

Illness, Narration and Healing: Women's Perspectives

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Abstract. The history of the illness is linked to the history of suffering and pain. Every historical period, every human event has been characterized by the explicit expression of ever new “pathologies” which over time have diversified and multiplied. Illness and suffering are not an “exasperation of sensations”, but tell the story of a body and a mind that together go through a multitude of experiences and try to reconstruct the meaning of a human story condemned by illness and, perhaps, to death. The meaning of the illness pass primarily through the “word” and there are many narrative strategies used to tell the painful experience that becomes a shared emotional experience. The female narrative is examined here as a research paradigm and the inner and emotional dynamics are highlighted. Self-care through storytelling

Keywords. Storytelling – Education – Illness – Woman – Care

The *ill body* has always been an object of inquiry and wonder. The experience of the *limit* is the prelude to the sentiment of the *end*: as Martin Heidegger often emphasized in his axiomatic reflections, all existence is confronted by that feeling of anxiety and suffering that accompanies humans in their terrestrial experience¹. Together with a sense of incredulity vis-à-vis an adverse fate, the fear of not knowing how to manage a new *form of the body* – and of the mind – marks the beginning of an *other* life, made up of discomfort, refusal and uncertainty. This process is recursive, cyclical, erosive and often transitional; it repositions the *ill body* at the center of experience and attention, showing that it is neither inexhaustible nor infallible as it rationalizes its possibilities in the space of physical and mental experience². In illness the body discovers that it is both victim and oppressor, with hostile and contrasting feelings: «If in a state of pain my body becomes the world for me, then we are in the presence of not only a polar reversal but also a radical existential disturbance. This is because I am surrounded by the world and not by my body, because my body is not the horizon on which my presence unfolds: *I am that body*»³. The illness that inhabits my body becomes part of my identity; this unexpected “guest” dramatically changes the phenomenology of becoming. «Every form of consolation is weakened in the face of pain because through this pain the individual is violently hurled into his or her finitude»⁴. In narrating the illness, in accepting the

¹ See M. Heidegger, *Introduction to Metaphysics*, New Haven, Yale University Press, 2000.

² See U. Galimberti, *Il corpo in Occidente*, Milan, Feltrinelli, 1987.

³ Ivi, p. 45.

⁴ S. Natoli, *L'esperienza del dolore. Le forme del patire nella cultura occidentale*, Milan, Feltrinelli, 1992, p. 22.

change and through rendering this experience problematic, spaces and practices of healing are created, which are simultaneously quite similar and dissimilar for each of us.

1. From Antiquity to the present: illness and human history

As Jacques Le Goff and Georges Minois have shown⁵, as far back as ancient Babylonian culture proto-medical science attempted to make sense of the discomfort and suffering that afflicted humans and often led to death. Documents from ancient Mesopotamia dating to the third millennium describe the setting up of hospitals and the use of surgical techniques; above all, though, this evidence speaks of medical knowledge conjugated according to two divergent approaches, both of which were marked by creative impulses: science and *magic*. Scholars show that as early as the Code of Hammurabi, composed just several centuries after the emergence of writing, the doctor, called the *asù*, figures prominently as a specialist in the observation and identification of various illnesses. The *asù* personally prepared and administered different potions taken from plants, buds, animals, etc. in the attempt to bring relief to patients or to heal them altogether⁶. But the most important question remained unanswered: why does the body get sick? «In the eyes of the population of Mesopotamia, physical ailments and illnesses were no more than manifestations of that omnipresent parasite of our existence which we might define as the ‘evil of suffering’, everything, that is, that occurs to hinder our legitimate aspiration to a happy life. [...] What is the cause for which we are burdened with illnesses of the body – but also of the mind and the heart – with that pain, affliction, privation and adversity that visit our lives, tarnishing and brutally interrupting our existence ‘before our time’? These questions are as old as humans, and every culture has tried to provide satisfactory answers to them in accordance with their particular circumstances»⁷.

Lacking accurate and certain medical knowledge, the peoples of Antiquity used *fiction* and *imagination* to explain – especially to themselves – the origins of *disease*, which almost always involved divine prophecies and curses connected to supposed immoral and heinous actions committed by women and men. It was often diabolical divinities who oppressed and punished humanity; without the means of resisting their brutality, ancient peoples had recourse to *magic*, inventing a series of practices, amulets and rituals that were able to *heal the ill body*, at least in intent.

Papyri from Egypt’s Middle Kingdom provide evidence of instances of laments and suicides on the part of persons who threw themselves in the path of crocodiles to escape the “effort of living”; likewise, the Psalms of Hebrew culture contain reflections linked to illness and death, expressing the desire for a premature end in the maternal womb, as in the case of Jeremiah. Greek philosophers and poets – from Hesiod to Theognis, from Homer to Sophocles and to Euripides’s splendid tragedy *The Trojan Women* – treat the theme of inner illness (and pain), which, in the opinion of several scholars today, can

⁵ See J. Le Goff, “Una storia drammatica,” in J. Le Goff and J-C Sournia (eds.), *Per una storia della malattia*, Bari, Dedalo, 1985; G. Minois, *Storia del mal di vivere*, Bari, Dedalo, 2005.

⁶ See J. Bottéro, “La magia e la medicina a Babilonia,” in Le Goff and J-C Sournia (eds.), *Per una storia della malattia*, op. cit.

⁷ Ivi, p. 16.

be linked to what we now call depression⁸. Human history is characterized by an extraordinary proliferation of reports connected to the distress felt by man in the face of the irrationality of pain and suffering. In more recent times – in particular since the mid-19th century – this field of inquiry has become more detailed and specialized, thanks above all to the emergence of new sciences able to probe the most hidden corners of consciousness and the soul. Physical pain is a reality which manifests itself in many visible forms; yet there is also the pain of *anxiety*, which silently corrodes and weakens the human will, rendering it helpless and irresolute in the face of the unceasing demands of the world. «My life began with dreadful melancholy and without spontaneity; from childhood my existence was disturbed to its deepest roots»⁹. Jean-Charles Sournia maintains that «illness does not have an existence in itself; it is an abstract entity to which humans gave a name. Starting from the discomforts of which a person complains, doctors create an intellectual notion that groups together symptoms from which the 'ill person' suffers, signs that an observer notices, anatomical lesions and sometimes a cause or origin: on the basis of these, a label is given which goes by the name of diagnosis, from which a treatment is developed which acts on the symptoms and possibly on the cause»¹⁰. In any case, illness leaves behind traces, a body that suffers the consuming effects of painful and conflictual events. This is the body that Virginia Woolf calls *this monster*: rather than respond to the joyful desires of life, it manifests its vulnerability through pain, mutilation and a changed perception of itself, as claimed by Charles Lamb in his essay "The Convalescent," a work that Woolf knew well and appreciated¹¹.

All day, all night the body intervenes; blunts or sharpens, colors or discolors, turns to wax in the warmth of June, hardens to tallow in the murk of February. The creature within can only gaze through the pane – smudged or rosy; it cannot separate off from the body [...]; it must go through the whole unending procession of changes, heat and cold, comfort and discomfort, hunger and satisfaction, health and illness, until there comes the inevitable catastrophe; the body smashes itself to smithereens, and the soul (it is said) escapes¹².

Illness is understood as agony, as a weakness of our minds; it introduces the theme of death, a taboo topic; it sensitizes human feelings vis-à-vis the most common and reasonable way of living. «Because illness does not become joined to our bodies, it isn't a contingent disease but rather a mode of living – the most sublime and most difficult one, and for this reason the most beautiful»¹³.

Medical science, biology and all those fields that have always been concerned with providing a *cure* and an interpretation of illness from a clinical and pharmacological point of view are still today unable to describe the complexity of the painful and polymorphous experience of illness. «Humanity is maturing, or reemerging from oblivion, ready to tear the concept of life and health from the hands of biology, con-

⁸ For a detailed reconstruction of this topic, see G. Minois, *Storia del mal di vivere*, op. cit.

⁹ S. Kierkegaard, *Diario*, Milan, Rizzoli, 2000, paragrafo 974 (author's translation).

¹⁰ J-C Sournia, *Uomo e la malattia*, in J. Le Goff and J-C Sournia (eds.), op. cit., p. 399.

¹¹ «How sickness enlarges the dimensions of a man's self to himself! he is his own exclusive object». C. Lamb, *The Convalescent*, in «Last Essays of Elia», London, G. Bell and Sons, 1913, pp. 245.

¹² V. Woolf, *On Being Ill*, «The New Criterion», 4:1 (January 1926), pp. 32-33.

¹³ N. Gardini, *Postfazione*, in V. Woolf, *Sulla malattia*, ed. N. Gardini, Turin, Bollati Boringhieri, 2018, p. 64.

vinced that it has the exclusive right to do so. [...] Indeed man is not only a biological creature»¹⁴. This is an existence afflicted with the presence of an *unexpected guest*, one which is not benign (to paraphrase the thought of Umberto Galimberti), one which corrodes and transforms our perception of and relationship to reality, giving rise to a series of contrasting emotions and thoughts connected to pain and death. From Virginia Woolf to Freud, from Michel Foucault to Kristeva, writers have provided important reflections on the cellular and emotional degeneration of our bodies. They describe a process which confounds the relationship of familiarity that each of us has with his or her existence; at the same time, this process develops new abilities and sharpens sensibilities, allowing unexpected thoughts and emotions to reach the consciousness. Each existence characterized by illness tells a different story: it is our shared responsibility to know how to recognize and appreciate the intensity of these narrations, such that we are able to identify their *essential* points, from which potential healing strategies can be set in motion.

New fields of research dedicated to *narrative medicine* are making their appearance with increasing frequency. These areas aim to develop the «competence to recognize, absorb, interpret, and be moved by the stories of illness»¹⁵ in order to react to them appropriately. The narration of illness is important because it forces us *to adopt the point of view of the ill person*; it takes us into another dimension which no longer adheres to the dynamics of health and pleasure but rather transforms fear into a constant and pervasive feeling¹⁶. Within the feminine world, all of these points take on an even broader – and to some extent exceptional – array of features: because women have always fought against atavistic prejudices linked to inferiority, subjection and the incapacity to act and think independently, in illness they are forced to experience yet another of many defeats¹⁷. When ill, their bodies are further violated by mutilations which are at times inevitable, while their minds do not sufficiently react to pressures brought about by suffering (physical, psychological and social). Their *being-in-the-world* comes under heavy attack as a result of a persistent feeling of inadequacy – the pernicious legacy of a society dominated by male cultural models.

Through narration, whether written or oral, many women are able to give their feelings and emotions a physical presence: by acknowledging the force of words and by choosing their arrangement, they embark on a process of reconstructing themselves in a way that is both curative and thaumaturgic (at least in part). Narration contains an intentional dimension which is not only phenomenological but also extremely pragmatic; in narration are traced all the paths of the new feminine identity in *trans*-formation. Many are the examples of women who decide to recount their experience when faced with illness. Their aim is not only to leave a trace of what they have lived through, but also – perhaps – to look for someone who will listen to them and embrace their suffering without false pity or passive indulgence, someone who will instead give meaning to the moment of the encounter and the

¹⁴ T. Mann, *Dostoevskij, con misura*, in *Nobiltà dello spirito e altri saggi*, Milan, A. Mondadori, 1997, pp. 871-872 (author's translation).

¹⁵ R. Charon, *Narrative Medicine: Honoring the Stories of Illness*, Oxford University Press, 2006, p. vii.

¹⁶ See Ivi.

¹⁷ See S. Ulivieri (ed.), *Corpi violati. Condizionamenti educativi e violenze di genere*, Milan, Angeli, 2014; S. Ulivieri and R. Pace (eds.), *Il viaggio al femminile come itinerario di formazione identitaria*, Milan, Angeli, 2013.

exchange. Narration is an act of *healing* that requires multifarious forms of listening, given that it is made up of experiences and not abstract and empty gestures.

2. Narrating experiences in the discovery of feminine identity

In her essay on illness, Virginia Woolf states that «[w]e do not know our own souls, let alone the souls of others. Human beings do not go hand in hand the whole stretch of the way. There is a virgin forest, tangled, pathless, in each»¹⁸. This forest is an unknown place; it is a private space

– not public – and needs to be narrated to generate consciousness and awareness. Illness is one of those spaces: narration reconstructs the experience, not simply by putting events into chronological order but by shedding light on the relations of cause and effect which triggered its critical and tragic phase. To these are added the private thoughts of the patients: ill women reveal the sensations and sentiments connected to an empathetic process – necessary and extraordinary at the same time – in which the painful epiphenomenon definitively upsets their routines and the wellbeing of their bodies and minds.

Alda Merini wrote in her diary:

When I was admitted to a mental institution for the first time, I was in a certain sense still a child. Although I already had two daughters and some life experience, my soul was still simple and clean [...]. So I was a happy wife and mother, even if sometimes I showed signs of fatigue and my mind became sluggish. I tried to speak about these things to my husband, but he didn't seem to understand; and so my condition grew worse [...]. One day, exasperated by the all the hard work and continuous poverty and also – who knows – in the grip of the effects of the illness, I burst into a fit of anger. My husband couldn't think of anything better to do than call an ambulance, not foreseeing that they would take me to the mental hospital. But at that time the laws were explicit: in 1965 women were still subject to the will of men, who could make decisions for things that regarded their future. So I was admitted to the institution without realizing it [...]. Suddenly, all my relatives disappeared. In the evening, the bars of the ward were lowered, producing a hellish reaction in me. [...] I started kicking and screaming as loud as I could, with the result that I was tied down and bombarded with injections of tranquilizers¹⁹.

This passage captures a horrendous and painful life experience, a process of impossible healing, the inability to take care of the feminine world and of each woman before turning all attention to the diagnosed illness. The need to narrate in order to understand is made clear, to know and especially to build paths toward recovery and awareness, which are above all tools of knowledge and comprehension: «Narrative medicine – or medicine practiced with narrative competence – is [...] attuned to the individual patient, [...] generating and imparting medicine's knowledge, and cognizant of the responsibilities incurred by the public trust in medicine»²⁰. The accounts of women who live with illness are many: blogs, eBooks and social network pages tell important life stories of young girls and adult women who in the course of their lives have faced traumatic experiences connected to the onset of illness. Some speak of a body that is both *victim* and

¹⁸ V. Woolf, op. cit., p. 36.

¹⁹ A. Merini, *L'altra verità: diario di una diversa*, Milan, Bur-Rizzoli, 2000, p. 16.

²⁰ R. Charon, op. cit., p. 10.

oppressor – as we have already seen – and of the will to put back together and *repair* those material (and spiritual) fragments that for some time – or all of a sudden – have ceased to function. Through narration, many women are perhaps able to overcome the prejudice that an ill body is one that has nothing left to offer or tell; they may manage to deconstruct the fear of the unknown and accept the limits of experience, passing beyond that perceptual border that Freud called *taboo*, one which is imposed and constructed by the dominant society and culture.

As Simon Weil reminds us, without the sign of desire of the other, without cures able to recognize the subject in her irreplaceable particularity, without that grace of attention, human life is extinguished – it becomes ill and dies. [...] Human life is fueled by signs, and in this we can detect a great pedagogical lesson: true liberty in the face of illness does not consist in refusing the limitation, but in interpreting and accepting it²¹.

This process is no doubt complicated and difficult: it is anchored in that feeling of death which accompanies the ill in their daily lives and definitively compromises that intricate relationship between *logos* and *pathos*, leaving them disoriented and prey to a tragically *finite* view of their existence. In the same way that the mothers, wives and daughters of Troy grieve the end of their men and the death of their city – with incessant narrative rituality – so today women tell the stories of their illnesses with equal lucidity and emotion, bestowing humanity upon their profound anguish, which appears infinitely *inhuman*.

Fabiola De Clercq writes:

Several years ago I asked myself how I could lend a voice to this suffering, how I could amplify a desperate scream which was at the same time studiously suffocated behind an unpleasant mask of apparent invulnerability. It seemed easier and more direct to narrate fragments of my story. While writing I realized that analysis doesn't erase the memory of the wounds. It was easy to recall them; they were all close at hand, even if I had thought otherwise. I only had to tune back into those years to recover feelings, fears and emotions, to describe through writing a suffering that was terrible and dreadful in every sense²²

In the face of the neoplasms, chronic diseases, degenerative pathologies, mental illnesses and psychological disorders that severely and irreversibly afflict the world of women, what is needed is the development of therapeutic understanding, which indeed may well begin with narration and writing: those traces, those *scratchings* of the pen (to echo Jean-Paul Sartre), those voices can constitute the origin of a dense network of empathetic relationships, which are in fact of inestimable pedagogical value. Writing then becomes an act of *healing*, confession becomes *liberation*, in spite of the pain and anger, because they give expression to many unspoken doubts. By means of these techniques that recognize the Self who suffers, the patient can enter onto a path that recontextualizes the world and moves closer to life. Narration creates *sharing*: when the illness is shared, the pain, fear and shame are alleviated. As Rita Charon writes,

²¹ M. Recalcati, *I tabù del mondo*, Turin, Einaudi, 2018, p. 68.

²² De Clercq F., *Donne invisibili. L'anoressia, il dolore, la vita*, Milan, Bompiani, 2018, p. 6.

Medicine is itself a more narratively inflected enterprise than it realizes. Its practice is suffused with attention to life's temporal horizons, with the commitment to describe the singular, with the urge to uncover plot [...] and with an awareness of the intersubjective and ethical nature of healing. [...] As a living thing, narrative has many dimensions and powers. [...] [N]arrative does things for us, perhaps things that cannot be done otherwise²³

We can enter into contact with those existential disruptions, which for women are colored by infinite complexity in the wake of centuries of subjugation and humiliation, conditions which still today clearly persist in our own culture and beyond. Healing these afflicted women demands basic spiritual practices that rise from the metaphysical horizon and evolve into "noetic practices" aiming to construct a new identity, one that is more troubled but also stronger²⁴.

3. Words that heal: giving expression to the fear of the unknown

«Every woman responds to the crisis that breast cancer brings into her life, begining with the marks that plot the story of who she is and how she has lived her life»²⁵

Illness strikes at the woman's identity and at the general context in which she finds herself. The misery of the individual becomes a narration for all those who inhabit her world. By means of *words*, paths toward *healing*, *recovery* and *rebirth* are opened; they constitute an *ethical* approach which protects the woman – in her position *as subject/object of the cure* – from the casual character of improvised, unmotivated and useless treatments. Through the words of Alda Merini, we not only discover her illness but also move closer to her life, "uncovering" it such that we can make *choices*. We can either regard her narration as simple entertainment, or we can try to *feel* the pain she experiences, transforming words into *emotions that heal* – both the woman who writes and those who read her story²⁶. In the interesting volume edited by Cristina Malvi²⁷, a number of women narrate their experiences of confrontation with illness. These accounts contain stories of healing and desperation, of illusions and the bitter awareness of the inhumanity of fate; yet through all these *words* that arise from the profundity of their experiences, narration performs that noetic and pedagogical exercise necessary for better understanding themselves:

Narration as reflective practice, which generates awareness and creates that ontological connection between *logos* and *pathos*, which cannot be investigated in any other way. For Virginia Woolf, reflection on illness gives shape to *compassion*, which marks the *passage* between experienced and imagined life as well as the beginning of the progressive flowering of the blossoms of our existence. A patient of Rita Charon's confessed to her: «If only they knew. If only they knew how foreign I feel to myself. I am not myself. I

²³ R. Charon, op. cit., p. 39-40.

²⁴ L. Mortari, *Avere cura di sé*, Milan, B. Mondadori, 2009, p. 25.

²⁵ A. Lorde, *I diari del cancro*, in *Sorella Outsider. Gli scritti politici di Audre Lorde*, Il dito e la luna, Milan, 2014, p. 85.

²⁶ See F. Cambi; *La cura di sé come processo formativo*, Roma-Bari, Laterza, 2010; Id., *La forza delle emozioni: per la cura di sé*, Pisa, Pacini, 2015.

²⁷ See C. Malvi (ed.), *La realtà al congiuntivo. Storie di malattia narrate dai protagonisti*, Milan, Angeli, 2011.

have become a different person. I will never be the person I was»²⁸. This expresses the realization of a definitive change that is made explicit through intentional narration techniques, which are supported by as many thought processes.

Then, narration as a technique for uncovering inner darkness, so as not to create unrealistic expectations. In this case, narrative tension puts us face to face with a definitive and total transformation of the body and the mind. Another patient writes, «There's also the oncological question to deal with [...]. But I'm already facing that. In the meantime, I'm going to take a deep breath and get ready to get back into the world, to walk again on life's tightrope wire without a safety net»²⁹

Narration as a critical *re-thinking* of our *being-in-the-world*, the ability, that is, to connect our thoughts with the pragmatic side of human existence.

Narration as the telling of *emotions*, those vulnerable areas of our mind and existence which at the same time represent elements of *healing* through which we are able to build new paths of reconciliation between our minds and the space of our consciousness. Luigina Mortari maintains that «where there is life there is movement, vibration and bustle. If we activate the gaze of our minds, we discover that our interior space is never at rest, never empty or silent»³⁰. This is an emotional space in which our experiences coincide and intertwine and in which our affective lives take shape.

Narration is certainly a *vital force*, one that can deconstruct experience and identify possible strategies for recovery and rebirth, for ourselves and for others. «*Vital force* is the positive energy that is indispensable for the carrying out of every personal act»³¹ – especially during illness, a state in which each action of the ego is subjected to the anguish of suffering and the fear of death, which in turn trigger feelings of uncertain expectation and total anxiety.

Narration as *pedagogical practice*, both spiritual and worldly. This sense of the term is linked to pragmatism by Pierre Hadot, who following the teaching of Socrates recreates an idea of education which has its origins in the generative force of action and self-reflection. The *unexpected guest* does not introduce an imperceptible element into our lives – that semantic abstraction that we have already encountered – but rather a terrestrial movement that phenomenologically redefines all human dimensions. From a pedagogical point of view, narration means observing the events of our lives with an authentic gaze, recognizing in them the discordant moments that characterize change, the finitude of existence, and the need to struggle and react with lucidity and foresight.

Narrating illness becomes a pedagogical exercise that is perhaps necessary and inevitable, or at least very useful. Words leave traces and reveal the presence of a participatory community which supports the patient in the difficult experience of recovery and healing. Narration uncovers *taboos* and heightens the need felt by many women to sense that they are understood and acknowledged with regard to their inner anguish. The

²⁸ R. Charon, op. cit., p. 184.

²⁹ These are the words of a cancer patient taken from an Internet site dedicated to life stories of patients affected by neoplasms. There are a number of online sites on these themes, making it necessary to proceed with great caution in selecting documents only from the most authoritative and valid sources. From the blog *oltreilcancro.it*.

³⁰ L. Mortari, op. cit., p. 77.

³¹ Ivi, p. 142.

pedagogical impulse that accompanies the confessions and accounts of many sick and suffering women can become an important tool as they confront illness. This impulse lends substance to that sense of confused unease which poisons their existence, one which is increasing distressing but which contains a vital, fundamental objective – the incessant *search for meaning*.

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