

Illness as journey: narrative medicine in the patient quest

Alda Correia

UNL - CEAUL

Abstract: In her book *Illness as Metaphor* (1978) Susan Sontag writes that “everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place”. Illness is therefore a kind of travel into another space and kingdom and it can be felt as a frightening journey. The stages of the archetypal hero quest journey can be perceived in the patient evolution, namely their reflexive quality. Narrative medicine can enable the patient to take over the reins of this journey, to look at himself and re-evaluate every moment of existence, to reconsider the steps of the way in a relatively distanced and self analysing attitude. This paper will show how the patient evolution can be interpreted as a journey quest and how narrative medicine can support this purpose.

Keywords: illness, journey, patient

In *Illness as Metaphor* Susan Sontag (1978) writes that everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. Illness is therefore a kind of travelling into another space and kingdom and it can be felt as a frightening journey or as a way to go through a profound, vital, psychological experience, be it positive or negative. Literature has impersonated some of the most popular metaphors related with this notion. The myths

around tuberculosis are well-known, starting with Romanticism (Byrne 2011; Wilsey 2012). It was fashionable and attractive to have a pale and fragile appearance, illness was a way of being “interesting” and “singular” as a person. Novalis says in the *Aphorisms* (1798-1800) that “the idea of perfect health is interesting only from the scientific point of view. Sickness is necessary to individualization” (Novalis 1798). Tuberculosis was also associated with creativity as it was believed that illness amplified consciousness and sensitivity, opening to a superior control of the mind. Katherine Mansfield, for example, wrote in her diary: “A bad day. I felt ill in an obscure way – horrible pains and so on and weakness. I could do nothing. The weakness was not only physical. *I must heal myself* before I will be well. Yes, that is the important thing. (...) It is at the root of my not getting better. My mind is not *controlled*.” (Mansfield 1962). In other cases literature represents illness as a positive quest. In Tolstoy’s *The death of Ivan Ilytch* the suffering of the fatal illness finally brings a glimpse of light, a revelation to the protagonist about how his life should have been. In the hero’s last day of life his thoughts are described thus: “He sought his former and accustomed fear of death and did not find it. ‘Where is it? What death?’ There was no fear because there was no death. In place of death there was light” (Tolstoy, 1886: 52). This light can be paralleled to Virginia Woolf’s “tremendous spiritual change” (Woolf 1994: 317), “undiscovered countries” or “rise into the raptures of transcendentalism” attained by the body in illness. In a parodic tone she remembers, in “On being Ill”, that “lying recumbent, staring straight up” we discover many different shapes, a “gigantic cinema played perpetually” (*idem*: 321)¹. Illness brings time and concentration and it needs the imagination of a poet. According to her, turning to the reading of poets brings words and in illness words seem to possess a mystic quality (*idem*: 324). This privileged space for Woolf’s imagination, which would frequently nurture ideas for her subsequent novel writing, testifies to how experience, memory of events and human perceptions are organized in the form of narrative – stories, reasons, hesitations, beliefs; they are a version of reality whose acceptability is governed by convention and narrative necessity (Bruner 1991: 4). It is precisely narrative competence and ability that are recently being applied in the doctor/patient relation in the area of Narrative Medicine as part of the journey through

sickness and healing. What is, then, the role of narrative medicine practice in the patient quest and in the construction of journey narratives if we consider that illness tends to be faced as a journey towards a balanced healthy condition?

The writing of narratives by patients enables them to endure their suffering better as they try to understand it, to redraw a map of their life and find another destination for their journey, and doctors' writing about patients and themselves brings them more knowledge about their patients and changes their relationship with them (Charon 2001; Frank 1995). Although Sontag plainly declares that illness is not a metaphor, on the contrary, it may be a trap that deforms the patient's experience (Sontag 2009: 109), narrative medicine theorists argue that the selection of metaphors and symbols and the empathic connection (empathy, genuineness and unconditional positive regard) are essential to the medical practice and the healing, together with (but not instead of) detachment, objectivity and evidence (Coulehan 2003). Here we are not dealing with intentional literary representations of sickness but with the creation and co-creation (with doctors and nurses) of self stories, a search for meaning through a metaphoric and sometimes aesthetic process (Gaydos 2005).

Narrative Medicine is medicine practised with "the narrative competency to recognize, interpret, and be moved to action by the predicament of others" (Charon 2001: 83). Its practice and intellectual stance enables physicians to look beyond the biological mechanisms at the centre of conventional approaches to medical practice, towards domains of thought and ways of telling that focus on language and representation, on the emotions and relationships which illuminate health care practice. This implies representation, an interpretation with shape, tone and emphasis, which comprehends temporal change, character development, personality, predicament and the layers of feelings, thoughts and suffering (Hurwitz, 2006). Narratives of illness provide a framework for approaching a patient's problem globally, an interpretation that may uncover diagnostic and therapeutic options (cf. *Anatomy of Illness*); they offer a method of addressing existential qualities such as despair, hope, grief or moral pain; they encourage empathy and understanding between the patient and his/her doctor; they construct meaning or allow for his/her search; they

may be therapeutic and palliative; they may suggest other therapeutic options; they may generate new hypotheses for the patient (Greenhalgh/Hurwitz 1999).

In all literatures the journey is a symbol of adventure and quest, a search for truth, peace and immortality. When the sick person gains awareness of his/her illness he/she is more acutely in presence of mortality. This experience of the limits demands heroic strength to be overcome; it is in a way a search for truth and peace but also a way of knowing (as happens to Oedipus) how the patient rose to the occasion, responded to it. The healing process begins when patients tell of symptoms or even fears of illness, first to themselves, then to loved ones and finally to health professionals (Charon 2006: 65). The role of narrative medicine is first to “honour”, that is, to validate the patient’s experience, also bringing reflexion and creativity to the doctor; to achieve this goal a “close listening” and then “reflective writing” are necessary (Charon 2006). Rita Charon reports the case of one of her patients, a 51-year-old man who, complaining from abdominal pain, was clinically depressed after the long recovery from a sports injury. He had decided he had pancreatic cancer and was prepared to die. After a simple treatment of his intestine and talking to the doctor about his feelings she recognized the depth he had travelled within himself. Recognizing his feelings as passive suicidality he was encouraged to re-enter analytic treatment and started to change the direction of his attitude to life (Charon 2006: 85). This case reveals the intimate relationship between our bodies and our selves and a two way journey lived by the patient.

In the quest narrative, to be differentiated by Arthur Frank from the restitution narrative² that renders illness transitory and from the chaos narrative³ where the suffering is too great for the self to be told, the ill person gradually realizes a sense of purpose. Suffering is met head on, the patient accepts illness and tries to use it on a journey that becomes a quest. The idea of journey and of the challenge to find out where one is being taken, emerges and the writing can, according to Frank, assume different forms: “memoir”, “manifesto” or “automythology” (Frank 1995). The memoir includes events of the writer’s life and the illness story; although events are not told chronologically, the memoir is very close to the autobiography⁴. In manifesto stories writers try to draw attention to the social

suppression of truth about suffering; they want to assume suffering and handicaps to move others and themselves forward⁵. In the automythology narrative authors/patients have to reinvent themselves, to reconstruct life from new individual patterns, to find a personal myth that works and this is an individual exploration. As to doctors narratives there are at least five distinct genres of narrative writing in medicine: medical fiction, the lay exposition, medical autobiography, stories from practice and writing exercises of medical training (Charon 2001) Charon states that the more she wrote stories about patients who troubled or baffled her, the more confident she became that this act gave her access to knowledge about the patient and herself. She would not have had access to this knowledge otherwise. Then she showed the patients what she had written about them. And this process went on,⁶ reaching what she calls a therapeutic disclosure. It could also be seen as a journey through writing for the doctor.

I would like briefly to give as examples two narratives used as a journey or quest: one from the point of view of the patient, *Anatomy of an Illness – as perceived by the patient – reflections on healing and regeneration*, by Norman Cousins (1979) and another from the point of view of the doctor, “Lessons about patient deception” by Dwight Davis (Charon *et al.* 1996).

Anatomy of an Illness was published for the first time in December 1976 in the *New England Journal of Medicine* (nr. 295.26)⁷. It is the story of the fight of the author against a crippling disease diagnosed in 1964 – *ankylosing spondylitis* in which the connective tissue in the spine gradually disintegrates. The patient has a general feeling of achiness, difficulty moving neck, arms, legs, sedimentation rate over 80 and then 115 and goes into critical condition. The chances of recovery were very remote and the specialist stated that he had not witnessed a single recovery from this condition. The book published in 1979 goes beyond this. After the description of his convalescence, the author develops five more chapters to show the role of the mind and the development of a holistic medical attitude in healing and longevity, presenting medical evidence and the effects on the medical community of his cure experience. The first chapter is therefore a journey within a wider one – at first Cousins is put before the possibility of paralysis and then he decides to

involve himself in his own recovery. In this chapter he explains how he discarded aspirin and decided to use vitamin C to combat inflammation, in doses not yet studied by science, and how he conceived a programme to develop affirmative emotions to enhance body chemistry, in which films and reading that provoked belly laughter were used. With the support of his friend and physician who stood by him from the beginning Cousins recovered almost completely. The second and third chapters deal with the importance of the placebo and with creativity and longevity in the Pablo Casals and Albert Schweitzer life stories. The placebo is considered proof that there is no real separation between mind and body. Cousins refers to medical studies on its use and raises the problem of telling the truth to the patient: when is a physician justified in not being completely candid with the patient? The placebo is an emissary between the will to live and the body, a kind of doctor who resides within the patient (Cousins, 1979: 27; 29; 30). This is a central problem in terminally ill patients as illustrated in my second example, where the doctor feels guilty for deceiving the patient. Bioethics is called into question. To Rita Charon narrative competence may change what the ethicist does with patients, families, with health care professionals and with the self. From the point of view of a quest narrative, the discussion of placebo use is important, as it connects our imaginary and physical capacities, and this can be done through narrating processes, reading and writing. Cousin's fourth chapter is about pain and its role as "the warning system and protective mechanism that enables the individual to defend the integrity of [his/her] body" (Cousins 1979: 48). Its signals help the individual to mobilize its response. In the last chapter, titled "What I learned from three thousand doctors", Cousins illustrates many of the questions faced by doctors and patients in narrative medicine: the reactions of the medical community, the conflicts of a doctor with cancer between medical and philosophical convictions, the barrier of silence between doctors and patients who need to talk and/or write about things such as the feeling of helplessness in a serious disease, the subconscious fear of never being able to function normally again, the reluctance to be thought a complainer, the conflict between the terror of loneliness and the desire to be left alone, the desire not to add to the already great burden of apprehension felt by one's family, the power of the mind in overcoming disease (Cousins 1979: 69 and 71). He

concludes this journey by narrating the meeting he had on the tenth anniversary of the onset of his illness with one of the specialists who had made the diagnosis of progressive paralysis, whom he reminded that doctors should be careful about what they said to others; they might be believed and that might be the beginning of the end. This is a very clear example of automythology created by the patient in which he was driven to read a great deal of specialized literature creating the automythology of his own recovery, showing how anyone can step beyond his/her limits, bringing with his cure the concepts of perfectibility, regeneration and freedom. Humour also plays a very important role in the cure. But things can develop the other way round.

The second example - "Lessons about patient deception" by Dwight Davis (Charon *et al.*, 1996) - is an essay/story written by a practising physician about his patient and the contribution of reading *The Death of Ivan Ilych* by Leo Tolstói to the clinical clarity of the case. Davis had been caring for Mrs R. L. several months before reading the novel; the patient had been transferred to the hospital with "severely compromised heart function and refractory myocardial ischemia for consideration of cardiac transplantation. She had other significant medical problems, including insulin dependent diabetes mellitus, long-standing hypertension, moderate obesity, chronic obstructive pulmonary disease and significant peripheral vascular disease". She was, however quite active at home and with her grandchildren (Charon *et al.* 1996). The patient, the family and the doctor decided to attempt a high risk procedure to open one of the blocked coronary arteries. But she developed a systemic infection and in ten days her condition deteriorated. The family felt that the patient would not be able psychologically to handle knowing the severity of her illness. It was obvious that she would not survive hospitalization but the family insisted on developing a ritual meeting before meeting with the patient. With her, they sustained a lie. Her final days, writes Davis, were much like Ivan's. The death of Mrs. R.L. had a devastating effect on the author because he felt guilt for participating in deceiving a patient. Reading Tolstói's novel provided him with a heightened sense of empathy, a need to reassess the handling of communication with the critically ill, trying to provide honest responses to the question posed by Ivan Ilych: how serious is my illness? It also changed the procedures of

the heart failure service team in the hospital. Both cases show that illness tends to be faced as a journey towards a balanced (homeostatic/regulated) healthy condition, one that results from our genetic programme to survive.

To conclude I would say that Narrative Medicine can play a central role, first of all in the journey from life to death; then, in a more specific sense, in the quest of life journey of every individual and also in moving a literary space into actual action in a patient's life. This dislocation from text to life is acknowledged by Ricoeur's (1983) three movements of mimesis: mimesis 1 refers to the "pre understanding" of human action with which one beholds the world, mimesis 2 refers to the act of composition itself, mimesis 3 refers to the consequences, for the reader, of receiving what another composes. For him, the understanding of narratives and symbolic expressions is not only a task of exegesis, it is an essential stage in every person's trajectory or journey through life, in search of the comprehension of him/herself. This implies the connection of the semantic approach with the reflexive approach. If humans understand the world and understand themselves through narratives, in narrative medicine the hermeneutics of the text is connected with a hermeneutics of life and survival. Reading may distance the subject from him/herself, opening him/her to the other through the text, because this projects a world and a different form of being in the world. Medicine, like literature, deals with temporality, singularity, causality/contingency, inter subjectivity, ethicality, coda, attention and representation. To start the journey with their patients doctors have (as in old travel journals in which the experiences of an author were evoked and described, trying to instruct) to gather information, keep medical records, make therapeutic decisions and be able to use narrative to tread a path that opens doors for the patient and bears witness for the community. The quest narrative can become the cornerstone of Narrative Medicine; it implies the reactivation of the past through memories, it gives testimony and is looked upon as an inspirational example.

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NOTES

¹ “On being Ill”: “The first impression of that extraordinary spectacle is strangely overcoming. Ordinarily to look at the sky for any length of time is impossible. Pedestrians would be impeded and disconcerted by a public sky-gazer. What snatches we get of it are mutilated by chimneys and churches, serve as background for man, signify wet weather or fine, daub windows gold, and, filling in the branches, complete the pathos of dishevelled autumnal plane trees in London squares. Now, become as the leaf or the daisy, lying recumbent, staring straight up, the sky is discovered to be something so different from this that really it is a little shocking. This then has been going on all the time without your knowing it! – this incessant making up of shapes and casting them down, this buffeting of clouds together, and drawing vast trains of ships and wagons from North to South, this incessant ringing up and down of curtains of light and shade (...) But watch a little longer and another emotion drowns the stirrings of civic ardour” (Woolf, 1994: 321).

² Frank points out that the plot of the restitution narrative has the basic storyline: “Yesterday I was healthy, today I’m sick but tomorrow I’ll be healthy again” and that restitution stories can be told prospectively, retrospectively and institutionally; in this case people may learn the narrative from institutional stories that model how illness is to be told. He gives the example of an American hospital brochure which included the restitution stories of three cancer patients. He also considers restitution narratives of popular culture. According to him the purpose that restitution narratives aim toward is twofold. For the individual teller, the ending is a return to just before the beginning: “good as new” or status quo ante. For the culture that prefers restitution stories, this narrative affirms that breakdowns can be fixed (Frank, 1995: 77-90).

³ “The teller of chaos stories is, pre-eminently, the wounded storyteller, but those who are truly *living* the chaos cannot tell in words. To turn the chaos into a verbal story is to have some reflective gasp of it. The chaos that can be told in story is already taking place at a distance and is being reflected on retrospectively. For a person to gain such a reflective gasp of her own life, distance is a prerequisite. In telling the events of one’s life, events are mediated by the telling. But in the lived chaos there is no mediation, only immediacy. The body is imprisoned in the frustrated needs of the moment. The person living the chaos story has no distance from her life and no reflective grasp on it. Lived chaos makes reflection, and consequently storytelling, impossible. (...) Although I will continue to write of chaos stories as being told, these stories cannot literally be told but can only be lived. Yet if the chaotic story cannot be told, the voice of chaos can be identified and a story reconstructed” (Frank, 1995:98-99).

⁴ “The memoir is the gentlest style of quest story. Trials are not minimized, but they are told stoically, without flourish. No special insight is claimed at the end; the insight is rather the incorporation (...) of illness into the writer’s life” (Frank, 1995: 120)

⁵ A good example is Audre Lorde, *Los diarios del cáncer*, transl. Gabriela Adelstein, Hipolita Ed, 2008 (1980). She protests, in this book, against the pressure for mastectomized women to wear a prosthesis; Lorde defends her own right to define and claim her own body, not to conceal difference and mortality. She says: “No quiero que mi ira y dolor y miedo sobre ele câncer se fosilicen en outro silencio más, ni me roben la fortaleza que puede haber en el centro de esta experiencia, abiertamente reconocida y examinada. Para otras mujeres de cualquier edad, color e identidad sexual, que reconocen que el silencio impuesto sobre cualquier área de nuestras vidas es una herramienta para la separación y la falta de poder, y para mí misma, he tratado de expresar algunos de mis sentimientos y pensamientos sobre el engaño de las prótesis, el dolor de la amputación, la función del câncer en una economía de lucro, mi confrontación con la mortalidad, la fuerza del amor de las mujeres, y el poder y las recompensas de una vida consciente (Lorde, 2008:1).

⁶ Charon explains: “On the next visit with that patient, I would invite her to read what I had written and would ask wether I had gotten her story right. I would do this several times so that each visit resulted in a ‘chapter’ about the patient’s life. In two early efforts the patients read what I had written and then said, in effect, ‘We left something out.’ These two patients then told me about episodes of abuse (...) that in their minds were related to their current clinical situations” (Charon, 2001: 84).

⁷ At the beginning of the article the author states: I have not written until now about my illness, which occurred in 1964, largely because I was fearful of creating false hopes in other persons similarly afflicted.