

The Patient's Voice in Psychoanalysis, Narrative Medicine and Patient-based Research

— *What is the clinical impact of patient-based research?* —

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Abstract: The patient's voice is increasingly present in various contexts. I focus on two clinical contexts, *psychoanalysis* and *narrative medicine*, and consider the clinical impact of speaking and being listened to in the epistemic context of *patient-based research*. I first consider the relation between epistemic and clinical values within clinical contexts and show that *words are not healing in virtue of their epistemic value*, neither in psychoanalysis, nor in narrative medicine. I then underline that, in different ways in psychoanalysis and narrative medicine, the healing power of words is tied to the recognition of the speaker as the owner of his own voice. Listening *singularly* to the subject, however, conflicts with academic research, as the latter imposes to make the patient's experience fit in the *standardized* format appropriate for the generation of data, and requires the *anonymity* of the patient participating to research. Over and above these tensions between clinical and epistemic contexts, the use of narratives both in medicine and patient-based research have in common to rely on an ethic of mastery, aiming at domesticating meaningless illness with meaningful words. Even though such process may be psychologically gratifying, it relies on an illusion masking the patient's vulnerability, inherent to his sufferance, and pressures him to neglect aspects of his experiences which cannot be narrated: in narrative contexts, meaninglessness remains unheard. These difficulties are inherent to narrative approaches, both in clinical and epistemic contexts, but may not occur in psychoanalysis. I conclude by underlining that, in healing or harming ways, addressing oneself to another is a transformative experience insofar as it involves speaking and being listened to as a singular subject. This is the case not only in clinical but also in epistemic contexts. Therefore, *patient-based research is not and never clinically inert: the patient-based researcher should always be clinically responsible*.

Key words: clinical ethics, patient's singularity, anonymity, normativity, sufferance

1. The patient's voice in clinical and epistemic contexts

Today, the narrative approach is growingly influential in medicine. Howard Brody offers a particularly vivid way of describing this approach: "The physician who takes stories seriously will, in any case where there is any mystery about the patient's reason for seeking help, adopt as a working hypothesis that the patient is asking a question like the following: "Something is happening to me that seems abnormal, and either I cannot think of a story that will explain it, or the only story I can think of is very frightening. Can you help me to tell a better story, one that will cause me less distress, about this experience?" If this formulation seems overly wordy, a shorter form of the patient's possible plea to the physician might be, "My story is broken; can you help me fix it?" (1994: 85). This can't help reminding us that, back at the end of the XIX^e century, the birth of psychoanalysis initiated a radical transformation of the stance the medical doctor takes

upon his patient, by involving, as its main act, listening to the patient's words. Are we going through that history again? Interestingly, psychoanalysis and narrative medicine hardly mention each other. This may seem surprising since these two approaches share an obvious common point: both believe that "the word can be a powerful instrument of healing. [Words] have the power to relieve illness and reduce suffering when they are employed in an appropriate healing context" (Coulehan 1991: 111). Let me repeat and underline: it is when it is "*employed in an appropriate healing context*" that the patient's voice may have the power to relieve suffering. This may explain why psychoanalysis and narrative medicine tend to ignore – or discredit – each other: they don't share the same conception of what "an appropriate healing context" amounts to. I will return to this issue below. But first, let me insist on the very idea of *contextuality*: the impact of narrating one's story or free-associating words is dependent upon the context of enunciation.

Keeping the idea of contextuality in mind, we can observe an increased presence of the patient's voice in seemingly non-clinical contexts, and in particular in the epistemic context of academic research. This is particularly the case in *patient-based research*, i.e. research relying on patients' reports to generate data about the condition these patients suffer from, while avoiding generating any aggravation of these patients' suffering. The development of this approach is epitomized by the development of Tojisha Kenkyu in Japan (Ishihara 2013; Kamagaya & Ayaya 2013), a form of patient-based approach which (radically) blurs the boundary between epistemic and clinical contexts. In this approach, the patient is not an academic researcher¹ but, together with academic researchers, he takes his own condition as an object of investigation. Two aims at once are targeted: knowing better the condition the patient suffers from, notably by relying on his narratives, and *by doing so*, alleviating the patient's suffering, notably by giving an audience to the patient's voice, thereby inserting the patient into a community of fellow-sufferers and into the society². Such insertion of the patient as an actor of research, alongside academic partners, is a special case of a more common practice which involves the patient as an "informant", a practice which is at stake anytime patient and researcher both acknowledge that "in regards to the experience of pain and illness, the patient rather than the physician is the expert" (Garden 2007). In such cases, unlike in Tojisha Kenkyu, neither the patient nor the academic researcher aim at any therapeutic outcome – they don't aim at alleviating the patient's suffering – but they nonetheless have clinical concerns – provided that they aim at avoiding any aggravation of the patient's condition by his participation to the research.

In this sense, *any patient-based research is clinical since it is concerned by the impact on the patient himself of the very fact that his voice is "given to science"*. The question thus surfaces: *What is the clinical impact of patient-based research?*

2. Are words healing in virtue of their epistemic value?

The first issue to be considered here is the relation between epistemic and clinical values within clinical contexts themselves. As both psychoanalysis and narrative medicine rely on the "healing power" of words, *in these clinical contexts, are words healing in virtue of their epistemic value?*

2.1. Historical truth in psychoanalysis

In psychoanalysis, it is believed that symptoms manifest conflicts or events which have been repressed from conscious experience, and which can thus be manifested only in symptomatic forms. Thus, if psychoanalysis aims at alleviating the symptoms a patient suffers from, it aims at doing so by alleviating the repression of conflicts and events which the symptoms manifest. To achieve this aim, the task of the patient is to "remember something that has been experienced by him and repressed" (Freud 1937). Meanwhile, the task of the analyst is "to *construct*" what has been forgotten by the patient "from the traces which it has left behind" (*Ibid.*). This "construction

is only effective because it recovers a fragment of lost experience" (*Ibid.*: 5059). The analysis gains its therapeutic efficiency from the recovery of what Freud names here an element of "historical truth" (*Ibid.*: 5053–58–59), i.e. an element which is *truly* part of the *history* of the patient. What manifests the truth of the analyst's constructions is precisely their therapeutic efficacy: it is only an element of historical truth which can have been repressed from the patient's consciousness, which can in turn manifest itself in the presence of dreams, neurotic symptoms, psychotic delusions, and which can likewise manifest itself in the therapeutic effect of the patient's recollection or the analyst's construction of it.

A subversion of the notion of truth is operated here. Indeed, whether what is historically true has been factually true or not, neither the analyst nor the patient may ever be in a position to verify it. But acquiescing to one's past experiences as historically true is alleviating the repression that had been imposed on them, thereby alleviating their presence in symptomatic manifestations which resulted from such repression. Analysis thus consists in "liberating the fragment of historical truth from its distortions and its attachments to the actual present day and in leading it back to the point in the past to which it belongs". Or in Lacan's terms: the patient "relates in the present the origins of her person" (2002: 212) and while such recollection may be "made up of lies", it nonetheless presents us "with the birth of truth in speech"; the "assumption by the subject of his history, insofar as it is constituted by speech addressed to another, is clearly the basis of the new method Freud called psychoanalysis [...]" (*Ibid.*: 213).

We see here that speech as it occurs in psychoanalysis is a process aiming at the recollection of, the consent to and the distancing from who one is always already. By contrast, narrative medicine conceives of narration as a process of self-making whereby one unceasingly aims at becoming who one is never yet. It is this point which I will now unfold.

2.2. The teller illusion in narrative medicine

In narrative medicine, the clinical effect of what lacks epistemic value is accepted and even defended: "The truth of stories is not only what *was* experienced, but equally what *becomes* experience in the telling and its reception" (Frank 1995: 22). It is because what the stories tell is not true before the stories are told that the very act of telling them can make their content become true, and it is such process that gives these stories their transformative effect, i.e. what grants them a clinical impact. However, it is also precisely what prevents such stories to describe the teller's experiences as if these experiences pre-existed the act of reporting them, i.e. it is also what deprives them of epistemic value. The transformative effect of narratives comes from the fact that they don't report experiences truthfully but rather creates them as true: "The self-story is not told for the sake of description, though description may be its ostensible content. The self is being formed in what is told" (*Ibid.*: 55). In this sense, narratives are performative. Just like someone saying "I promise" performs the very act one utters, someone saying "I am" performs one's identity in the very act of narrating it. Just like "I promise", "I am" is not a proposition describing anything truthfully but is an act which one cannot utter without performing it.

In narrative approaches, therefore, what is aimed at is not the knowledge of what there is but the construction of what ought to be, not the description of who one is, but the making of who one ought to be. Therefore, in illness narratives, what matters is not the meaning of the illness *per se*, nor the meaning which the symptoms can acquire after being interpreted by experts, but the "meanings that people attach to symptoms" (Coulehan 1991: 111), "the way the patient has tried to organize, and hence to make sense of, the various manifestations of disease within the context of his own life" (Brody 1994: 80).

A divorce between epistemology and therapy is also advocated by Paul John Eakin for who narrating is "an art of self-invention in order to create a space in which the self can live and move in response to its own volition" (1992: 71). But for him, the "belief in the possibility of self-determination" is one of the "sustaining myths of autobiography" (*Ibid.*). It is not autonomy but an

“illusion of autonomy” (*Ibid.*) which self-narration produces. The expression of oneself in autobiographical narrative “generate[s] the illusion of a teller”: “When we talk about ourselves, and even more when we fashion an I-character in an autobiography, we give a degree of permanence and narrative solidity—or “body,” we might say—to otherwise evanescent states of identity feeling” (Eakin 2004: 129). What needs emphasis is that Eakin maintains that the reification of the self is a positive outcome of self-narration: “We get the satisfaction of seeming to see ourselves see, of seeming to see our selves. That is the psychological gratification of autobiography’s reflexivity, of its illusive teller-effect” (*Ibid.*). Thus, narratives are false but good. If narratives are therapeutically effective, it is not despite but thanks to their lack of epistemic value; rather than reporting the truth about oneself, they valorize a gratifying illusion.

3. Who’s voice?

As we saw up to here, there are different ways of conceiving of the epistemic value of healing words: In narrative approaches, self-making stories gain their therapeutic value from creating what becomes true of oneself in virtue of the performative power of narrative; in psychoanalysis, the “talking cure” operates within the realm of historical truth which is constructed for the sake of its therapeutic efficiency. Each in its own way, both clinical practices here depart from the epistemic context of academic research where what is targeted is reliable knowledge about the condition the patient suffers from. In this sense, we could thus say that clinical practices are not epistemic. But are epistemic practices clinically inert? This is the question that will now be considered.

3.1. One’s own voice vs. the burden to fit into an academic format

It is widely acknowledged that narratives are “performed not in some wholly private, fictive realm of the isolate self but rather in strenuous engagement with the pressures that life in culture entails” (Eakin 1992: 71). We find here again the notion of contextuality introduced above, i.e. the idea that the impact of narratives on the narrator is contingent upon the narrative context. The narrative context impacts the interpretation of narratives, since meaning does not emerge by the discovery of a truth that would be inherent in the narrative, but “by the process of interaction between reader (or auditor) and text (or speaker)” (King 1992: 191; see also Charon 2001: 1898); the narrative context also impacts the very “shape of the telling [that] is molded by all the rhetorical expectations that the storyteller has been internalizing” (Frank 1995: 3); most importantly, the narrative context also impacts the lived experiences these narratives report. Indeed, if narratives perform the identity of their protagonist (Frank 2002; Eakin 2004), and if such self-making performances are contextually constrained, then necessarily the identity they perform is too. Arthur Frank exemplifies this idea strikingly. As he publishes the narratives of other patients, he considers that his “most provocative, and often troubling, editorial task has been requesting revisions to people’s stories” (Frank 1995, 23). He indeed recognizes that “in asking authors to revise their stories, [he] may be asking them to revise their experiences” (*Ibid.*): “The truth of experience is malleable” (*Ibid.*) and this has consequences not only in the epistemic but also in the clinical domain: the modification of the context in which narratives are performed can hardly be inert clinically. As the patient cannot avoid shaping his story to make it fit into the format that is thought to be appropriate in the context of its enunciation, he may or may not retain ownership over what he reports, he may or may not retain ownership over what he experiences. This may go as far as not recognizing one’s own voice as one’s own as it utters one’s own narrative. As reported by Frank, when he had to repeat his own illness story, he felt that “a voice outside of me was talking, and I was listening to that voice. I was not speaking of how I felt; I was addressing the interests of particular listeners in rhetoric appropriate to our relationships” (*Ibid.*: 71).

As a consequence of these considerations, as far as the applicability of illness narratives to the epistemic context of patient-based research is concerned, we are led to adopt “a critical

approach that acknowledges [not only] the formal and social conventions that shape illness and disability narratives [but also] the effect these scripted narratives can have on the lived experience of illness and disability” (Garden 2010: 122). When participating to patient-based research, not only should the patient make his experience fit into a narrative format for the sake of ameliorating the therapeutic efficacy of his encounter with his clinician, but also the patient should make his experience fit into the narrative format relevant for the transmission of information required to increase knowledge in the academic context. Should the patients be confronted to that, and in which aim; “who benefits?” (Garden 2010: 130).

3.2. One's own voice vs. anonymity in patient-based research

As we just saw, the performance of narratives as an act thanks to which the patient reclaims his own voice may be jeopardized in the epistemic context of academic research, as the latter imposes upon the patient a burden to fit into a narrative format which is standardized enough to allow the increase and sharability of reliable knowledge. Now, in addition, what needs to be pointed out is another tension between clinical and epistemic contexts of utterance of the patient's voice, namely, the tension between the clinical impact and potential therapeutic value of reclaiming one's own voice as one's own, on the one hand, and the effacement of the patient's singularity on the other hand. This is the point I consider now.

Whereas some narrative approaches, and Tojisha Kenkyu in particular, emphasize the act of talking over and above the fact of being listened to, the insertion of narratives in the context of academic research does involve an academic researcher, who is not the patient himself, and who listens to the patient's narratives, interprets them in his theoretical framework, gives generalizable meaning to them, etc. Using the patient's narratives as data is required to perform patient-based research, and this necessarily involves the act of listening. More than in academic research, such act of listening has been taken into serious consideration both in narrative medicine and in psychoanalysis.

Narrative medicine is first and foremost defined as “medicine practiced with narrative competence” (Charon 2001: 1897). That is, aside approaches focusing on the narration of the patient himself, narrative medicine cultivates the act of listening and emphasizes the narrative competence of the medical doctor. Rita Charon summarizes this competence as involving “the ability to acknowledge, absorb, interpret, and act on the stories and plights of others” (*Ibid.*), the aim being to achieve a position that is “relaxed, absorbing, accepting, oceanic, filling” (Charon 2008: 23). Empathy is a key ingredient here. As Macnaughton underlines, “the “practice of empathy” has become an icon of the growing medical humanities movement in the USA and the UK. US physicians have even gone so far as to adopt empathy as one of the accredited “skills” required by the American Council for Graduate Education” (2009: 190)³.

Contrastively, the act of listening in psychoanalysis is not tied to empathy but to unconditional hospitality (Derrida 2000; Dufourmantelle 2009; Habib 2012)⁴. This is related to a fundamental rule: the patient is meant to talk and the clinician is meant to listen – without filtering what may seem more or less relevant. As it applies to the clinician, this practice enforces a stance where the patient is listened to unconditionally, as a subject owing his own voice whatever he says, beyond or below any transmission of what could be a relevant piece of information (Lacan 2002: 214). The analytic act of listening is an act of hospitality which the clinician gives unconditionally to the patients' speech, thereby designating him specifically as a subject, exposing himself as a “subjectivity that speaks” (Levinas 1979: 182).

In different ways, therefore, both narrative medicine and psychoanalysis insist on the act of listening to the singular voice of the sufferer. What ought to be underlined is that the act of listening to a speaker *in his singularity* is an act which gives him a singular name. To ask “what's your name?” is not a precondition to listen to the speaker; rather, listening to *you* is already in and of itself a recognition that you, not someone, but *you* are here, you speak to me singularly, and

thus you have a name. As it implicitly conveys the question “what’s your name?”, listening to a voice as the speech of someone-who-holds-a-name is a minimal, maybe the most minimal act which singularizes the subject in its very subjectivity.

Now, such act of listening hardly fits into academic research. Indeed, to ensure that patient-based research is clinically sound, ethical committees impose a basic rule: anonymity. The researcher is required to efface the patient’s name from his data and their publication, in the aim of protecting his privacy. However, covering the patient’s name with anonymity renders impossible to relate the patient’s voice to his own singularity. The anonymized patient is no one in particular. What is of relevance is not *his* story of *his* sufferance but what his report can teach the researchers about the condition he suffers from. The appropriation of the patient’s voice in the field of academic research thus evolves in a disease-based perspective. As they break privacy, researchers attempt to repair it thanks to anonymity but this practice of academic research is diametrically opposite to the event of singularly listening/being-listened-to that occurs in the encounter with a clinician.

4. What is the clinical impact of narration?

4.1. Narration as mastering the unknown

As identified in the previous sections, there are several points of incompatibility between clinical and epistemic contexts in which the patient may give voice to his sufferance. Nonetheless, as underlined in the beginning, the patient’s voice, and in particular patient’s *narratives* are increasingly present in academic research. Better understanding the clinical impact that this may have also involves better understanding the clinical impact of narratives in general. To start considering this issue, I will now underline what narrative medicine (vs. psychoanalysis) *shares* with academic research.

Narrative medicine relies on the idea that the experiences of illness ought to be mastered into self-understanding: “as a general rule, patients will be more inclined to get better when they [...] are helped to achieve a sense of mastery or control over their illness and its symptoms” (Brody 1994: 83). In turn, it is believed that mastery and control come together with sense making: illness and sufferance ought to be “rescued from formlessness” by narratives (Charon 2008: 26). In this view, it is the performance of the narrative itself which is conceived of as an act of self-mastery, even if it describes one’s vulnerability. The storyteller, by its very act of storytelling, is performing a way of being ill where he refuses surrendering to the control of others upon his sufferance as well as to a total lack of control; a way or being ill where the patient refuses to be subjected to others’ interpretations as well as to meaninglessness; the storyteller is rather performing a way of being ill which is given a purpose (*Ibid.*: 117), the purpose of self-making. This view relies on an ethic of self-mastery which Frank proclaims in a radical way: “The moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one’s story is shaping one into, entailing the requirement to change that self-story if the wrong self is being shaped” (*Ibid.*: 158).

We see here that, despite the divorce it operates between epistemic and therapeutic values, the practice of narratives shares a fundamental perspective with academic research: the search for meaning, the domestication of the unknown. In this way, even if the narrative approach is not a standard form of academic research, it can nonetheless be conceived of as a form of self-research aiming at increasing (self-)knowledge, relying on the idea that such process has therapeutic values, as it reduces the anxiety of being the object of uncontrollable, unknowable, un-name-able, un-narrate-able sufferance. However, even though seeking the mastery of illness may provide a “psychological gratification”, it may rely on an illusion (Eakin 2004: 129). Indeed, as we shall now unfold, it belongs to the very nature of illness and sufferance to escape the patient’s mastery. This does not imply that narratives are clinically inert. On the contrary, it implies that narratives have

therapeutic effects precisely in virtue of the transformation of meaningless events into meaningful stories. The clinical impact of such illusory process, common to narrative medicine (vs. psychoanalysis) and academic research, ought to be examined more in details.

4.2. The burden to narrate meaningful stories about meaningless suffering

Notoriously, Susan Sontag criticized – what was not yet named – the narrative approach as it operates a metaphorization of illness. “Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. [...] The disease itself becomes a metaphor” (1978: 58) in an approach that “asserts that people [are] made singular, made more interesting, by their illnesses” (*Ibid.*: 31), “that people are made more conscious as they confront their deaths” (*Ibid.*: 30); that disease is “the occasion finally to behave well” (*Ibid.*: 42); that illness is “the will speaking through the body [...] a form of self-expression” (*Ibid.*: 44). This attitude which tends to “glamorize” (*Ibid.*: 35) illness and suffering relies on the ethic of mastery, which prevails in narrative medicine and patient-based research. It works towards the effacement of one’s vulnerability to one’s own materiality, by operating a reduction of meaningless suffering to the sphere of knowledge and by providing a sense of control over experiences which people in fact do not control (*Ibid.*: 55). Whereas illness is attributed meaning in narratives, such explanations neglect that what illness reveals is primarily, or only, that “the body is, all too woefully, just the body” (*Ibid.*: 18). These critiques challenge the very idea of “symbolic healing” (Brody 1994: 79) by tying it to a gratifying illusion. It may relieve anxiety to cover the intrinsic meaninglessness of illness with meaningful stories, but, as it attributes meaning to what does not have any, isn’t this process potentially harmful as well?

As underlined by Crispin Sartwell, the “distinguishing feature of narrative in all its uses is that it lends meaning to what is organized under its auspices” (2000: 10). However, Sartwell underlines, it is questionable “whether and to what extent human experience and human life are organized narratively” as well as whether and to what extent “human experience and human life are meaningful” (*Ibid.*: 10). Consequently, “unless one can simply eradicate massive zones of oneself, including various bodily recalcitrances”, narrative approaches is “experienced at times as an oppression” where one finds oneself “in a hopeless project of self-mutilation” (*Ibid.*: 35) imposing to neglect or stifle “the ways in which [...] we exceed our own grasp” (*Ibid.*: 4), the ways in which “experience is radically in excess to the sign” (*Ibid.*: 48).

The increased presence of narrative approaches both in clinical and epistemic contexts may entrap the patients in a world governed by “narrative imperialism” (Phelan 2005: 206), i.e. in a world governed by the idea that everyone lives and should live narrative lives and align with the narrative structure each and every aspect of all of one’s experiences⁵. When it becomes the *norm*, the narrative approach may become a burden: “identity narratives, delivered piecemeal every day, function as the signature for others of the individual’s possession of a normal identity”; but “the verdict of those for whom we perform is virtually axiomatic: no satisfactory narrative, no self” (Eakin 2006: 182; see also Eakin 2001: 120). *Normally*, one shall not break the rules of narratives: “these rules are tacit because the daily performance of identity story is instinctive and automatic” (*Ibid.*: 113) but failure to cope with these rules “may entail institutional confinement” (Eakin 2006: 182); “de-storied individuals” (Eakin 2001: 121) are rejected out of narrative normalcy by others. We see here another aspect of the idea exposed above: the patient narrating his illness story does so under the burden to fit: a narrative context “may be a burden on those ill and disabled people who do not fit or do not wish to fit into that script” (Garden 2010: 131).

The pressure is all the more pervasive that it is not a particular narrative context or another that is at stake here, but the very structure of narration, since, in and of itself, it constrains what can and what cannot be narrated. In particular, a major “conventional expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place a foreseeable future” (Frank 1995: 55). In this framework, inevitably, “the illness story is

wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable" (*Ibid.*). In a context governed by "narrative imperialism" (Phelan 2005: 206), therefore, the wrecked stories of illness and, even more, the chaotic words of helplessness uttered in suffering "erect a wall around the teller" (Frank 1995: 102). Not only suffering captures the person into "the claustrophobic terror of [...] muteness" (*Ibid.*: 109) but once one finds a voice to "speak *about* the chaos, from *outside* that chaos" (*Ibid.*: 190), no one is there to listen (*Ibid.*: 101) because what is uttered breaks the rules of narration. The lack of space the narrative approach leaves to unnarratable suffering "only makes its horror worse" (*Ibid.*: 112).

4.3. Useful and useless suffering

In the present consideration of the clinical problems related to the use of narratives both in medicine and academic research, what is of further interest in Sartwell's position is his denunciation of "the *teleological order*" (2000: 12) which "regards the world and other human beings as stuff to be used, to be transformed toward ends" (*Ibid.*: 3). Sartwell protests and emphasizes that "it is far from obvious that experience is organized teleologically. Experience seems to be something that happens to us" (*Ibid.*: 41) and as such it is "ateleological" (*Ibid.*: 16). Both the narrative approach and patient-based research insert illness in a teleological order and in this sense, both neglect the "ateleological" nature of experiences in general and illness experiences in particular.

Evidently, patient-based research inserts illness into a teleological order in that it seeks to *use* illness as a source of information, understanding, knowledge. This is not only acknowledged but advocated explicitly, e.g. by Havi Carel (2013: 1). Considering not only the epistemic but the clinical impact of the use of illness in narratives, a teleological approach is also defended in narrative medicine. In this approach, it is thought that, by telling their illness stories, the tellers "accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. [...] the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank 1995: 115). Narratives are thus the occasion for creating "alternative ways of being ill" by realizing "a sense of purpose" (*Ibid.*: 117).

To elaborate on this point, Frank proposes a reading of Levinas' distinction between useless suffering and a suffering which acquires a meaning. Frank adapts this distinction to make it fit his own. On the one hand, the chaotic illness is "the unassumable, nameless suffering" (*Ibid.*: 178); on the other hand, the "just suffering" is the one narrated in stories where the sufferer is a witness of himself and a testimony for others. Suffering "becomes useless" (*Ibid.*: 179) when it is left at what it is: meaningless. According to Frank, witnessing my own suffering, calling upon others' attention upon my own suffering, is what makes it useful: what is useful is the suffering I can narrate to others. In my understanding, this view completely reverses the characterization of suffering offered by Levinas in the text Frank refers to: "*Useless Suffering*". Indeed, for Levinas, suffering becomes meaningful "in becoming a suffering for the suffering (inexorable though it may be) of someone else" (1998: 94). The "inescapable obligation" to give "attention to the other" (*Ibid.*) is the one and only way to conceive of my suffering as non-useless.

We see here the distinction between two modes of conceiving of suffering: the narrative approach, both in medicine and academic research, involves a conception of the sufferer as (potentially) mastering his illness story, thereby using his suffering as a means to become more knowledgeable, thus ameliorating his life; this view, however, conflicts with the idea that suffering fundamentally confronts oneself with one's vulnerability, with one's lack of control, with the loss of one's sovereignty, with one's dependence upon others. Is there a way to give a voice to these aspects of illness and suffering without succumbing to the teleological order where they would lose their specificity? To which extent can psychoanalysis escape the narrative format in a way to give voice to the singular suffering of the patient? I leave open these questions here, to conclude on the issue I started with: the clinical impact of patient-based research.

5. Clinical research

An idea runs throughout this paper: words are not healing in all contexts but, whatever is said in whichever context, addressing oneself to another, is always inevitably a transformative experience – correlatively, listening to the patient's voice in whichever context, opening whichever space inviting the patient to give a voice to his sufferance, always has consequences on the patient's experiences. Such impact may be conceived of as a gratifying illusion, or as the recognition of the subject as the owner of his own voice, or as a burden to fit into narrative normalcy, depriving him of his singularity. In any case, these transformative processes occur by the very fact that someone speaks to someone else who listens. This thus occurs not only in clinical but in epistemic contexts as well. This is why *patient-based research can only be ethically valid if it is performed with the conscience that it is not and never clinically inert: the patient-based researcher should always be clinically responsible.*

To assume this clinical responsibility, what ought to be considered is notably the demand of a patient when he participates to patient-based research, i.e. when he puts himself or agrees to be put in a position where his experience is attributed the status of an expertise. Is his demand to increase his own knowledge about himself? To increase knowledge about the condition he and his fellow-sufferers suffer from? To be inserted in a community of fellow-sufferers by being given a public voice? To be inserted in the society at large through the interaction with academic researchers? To be understood? To be listened to? To give a voice to what hurts? To get closer to his sufferance? To distance himself from his sufferance? None of these demands exclude each other, and none of them are clinically inert. For this reason, again, responding in an ethically valid manner to these demands requires a clinical context, in articulation with the epistemic context where patient-based research is conventionally performed.

Moreover, what ought to be considered is that, whatever the demand of the patient, his participation to academic research always involves an intersubjective encounter as the researcher puts himself in the position to listen to the patient, and asks him, explicitly or not, to report, give meaning, put words, share, expose his sufferance, his vulnerability. In this process, the patient may feel entrapped in the narrative format necessary to address meaningful words to the researcher, or he may feel recognized as the very subject owing his voice and being listened to in his singularity. Again, only clinical considerations can prevent the former while fostering the latter. But when the investigation is over, what does happen to these experiences which unfolded during and by the encounter between the patient and the researcher? The patient may retain ownership of his own voice and/or he may remain exposed in his vulnerability. By leaving the "field", the researcher confronts the patient to the "illusion of a listener" in a way the patient may or may not be prepared for psychologically. However, hardly any consideration has been given to the process of ending the intersubjective encounter that was generated for the completion of a patient-based research⁶. Considering that the relation between the researcher and the patient ends un-problematically as soon as the research is done is forgetting the transformative power that any intersubjective encounter may entail.

All together, I believe that it is the recognition of the irremediable differences between clinical and epistemic perspectives that allows the ethically valid practices of both patient-based research and clinical work. My intention in this investigation, therefore, is not to oppose clinical and epistemic contexts; quite on the contrary, it is to consider the conditions of their incessant articulations, to pave the way for a clinically informed and ethically valid patient-based research.

Notes

1. When an academic researcher investigates a condition he himself suffers from, the case is utterly different, and raises specific issues which I do not consider here.
2. Comparable approaches are being developed in various ways. See e.g. Gallivan et al. 2012 for a review.

3. Macnaughton argues, however, that genuine empathy is neither possible nor necessary in the practice of medicine. A critical stance is also held by Garden (2007) who underlines that “the problem of empathy begins with the preoccupation with self that obscures the other” (*Ibid.*: 555).
4. This should not be confused with the idea of “unconditional positive regard” developed in psychology e.g. by Carl Rogers (1961: 283).
5. *versus* the idea that “there are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative” (Strawson 2004: 429).
6. Contrastively, lots of thoughts have been given to the process of beginning any patient-based research by asking the patient to sign an “informed consent”. The process of ending the encounter between the “informant” and the researcher has been theorized in anthropology and ethnography.

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