G3, reading such pain descriptions makes her feel helpless, while for G1, it is an incentive to treat the patient.

A new scenario opens up beyond this apparent antithesis between the patient's subjectivity and the medical objectivity, the patient's and the doctor's story: "revisione" and "includere" are the keywords that represent this turn. The scale, says G3, is limited in some respects, but it can be reviewed and expanded, including other dimensions of the complex experience of pain. The meaning of the story written by the patient changes the perspective under which the doctor regards not only the assessment scale itself but also their own profession: it is the self-reflection moment, Charon's representation (2006), in which a new story, a new meaning is co-created. Commenting on another woman's critical stance on the assessment issue, G3's comment shows a change in the attitude towards the patients:

Table 48

Rethinking the NRS-based assessment

Doctor's comment in the interview	Translation
<p>Mi ha colpito la paziente che ha demolito la Scala NRS in una mezza pagina di commento e quindi come noi a volte continuiamo ad andare dritti per la nostra percezione di quello che è la nostra abitudine pratica come in realtà poi alle pazienti la Scala NRS [non importa]. Ora questo è un esempio, quindi più che l'andamento della malattia o se stanno meglio o stanno peggio, la percezione anche di come noi possiamo gestire le pazienti relativamente a questa malattia, questa è la cosa che a me è piaciuta di più di questa</p>	<p>I was struck by the patient who strongly criticized the NRS scale in a half-page comment and therefore how we sometimes continue to go straight ahead with our perception of what our practical habit is, when in reality the NRS scale for patients... [doesn't matter].</p> <p>Now this is an example, so rather than the progression of the disease or whether they are better or worse, the perception of how we can manage patients in relation to this disease is what I liked most about this platform, and I must say that the great thing is that the patient's narrative is certainly the goal, but probably the narrative and</p>

piattaforma e devo dire che la cosa bella, perception of the parallel file would be even
sicuramente la narrazione del paziente è better, that is my perception.
l'obiettivo, però probabilmente la narrazione
e la percezione della cartella parallela
sarebbe ancora più bello questa è la
percezione mia.

With the last statement, G3 confirms that in NM it is not only the mere collection of illness narratives that matter, but the process of interpreting their meaning (the patient's message is that NRS has limits), reflecting on it, and co-creating a new meaning negotiated between doctors and patients (the NRS reflects our need for objectivity, but not the patients' natural perception of pain). G3, the main patient recruiter for this project, also said she expects that the use of parallel charts will improve future NM projects, which suggests a stronger commitment to the writing activity.

To complete the diverse viewpoints on the current pain assessment systems, according to G1, a patient can report a pain less intense than it actually is, because she fears the medical or surgical consequences that a high VAS score could mean. So, despite the claimed objectivity of this tool, ambiguity in interpreting the pain severity can arise on both sides.

Table 49

Pain Assessment: a Controversial Issue (5)

Doctor's comment in the interview	Translation
G3: [...] è buffo quando si dicono "eh sì io ho dolore all'ovulazione 8, VAS 8" e poi gli dici "ma prendi antidolorifici?" "No, non lo prendo"	G3: [...] It's funny when they say, 'Yes, I have pain during ovulation, 8 on the VAS scale,' and then you ask them, 'Do you take painkillers?' 'No, I don't.'
G2: molte volte le ragazze ti dicono ho un dolore insopportabile poi mi quantificano e	G2: Many times girls tell you, "I have unbearable pain," then they quantify it and say, "VAS 4.5,"

ti dicono VAS 4 ,5. [...] Alcune volte hanno paura anche a quantificarlo secondo me cioè sentono dolore ma alcune tendono a minimizzarlo e viceversa.	[...] Sometimes they are afraid to quantify it, in my opinion, that is, they feel pain, but some tend to minimise it and vice versa.
G1: [...] tanta gente nasconde la levatura del numero e quindi del dolore che permette di apprezzarlo per paura di quello che può essere la conseguenza del medico, che può essere conseguenza medica, addirittura chirurgica quindi aspetta che gli ritenga un numero più basso quando lo prende la - scheda diceva beh questa sta bene così.	G1: Many people conceal the severity of the number and therefore the pain that allows them to appreciate it, for fear of what the doctor's diagnosis might be, which could be medical or even surgical, so they wait for him to consider it a lower number when he takes the card and says, well, this one is fine as it is.

The discussion on the validity of NRS has actually confirmed that assessing pain is a complex task, subject in turn to uncertainty both for doctors and for patients. After they discussed the limits of the numerical rating, the doctors stated they are willing to try a more comprehensive rating tool, as quoted in Table 50.

Table 50

Towards a new approach to pain assessment

Doctor's comment in the interview	Translation
R1: Voi considerereste l'idea di affiancare al questionario VAS, chiamiamolo così, anche una breve lista di domande più descrittive del dolore, in modo parallelo alla VAS? Lo sperimentereste?	R1: Would you consider adding a short list of questions that are more descriptive of pain to the VAS questionnaire, let's call it that, in parallel with the VAS? Would you try it out? A free text field next to the numerical value. Seeing this

G1: Un testo libero accanto al valore numerico. Vedendo questo, [i diari] potrebbe esserci di aiuto, secondo me.	could be helpful, in my opinion. G1: A free text alongside the numerical value. Seeing this, [the diaries] could be helpful, in my opinion.
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Asked about their view of the present and the future of endometriosis, G3 says she imagines a level, a plateau, since there is no current advance; G2 is more optimistic since in the last 20 years, he says, the diagnostic times have become much shorter and he envisions a future in which endometriosis symptoms can be zeroed, so his metaphor for the future of the treatment of endometriosis is a ray of sun. Lastly, G1 believes that narratives improve diagnosis since they provide information on patients' quality of life and that the clinical path is marked by *vagueness*, since there is no therapy. He associates the present with a full moon.

When I start introducing the uncertainty with which women with endometriosis say they live, G1 stops me by saying that there is no such issue, that patients' uncertainty is due to doctors who make promises they cannot keep:

Table 51

Uncertainty in the doctor's perspective

Doctor's comment in the interview	Translation
G1 [...] l'incertezza sull'endometriosi è causata dai medici che sono finalizzati a dare un contentino alle pazienti senza dir loro come stanno le cose. Malattia infiammatoria cronica e progressiva, con sintomatologia difficilmente debellabile. [...] Nella clinica quotidiana alle donne	the uncertainty surrounding endometriosis is caused by doctors who aim to appease patients without telling them how things really are. It is a chronic and progressive inflammatory disease with symptoms that are difficult to eradicate. [...] In everyday clinical practice, women need to be told the truth in a correct, elegant and kind

<p>bisogna dire il vero in maniera corretta, in maniera elegante, in maniera gentile, ma senza illudere, [...] perché ad oggi terapia per le endometriosi non c'è.</p>	<p>manner, but without giving them false hope, without giving false hope because, to date, there is no treatment for endometriosis.</p>
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<p>G2: Loro ovviamente hanno questa incertezza dovuta al fatto che noi per primi gli diamo poche certezze, ecco, perché una donna con endometriosi che magari è giovane, e magari se chiede “posso avere figli?”, non è che uno con certezza gli può dire no o con certezza gli può dire sì. [...] le certezze ce ne sono alla fine relativamente, quindi è comprensibile che loro abbiano questa percezione di incertezza sul loro futuro, sul loro andamento dei sintomi, sulla loro fertilità, questo è più che comprensibile, ma è così, è la malattia che è fatta così.</p>	<p>They obviously feel this uncertainty because we, first and foremost, give them little certainty. So, when a woman with endometriosis, who may be young, asks, “Can I have children?”, no one can say with certainty, “No,” or “Yes”. It is not that one can say no with certainty or say yes with certainty. [...] As in many things in medicine, there are ultimately only relative certainties, so it is understandable that they have this perception of uncertainty about their future, about the progression of their symptoms, about their fertility. This is more than understandable, but that's the way it is; that's how the disease is.</p>
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Interestingly, clinicians understand uncertainty mainly in terms of “diagnostic” uncertainty, while the idea of uncertainty for patients has a more practical meaning, since it concerns everyday life, such as not knowing how they are going to feel from one day to another, not attending to social events for the fear of sudden symptoms. I was trying to explain what patients mean by uncertainty, but G1’s reaction moved the conversation away from that and focused on the uncertainty in diagnosis.

The relationship between doctors and patients also seems to give rise to uncertainty regarding the expectations of each stakeholder. Should the doctor be more paternalistic, as in the child-adult simile used by the patient? How can a doctor live up to patients' expectations when it comes to a disease with so few neat and clear data and unfolding in unpredictable ways? The doctors agreed on the necessity to use soft communication skills, to be honest and firm about chronicity and fertility.

As can be evinced from the table, for the gynaecologists, uncertainty is common in medicine, and so they do not create expectations in patients, especially when it comes to pregnancy.

The "representation" step of Charon's methodological triad (2006) inspired a dynamic debate on the pain assessment methods currently used, and allowed the doctors to increase their awareness of the patient's pain perception, although the clinicians' viewpoint differs from that of the patients. As Bakhtin states, "Truth is not born nor is it to be found inside the head of an individual person, it is born between people collectively searching for truth, in the process of their dialogic interaction" (1984, p. 110).

The affiliation movement unfolds in a scenario in which a different and multidimensional approach to pain description could be adopted.

Conclusions

After exploring the relation between Medicine and the Humanities and reviewing the main research findings on the complexity of pain-related suffering (Cassel, 1982; Noe-Steinmüller et al., 2024), I discussed the theme of the narrative structure of medical practice and communication (Montgomery, 1991) and illustrated the method of Narrative Medicine set out by Charon (2006).

The research questions I aimed to answer in this thesis were whether and how uncertainty emerges from the digital narratives shared by patients, caregivers and doctors participating in the EndoNar project, with a special focus on the description and assessment of pain-related suffering.

Uncertainty characterises endometriosis in several respects.

At the clinical level, the causes of this disease are unknown, and the only certainty is that it is chronic and incurable at the moment. From a social point of view, patients experience uncertainty because of two controversial narratives: one is that their severe pain is unreal and just in their head (so they have also been told by their doctors), which makes them feel different from the other women. At the same time, they *are* like any other woman *just because* they are women, and pain is normal for women. This contradiction leaves patients uncertain about their condition, their physical perceptions and their mental clarity. As a consequence, they doubt themselves and are unsure of how to express their pain.

To answer my research questions, I carried out the first two steps of the triad theorised by Charon (2006): connection and representation. In the connection phase, I performed close reading according to the five elements of frame, form, time, plot and desire. Although I analysed the patients' notes based on the *interaction* of these five categories, some patterns could be evinced from the close reading: in the participants' narratives, time is determined by symptoms of endometriosis, and oscillates between sudden, unexpected events, and the relentlessness of pain, its cyclical coming back, and its chronicity.

The frame (in Charon's sense of the term) of this project's stories features a social and cultural context with specific assumptions and gender bias on female pain, which, in turn, supports self-doubt, mistrust and misinformation on endometriosis.

The plots of the stories share a common pattern: this includes a late and unexpected diagnosis, a strong impact of the disease on life quality, fertility and mental health, and, except in a few cases, a negative attitude towards the future. Yet, resilience and mutual support emerged, too.

As for the form of the narratives, on which I focused, this retains the key elements of autobiographic writing and is characterised by a frequent use of interrogative sentences, of figurative language in the description of pain, and of the verb "sapere" (to know) in negative sentences. The analysis results reveal how uncertainty on pain description is particularly evident in some patients and turns into expressive challenges, as if talking about pain were not possible ("ancora non riesco a parlarne"⁴⁴). Yet, this can be overcome thanks to figurative language and the relational and performative function of narratives that connect the sender to the receiver of the message in a request for acknowledgement of the pain experienced. In the specific case of endometriosis, in terms of acknowledgement, patients expect that doctors realise and confirm that their pain is real. Hence, a care relationship, a treatment can follow as a performative act (Austin, 1962). Being recognised as hurt and mistrusted sufferers is the deepest desire (again, in Charon's view of "desire") in these women; some notes also reveal the willingness to support other patients through story sharing.

Charon's representation phase was not properly performed through parallel charts since clinicians wrote just four comments. A semi-structured interview (see Annexe 2) was the alternative strategy. Of course, this was a backup plan due to the scarce narrative activity by doctors, and a semi-structured interview cannot equal the expressive and narrative freedom and depth of parallel charts.

⁴⁴ I still can't talk about it

Affiliation consists of the attitude with which doctors will approach the patients/writers after the project, with a different awareness. The gynaecologists themselves confirmed in the interview that the patients' notes had allowed them to know more and different aspects of the endometriosis, experience especially at a non-clinical level.

The results of the EndoNar case study align in many respects with the findings of literature and research on the same topic reviewed in Chapter 4, although they apply to the particular phenomenon investigated, and the case method has shortcomings in terms of generalizability, as highlighted by Gagnon (2010).

In the case of NM, this is even more significant because of the intersubjectivity and textuality on which the doctor-patient relation is built, since the medical team represents the readership, so the stories written by the same patients participating in this project would have been interpreted differently by other doctors.

Moreover, my position is also peculiar, since I, as a researcher, am a reader too and add an extra viewpoint to the interpretation process, based on Charon's theoretical framework. If it is true that doctors did not receive systematic and intensive training in NM as at Columbia, it cannot be overlooked that I am not a clinician; my project is based on the research activity and specific courses I illustrated in the first three chapters of this thesis, but I do not have any medical relationship with the patients. So the interpretation of both the readers of the endometriosis stories in this project (doctors and I) are partial, but can fit into an integrated perspective: mine, related to research in linguistics, and that of the gynaecological team, internally differentiated in terms of gender and professional role, as highlighted in the interview.

Although I relied on Charon's NM method based on close reading, in this project, I do not have the literary education and culture that inform Charon's approach to NM.

I integrated, to different extents, quantitative and qualitative methods in the case study, but the research project is not statistically representative, since the number of patients enrolled and of digital diaries completed is low.

Different factors may have contributed to this outcome: the most objective is the fact that only one out of three doctors carried out the enrolment phase.

Time availability is a crucial factor in this NM project. In the interview, the surgeon also stated that they would explore more features of the illness experience at the hospital through narratives if they had more time to do it. So the possibility of carrying out a NM project depends largely on the doctors' availability to actively engage in it.

Another factor could be the duration of the project. Patients received prompts one-to/ three-times a week over six months starting from the enrolment date: this timing aimed to create continuity between the private writing process and face-to-face communication (medical check-ups take also place every six months). Nevertheless, six months may have been a long time for some participants.

At the end of the project, the doctors informed the Unistrasi and DNM team of their desire to continue the narrative experience also after the end of the EndoNar project. One of the gynaecologists suggested testing an app with the same function as the digital platform, to make it easier to access it and write timely from their mobile. Lastly, the process resulted in a new attitude towards the choice and use of pain description tools, since the doctors opened up to the possibility of introducing new questionnaires to report and assess endometriosis pain, including more dimensions of pain-related suffering. I consider these changes to be among the results of this project, which confirms the performative function (Austin, 1962) of NM and, broadly speaking, of narratives: stories raise issues, introduce new ideas, but also new practices, since new representations of pain (the digital diary, the alternative questionnaire) are now welcome and included in the clinical practice. As Charon says (2006): "The narrating [...] creates that which is seen for the first and only time. The telling does not merely expose or report that which exists prior to the narrating. It produces it" (p. 45).

Through the whole project, I tried to keep a balance between the medical and the linguistic nature of my research, a balance that sometimes may have leaned towards medicine, sometimes

towards language, and that recalls the flexible but necessary relationship between medicine and the humanities. I can say with some confidence that I tried to highlight as much as possible the linguistic part of this research by stressing the performativity of language: the doctors' request to continue the project means, in my view, that the stories and the thoughts that patients and doctors shared through words and pictures turned into real and small, but meaningful, changes in the clinical practice.

Annexe 2

Follow-up Interview

R 1: Researcher 1 (Me)

R 2: Researcher 2 (DNM)

G 1: Gynaecologist 1 (surgeon, male)

G 2: Gynaecologist 2 (male)

G 3: Gynaecologist 3 (female)

R1: Dunque, siamo praticamente alla conclusione di questo progetto di raccolta disposto agli stimoli narrativi. Quindi, io oggi vorrei conoscere soprattutto il vostro punto di vista su quanto le pazienti hanno scritto, e in generale sul progetto. Quindi, prima di farvi delle domande, in realtà volevo proprio raccogliere un parere abbastanza spassionato di qualsiasi genere, senza filtri da parte mia su quello che avete letto, quanto avete letto.

Non è una specie di compito per testare quanto abbiate studiato, tra virgolette, le risposte delle pazienti, ma anche a noi in realtà interessa sapere quanto siete riusciti a seguire con questa piattaforma quello che scrivevano mano a mano le pazienti. Quindi, vi lascio subito la parola.

G1: Infatti, poi c'è anche un'interpretazione personale su quello che si è letto, chi si è letto e quanto se ne è letto.

Io dico che questo progetto è sicuramente un progetto interessante e dovrebbe essere da stimolo anche per chi non ha una conoscenza dell'esistenza di questo progetto, perché la comunicazione non vis-à-vis con le donne consente loro di essere il più possibile libere di esprimere quello che sentono, che pensano.

È chiaro che la tipologia di risposta, come appare sia nella globalità che in particolare in singole campionature, è completamente differente perché c'è gente che, ovviamente, insegue questa

possibilità di comunicare, ripeto, non di persona ma attraverso un sistema di raccolta di questa comunicazione, e la stessa persona ribadisce e anche modifica il proprio stato a secondo dei suoi umori, ma questo ci sta perché ogni persona, uomini, in particolare, le donne affette da determinate patologie hanno da dire determinate cose in determinato modo un giorno e cambiarle in modo differente, la stessa donna, un altro giorno.

A questo si aggiunge che ci sono tante donne, chiamiamole pazienti, che possono rientrare in questo gruppo, che invece hanno una loquacità completamente diversa, molto più contenuta, molto più riservata che quasi si sforzano di partecipare, ovvero di essere presenti, però non hanno gli sfoghi che alcune invece anche in maniera assai prolungata pronunciano.

Quindi credo che l'opportunità che questo sistema dà è estremamente utile ed è realmente conoscitiva, ma ben oltre il tempo che ognuno di noi, anche con tutta la buona disposizione nei confronti di certe patologie, può dare alla paziente. Nell'isolamento o comunque sia nell'ambiente familiare, l'ambiente che non sia un ambulatorio o un studio, è molto più facile per le donne dire quello che si effettivamente pensa, fermo restando le differenze caratteristiche.

G2: Sicuramente concordo con il professore per la paziente che abbiamo di fronte, in quanto normalmente ci troviamo con due profili, uno abbastanza loquace, uno che ha difficoltà ad esprimersi, ma anche durante l'ambulatorio classico in generale.

Quello che ho notato io per la mia esperienza per questo progetto in particolare è stato che, quando ho cominciato a cambiare anche io un pochino il tipo di informazione che davo alla paziente rispetto a questo progetto - e quindi all'inizio magari ero un po' più approssimativo, probabilmente perché dovevo anche io capire il sistema – successivamente, quando spiegavo il fatto che poteva essere un modo non solo per la paziente di poter esprimere tutto quello che aveva in mente rispetto sia alla visita sia alle proprie sensazioni durante la vita quotidiana, rispetto alla patologia, ma anche come uno strumento da cui noi in maniera indiretta ricavavamo delle informazioni utili poi per un approccio globale per la paziente endometriosa, quindi un

vantaggio rispetto alla patologia e alla persona - non intesa come la persona singola della visita - ho notato un miglioramento. Quindi sicuramente, all'inizio, anche probabilmente per un deficit mio comunicativo, poi ho cominciato a modificare il tipo di spiegazione del progetto e ho notato che poi la paziente era un po' più a suo agio nella descrizione di quello che gli accadeva.

R1: A voi in quanto personale curante ciò che hanno scritto le pazienti ha dato delle informazioni ulteriori, semplicemente diverse, e se utili e in che misura?

G3: Non tanto dal punto di vista clinico, perché obiettivamente a livello di come sta la paziente, come va il decorso della malattia, questo fondamentalmente, non è che si evince da quello che loro scrivono, o meglio non proprio la parte tecnica legata alla loro situazione di endometriosi. Sicuramente...dicevo, non tanto sull'entità dello stato fisico della malattia ma sulla percezione, di come noi ci rapportiamo a loro, perché l'ultima che a me mi ha colpito è stata quella della Scala VAS, che ha demolito la Scala VAS in una mezza pagina di commento, e quindi come noi a volte continuiamo ad andare dritti per la nostra percezione di quello che è la nostra abitudine pratica, quando in realtà poi alle pazienti la Scala VAS...

Ora questo è un esempio, quindi più che l'andamento della malattia o se stanno meglio o stanno peggio, la percezione anche di come noi possiamo gestire le pazienti relativamente a questa malattia questa è la cosa che a me è piaciuta di più di questa piattaforma. E devo dire che la cosa bella - sicuramente la narrazione del paziente è l'obiettivo - però probabilmente la narrazione e la percezione della cartella parallela sarebbe ancora più bello questa è la percezione mia.

R1: Infatti sì anche questo è lo scopo di questa intervista cioè raccogliere l'altro punto di vista che è assolutamente essenziale perché non ha molto senso la Medicina Narrativa se si limita a rappresentare solo una parte. Finora dal punto di vista delle conoscenze prevaleva - finora dico, le cose stanno cambiando, sono state introdotte le Medical Humanities - però c'era, soprattutto nel

campo delle endometriosi, questa cognizione parziale, soltanto medica, con tutti i limiti di quello che si sa e non si sa ancora sull'endometriosi, e poi invece è venuta fuori la voce delle pazienti sui motivi della sfiducia verso ciò che riportavano.

Per noi era importante conoscere invece anche la voce di chi cura.

C'è uno spettro di posizioni rispetto alla VAS e volevo capire appunto cosa ve ne sembrasse, in quanto gente che sta appunto dall'altra parte.

C'è chi dice: [mostro la diapositiva con le note dei pazienti sulle VAS]

G1: Lo strumento della VAS è uno strumento che è l'esatto contrario di quello di cui stiamo parlando, cioè è una sintetizzazione di quanto rispetto al sintomo o dolore la donna può riferire in un ambiente ambulatoriale, che va a sintetizzare numericamente il livello di dolore, che non è necessariamente da paragonarsi a quanto qualcosa o qualcuno può causare di dolore, ma è solo riferito alla malattia, cioè al dolore causato dalla presenza di questa malattia. La VAS è inserita, a mio dire - una come tante, perché non è l'unica scala di valutazione del dolore - però è inserita per cercare di dare ai numeri diciamo uno spazio crescente da 0 a 10, riferito al livello di dolore, ma non c'è un paragone rispetto come è stato riferito chiacchierando, e evidentemente si può dire di tutto, anzi il bello è proprio questo. Però la critica a questo tipo di valutazione del dolore può essere spiegata non in questa sede, ma anche con un'eventuale paziente che dovesse dire "ma io non mi sento di rispondere a questo perché per me non esiste un dolore che va da 0 a 10": Invece no, perché la quantificazione, anche se è estremamente soggettiva, quello è importante, perché il 5 di una persona non è il 5 per tutti, è per esempio da considerarsi tra 0 a 10 a metà tra il minimo e il massimo del livello di dolore. La differenza tra 3 e 4 è che 4 fa più male di 3. Questo è l'obiettivo, anche perché nella raccolta dei dati, che vengono poi utilizzati per passare al passo successivo, che è praticamente dopo la raccolta anamnestica, l'inquadramento clinico, l'esame obiettivo, gli esami strumentali e via scorrendo, è importante, non potendo dilungarsi all'interno della struttura ambulatoriale, raccogliendo anche le percezioni un pochettino più, come dire, non schematiche ma,

appunto, narrative, non potendolo fare sicuramente con ogni paziente, allora si cerca di sintetizzare a proposito di uno dei sintomi, e il dolore non è certamente l'unico - a 0 a 10 quanto male fa - questo è il senso della VAS. Cioè che mi dicono che il 10 è l'ustione profonda, dice poco, però il 10 a me serve per capire che è un dolore, non solo un dolore, ma a un livello inaccettabile.

G2: Anche io penso che la VAS ovviamente non è un sistema perfetto, ma comunque è un sistema di valutazione semi-oggettivo, quindi ci dà dei criteri da poter poi utilizzare e associare a qualsiasi paziente, quindi è fondamentale. Poi nell'esperienza clinica, capita spesso che questi pazienti non sappiano quantificarla e secondo me dei punti di riferimento che ovviamente poi cambiano da paziente a paziente possono essere d'aiuto. Io normalmente se ho una paziente che ha partorito, dico "il 10 è come il dolore da parto", se ho una paziente che purtroppo con l'endometriosi ha anche problemi di fertilità dico "man mano che aumenta il dolore è quella condizione per cui non riesco a fare alcuna attività quotidiana che normalmente farei", cioè cerco di dare dei riferimenti per dare un aiuto, però probabilmente non c'è nulla di perfetto ma qualcosa per quantificare ci serve.

R1: G3, non so se anche tu, grazie intanto, forse prima stavi per dire qualcosa a riguardo...

G3: Cioè a me piace come quella signora l'ha descritto, perché l'idea di bruciare viva rende molto più un'idea di un VAS 9-10 piuttosto che... quindi pensare che magari a volte oltre alle faccine che ci sono accanto alla VAS, perché spesso accanto alla VAS uno la potrebbe migliorare, facendo come ha detto G2: fare un qualcosa anche di strutturato, visivo, che può dar la percezione di farglielo anche capire meglio, perché obiettivamente è buffo quando si dicono "eh sì io ho dolore all'ovulazione 8, VAS 8" e poi gli dici "ma prendi antidolorifici?" "No, non lo prendo", perché poi un VAS 8 l'antidolorifico lo prende, quindi spesso è un po'... e allora magari poter migliorare anche queste scale mettendoci una correlazione di un qualcosa di esemplificativo sarebbe secondo me carino, per migliorare proprio la quantificazione. Poi, è ovvio, ci serve uno strumento per dire quanto, perché le mie VAS, conoscendomi, sono VAS molto alte rispetto a una persona normale,

ma perché io non sopporto niente concettualmente, quindi in questo momento ho una VAS 9 e magari ecco un'altra una VAS 1, 2.

G2: A volte anche il contrario scusatemi, perché molte volte le ragazze ti dicono ho un dolore insopportabile, poi mi quantificano e ti dicono VAS 4 ,5 nel senso, penso capita anche a te (riferendosi a G3).

Alcune volte hanno paura anche a quantificarlo secondo me, cioè sentono dolore ma alcune tendono a minimizzarlo e viceversa.

R1: Forse anche perché da quello che scrivono - ma questa è la percezione come lettrice esterna, non clinica e non paziente al momento - è che loro anche abbiano un'idea di dolore e sofferenza integrata, nel senso che il dolore, diciamo, forse inteso in senso soltanto fisico, loro, ecco, lo integrano nel concetto di sofferenza. Una paziente dice per esempio “dipende dalla voglia che hai di reagire, da come stai in quella giornata”, quindi di fatto anche da una serie di fattori non prettamente fisici. Volevo chiedervi se vi capita di confrontare le misurazioni VAS nel tempo, perché appunto la paziente diceva “ha senso se si possono fare poi dei paragoni su come evolve la situazione”. Vi capita di fare queste rilevazioni?

G1: Prima, dopo la terapia, che sia medica, che sia chirurgica. C'è un altro punto a proposito della VAS, tanta gente nasconde la levatura del numero e quindi del dolore che permette di apprezzarlo per paura di quello che può essere la conseguenza del medico, che può essere conseguenza medica, addirittura chirurgica, quindi aspetta che egli ritenga un numero più basso quando prende la scheda, dice “va beh questa sta bene così”.

R1: Questo è importante per noi da sapere.

G1: Di limiti ce ne sono, ma anche quello che diceva prima G3 - "sarebbe molto carino" - ma una raccolta dati di VAS con le faccine non si può fare, non è non è pensabile

G3: Ma c'è con le faccine, esiste quella con...

G1: Ma in verità devi trasferire poi tu, interpretarla tu, e quindi già è una è una deviazione.

Devi interpretare tu se la faccina con il lato più su o più giù è, diciamo, segno di un dolore maggiore o un dolore minore, penso che è impossibile. C'è la VAS numerica con a fianco la faccina corrispondente, quello è vero.

R1: Forse questa ha gli stessi potenziali limiti di quella numerica, perché anche lì la faccina non ha proprio una corrispondenza univoca.

G1: Certo, però poi quando riferisci in una scheda o raccogli i dati per uno studio, non puoi mettere la media della faccina umana, devi mettere un numero.

R1: A questo proposito, R2, ovviamente sentiti libera di intervenire, se hai domande.

R2: Più che domande, vi volevo riportare un'esperienza analoga in altri studi che abbiamo incontrato ma brevemente nel senso che noi lavoriamo con i PREMS, i Patient Reported Experience, e questi questionari spesso ci sono stati sono stati criticati perché tendono a evidenziare soprattutto gli aspetti negativi della malattia. Quindi magari alcuni sintomi mirano a rilevare magari una sintomatologia che a volte il paziente neanche ha sviluppato e quindi il nostro lavoro in questi anni, in realtà molto recentim è stato proprio quello di integrare, dare la possibilità nella piattaforma ai pazienti di integrare le risposte al questionario oggettivo - lì c'è una gradazione che mi sembra che vada da 1 a 5 quindi non abbiamo neanche dei numeri, abbiamo risposte o forse un sì/no - non

ricordo - dando la possibilità poi di integrare quelle risposte con un commento libero che poi sostanzialmente è una narrazione. Però ci è capitato tante volte che appunto i pazienti segnalassero proprio un disagio o addirittura a volte si spaventassero nel leggere quelli che erano dei sintomi che loro di fatto non avevano sviluppato, quindi poi magari andavano dal follow-up dicendo “ma cosa vuol dire, che allora avrò diarrea, però...?” Per dire, quindi, ecco insomma, questa era un po' la restituzione che volevo farvi, tutto qua, senza mettere in dubbio la validità per gli strumenti.

R1: Volevo collegarmi proprio a quello che è stato detto *sull'integrazione* che si può fare, se mai, più che la sostituzione, della VAS, con alcune descrizioni invece che hanno fatto proprio le pazienti del loro dolore e dei loro sintomi. Volevo sapere se, veramente senza alcun condizionamento - quindi mi serve davvero avere una vostra risposta libera - cosa ne pensaste invece del modo in cui loro hanno rappresentato diciamo l'intensità, la qualità del dolore, perché prima si parlava di quantificarlo, quindi, loro hanno usato queste immagini, cioè dicono “per me il dolore è come...” e vi mostro alcune immagini con cui loro lo hanno rappresentato.

Ora, questa è la logica che sottende un po' la cartella parallela: leggendo queste cose cosa provate? Non vi sto chiedendo un parere clinico, lo potete dare, ma non è la priorità della mia domanda. Sentitevi liberi di commentare qualsiasi cosa, vi ho messo anche l'immagine che alcune pazienti hanno usato.

G 1: Tutto quello che raccogli, che abbiamo letto, che hai raccolto in questa diapositiva è tutto corrispondente alla realtà, quello che effettivamente - chi più chi meno, chi più diciamo avvezzo al commento, chi meno, più riservato, eccetera... fanno anche negli ambulatori. Quell'informativa che avviene via mail è più utile. Il problema è che quella è solo una parte di inquadramento della malattia. E ovviamente noi siamo qui semplicemente per la parte narrativa, e quindi per la corrispondenza tra quello che viene narrato dalla paziente e quello che è l'esperienza clinica di ciascuno di noi, che in qualche modo rappresentiamo. Secondo me questa narrazione, ripeto, è

fortemente influenzata dalle caratterialità. La stessa narrazione, se uno avesse più tempo, la troverebbe anche all'interno della struttura della clinica ambulatoriale, è utile perché ci dà delle informazioni, a volte anche geografiche, perché ci vengono a descrivere quali sono le zone di maggior interesse. È evidente che nel percorso diagnostico-terapeutico di una patologia anche di una certa importanza benché benigna c'è bisogno di un'integrazione. Come dicevo all'inizio, il vantaggio di questa piattaforma è dare la possibilità, di massima libertà alle donne di dire tutto quello che nella loro intimità vogliono e possono raccontare, cose che magari in altre sede non farebbero.

G3: A me se la domanda è come mi fa sentire quello che leggo, mi fa sentire abbastanza impotente a volte. È una perfetta descrizione di quello che loro sentono, immagino che sentono, è come io di base mi immagino nella testa l'endometriosi, però se la domanda è la sensazione che provo io quando leggo questo, io medico che leggo questo, a me mi fa sentire impotente o poco aiutante, via.

G2: Sinceramente a me dà sicuramente un stimolo a far venire la paziente in ambulatorio.

R1: Posso chiedervi se questo linguaggio lo riconoscete come lo stesso che usano in ambulatorio nella comunicazione face-to-face o è molto diverso?

G3: No, ci si ritrova

G1: Ci sono donne che in ambulatorio hanno maggiori contenimenti

G2: Anche io, insomma, dipende da quanto la paziente è più o meno inibita. Ci sono alcune pazienti che sono dirette, come qui hai mostrato tu in questo slide, e pazienti che invece tendono a non essere così esplicite. Rispetto invece alla domanda precedente, da parere di persone non coinvolte

da un punto di vista medico, dico che il valore VAS 5, 6, 7 mi dà meno sensazione di disagio rispetto a quello che scrivono in questo caso.

Poi, da un punto di vista medico, ovviamente la reintegration in un concetto diverso, ma se io leggo questo “un pugnale”, piuttosto che “tanti coltelli che mi penetrano”, mi dà un'immagine più forte di quella di una paziente 8-VAS, francamente.

Quindi è un linguaggio più emozionale, diciamo, che va a coltivare la parte non professionale, la parte indipendente dal ruolo. Mi rende più l'idea di sofferenza, nonostante conosca la scala e conosca come funziona. Però se io mi sto estraniando dal mio ruolo di medico e lo leggo come persona, ha un senso diverso.

R1: Ci sono degli spazi, non so, anche di confronto tra voi come team, in cui condividete queste riflessioni e le esternate? Nel senso che - io immagino che l'agenda di un medico sia estremamente fitta - mi chiedo se ci siano proprio degli spot di tempo in cui ri-condividere, diciamo, quello che, appunto, si prova come reazione davanti a questo tipo di descrizione, di rappresentazione del dolore.

G3: Tipo debriefing?

G1: Sì, sì. Ma guarda, tra di noi capitava, perché esiste questa emissione di dati, questo confronto con quanto i pazienti dicono, questa piattaforma, capita di riferircelo “Hai letto questo, quell'altro?”. Però, come diceva G2 poc'anzi, queste espressioni, insomma, sono abbastanza comuni. Poi, ripeto, c'è quella che è più svezzata, perché magari la malattia ce l'ha da così tanto tempo, questa ha avuto una quindicina di ginecologi minimo, e quindi ha una dimestichezza addirittura anche per le risposte che ascoltano i medici, e c'è quella invece un pochino più timorosa, un pochino più riservata, insomma.

Però è valido, il sistema di narrazione, anche dettagliata, secondo me, è una cosa valida.

R1: Voi considerereste l'idea di affiancare al questionario VAS, chiamiamolo così, anche una breve lista di domande più descrittive del dolore, in modo parallelo alla VAS? Lo sperimentereste?

Lo state già facendo attraverso, ovviamente, il progetto Endonar con noi, però mi chiedo se, nella vostra procedura standard, se immaginate di poterlo accompagnare alla VAS.

G1: Un testo libero accanto al valore numerico. Vedendo questo, potrebbe esserci di aiuto, secondo me.

R1: Sì, esatto, un testo libero, oppure anche una serie di opzioni della serie.

Un dolore pungente, un dolore a ondate, un dolore così, in cui loro possono scegliere, oppure mettendo l'opzione “altro”, in cui loro descrivono liberamente, questo che intendevo, sì.

G1: Questo ha senso.

R1: E, come vi dicevo prima, appunto ci sono queste immagini, che loro hanno messo, di persone che si ripiegano un po' su loro stessi per il dolore, e poi c'era una domanda che diceva di rappresentare un po' il loro presente.

Io ho riportato appunto questa della statua che ha proprio inserito una paziente, un'altra ha disegnato un cerchio, un'altra ha detto “un'alternanza di nubi e sole”. Io invece volevo sapere, ecco, siccome c'era la domanda sia riguardo la percezione del presente sia quella del futuro, volevo sapere, voi quando pensate al presente e al futuro, diciamo, dello stato dell'arte sull' endometriosi, che cosa vi sentite di dire? Se fate anche voi dei pensieri, diciamo, proiettandovi in quello che potrebbe essere lo sviluppo futuro, e invece lo stato attuale della ricerca e del trattamento delle endometriosi.

G3: Chi comincia?

G1: Prego, G3.

G3: Non so, se penso al presente, mi viene in mente un plateau, ch  diciamo ora tante cose si sanno gestire, tanti atteggiamenti sono cambiati, quindi diciamo c'  un po' pi  di attenzione, non tanto alla malattia per s , quanto alla donna che ha la malattia, quindi un certo... per  mi viene comunque da pensare che ora, di nuovo, di cose nuove, di farmaci nuovi, insomma siamo un pochino in uno stand by, anche perch  obiettivamente tante cose ancora non si sanno, proprio anche di come questa malattia si sviluppa, c'  tante ipotesi sulla genetica, tanti punti di domanda, quindi per come noi gestiamo la paziente in ambulatorio siamo arrivati un po' a un plateau, quindi ci si gestisce sulla paziente ma con cose che ormai si utilizzano da tanto tempo.

Il futuro, diciamo che lo attendiamo a gloria, di focalizzarsi su qualcosa che magari va su tanti aspetti, non tanto sulla parte diagnostica probabilmente, ma quanto proprio sulla parte di prevenzione. Come si dice, prevenire   meglio che curare, quindi mi verrebbe da pensare a un futuro non tanto di trattamento dell'endometriosi, ma quanto di prevenzione dell'endometriosi.

G2: Vado io? Io la vedo con un po' di ottimismo, anche perch  magari mi sono avvicinato pi  recentemente a questa patologia, quindi tra virgolette fortunatamente, quindi rivedendo un po' la storia, rivedendo il periodo in cui ho iniziato ad affrontarla, quello che era un qualcosa che era nebuloso fino a vent'anni fa...io ho avuto la fortuna, lasciatemi usare il termine, di entrare gi  in una fase in cui noi riusciamo a diagnosticare e comunque rendere un po' meglio la qualit  della vita di queste ragazze a 20, 18, 16 anni, ragazze che riusciamo a inquadrare pi  precocemente rispetto a tanti anni fa, in cui la donna soffriva per vent'anni, trent'anni, poi magari a fine dell'et  riproduttiva, quando purtroppo magari neanche era riuscita ad arrivare a una gravidanza. Sono passati vent'anni e nel frattempo la ricerca avanzava e quindi si scopriva che era tutta espressione magari una patologia che era gi  preesistente. Quindi da questo punto di vista vedo, insomma, se devo immaginare qualcosa immagino tipo un raggio di sole dell'alba. Futuro spero, insomma, un'immagine che noi possiamo veramente andare oltre la diagnosi, oltre il trattamento del sintomo e arrivare, come dice

G3, non so se alla prevenzione ma quantomeno al trattamento tale da azzerare il sintomo o quello che ne comporta come qualità della vita.

Un'immagine per il futuro? Non dico proprio un solleone, però insomma da quel raggio di sole dell'alba... il sole che si innalza nel nostro orizzonte.

R1: Ok, grazie anche a lei.

G1: A me vanno bene tutte e due le interpretazioni, però volendo tornare su quanto di interesse attuale, anche la chiacchierata di oggi, io credo che la parte narrativa resta e resterà essenziale.

Vi dico che andrebbe proposta non solo per l'endometriosi, ma per così tante patologie: attraverso la narrazione si riesce ad arrivare molto prima e molto meglio a una diagnosi. È anche un percorso clinico e terapeutico che oggi, per quanto torniamo sull'endometriosi, come già detto, è vago perché non abbiamo una terapia medica mirata specifica, non abbiamo una chirurgia che stupidamente viene definita radicale, ma di fatti la malattia permane, per cui non abbiamo una possibilità di promettere una guarigione alla paziente, su questo non c'è nessun dubbio. Possiamo dire di riuscire probabilmente a ridurre i sintomi e a migliorare la qualità della vita della donna grazie anche alle informazioni che ci vengono date attraverso queste piattaforme e questi sistemi.

Ovviamente per scelta mia personale, la raffigurazione del sole in contrasto con una luna piena, è molto meglio del sole. Come quella che c'era ieri, quasi.

R1: Anche qua c'era una luna abbastanza eloquente in questi giorni. In parte avete già risposto alla domanda che volevo chiedervi riguardo l'incertezza sull'endometriosi perché molte pazienti dicono che proprio per l'imprevedibilità, l'irregolarità, la varietà dei sintomi, ovviamente loro non sanno da un giorno all'altro...

G1: Aspetta un attimo Marta, ti fermo perché ti dico che l'incertezza sulle endometriosi è causata dai medici...

R1: È causata dai medici?

G1: È causata dalle risposte dei medici che sono finalizzate a dare un contentino alle pazienti, senza dir loro come stanno le cose: malattia infiammatoria cronica e progressiva, con sintomatologia difficilmente debellabile. Tutto qui.

Se uno invece dice che è bianca la situazione, ma poi può diventare rosso, certe volte diventa verde e poi forse blu, però comunque “vediamoci”, non ha capito una mazza.

G1: La ringrazio per questa risposta, diciamo per me al momento nuova rispetto a quelle che avevo raccolto per ricerca, quindi sicuramente un punto di vista diverso e chiedo anche gli altri due medici se anche per loro comunicare l'incertezza, dove per incertezza intendo la non conoscenza al momento di origini...

G1: Non tutti i medici sono disposti a dire “non lo so”, perché non si sa.

Quello che nei report anche scientifici vengono assunti come tassativi ed evangelici sono delle imperfezioni, e parlo della cosiddetta *scienza*. Nella clinica quotidiana alle donne bisogna dire il vero in maniera corretta, in maniera elegante, in maniera gentile, ma senza illudere, senza illudere né per una terapia né per l'altra, perché ad oggi terapia per le endometriosi non c'è.

R1: Bene, non so se gli altri due dottori vogliono aggiungere qualcosa a questo proposito.

G3: Non no, perfettamente d'accordo. Loro ovviamente hanno questa incertezza dovuta al fatto che noi per primi gli diamo poche certezze, ecco, perché una donna con endometriosi che magari è giovane, e magari se chiede “posso avere figli?”, non è che uno con certezza gli può dire no o con certezza gli può dire sì. Uno, bisogna dare un colpo al cerchio e uno alla botte, perché su quello che si sa, ma come in tante cose in medicina, le certezze ce ne sono alla fine relativamente, quindi è

comprensibile che loro abbiano questa percezione di incertezza sul loro futuro, sul loro andamento dei sintomi, sulla loro fertilità, questo è più che comprensibile, ma è così, è la malattia che è fatta così.

G2: Io penso che sia anche purtroppo giusta questa cosa, perché dare un qualcosa che poi magari non si verifica, creare un'illusione che poi diventa una delusione secondo me sarebbe anche peggio. Da una parte probabilmente è anche deludente per la paziente che la prima volta si sente dire che molte cose non le sappiamo, però è una delusione parziale, nel senso: “Ma io guarirò?”. Probabilmente noi diremmo: “Signora, probabilmente lei non guarirà mai, probabilmente tratteremo questi sintomi”. “Avrò una gravidanza?” “Signora non lo so, probabilmente faremo in modo di aiutarla ad averla, ma non lo possiamo sapere”.

Ma dire a una paziente “Signora lei fa questa terapia e non sente niente”, piuttosto che “Signora lei fa... e poi ha 10 figli”, penso che possa essere ancora di più controproducente se purtroppo si verifica il contrario, quindi probabilmente l'incertezza è anche quello che ci spinge a migliorare in generale, perché le certezze ci bloccano in tutto ciò che facciamo nella vita.

R 1: Mi sembra di capire comunque che voi la mancanza di certezze sull'endometriosi dal lato clinico la comunicate con franchezza, con obiettività e questo vi permette anche di vivere voi, in quanto conoscitori della patologia o di quello che se ne sa, la cosa abbastanza serenamente. Mi pare di capire che non viviate l'incertezza come difficoltà nel momento in cui la comunicate...

G1: No, io personalmente vivo la manifestazione di incertezza come espressione di onestà intellettuale.

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