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THE STATUS OF
DOCUMENTS
*Medical Files and
Literary Genres-
The Case of Chronic
Fatigue Syndrome*

JOOST HAAN & FRANS-WILLEM
KORSTEN

GASTON FRANSSSEN'S ESSAY touches on important medical and literary topics: the experience of patients with unexplained somatic complaints, the importance of giving their symptoms a name or diagnosis, the verbal representation of what bothers them, or the uncertainty all parties have to live with when an underlying cause of the symptoms is missing. A diagnosis or name such as chronic fatigue syndrome (CFS) can be a relief for its sufferers, as is expressed by one of the patients in the article: "I wept with relief at having a name for it." Yet CFS is but a name for something that, medically speaking, has no substance except for the patients' complaints. CFS shares this lack of objective physical signs with other medical diagnoses. A diagnosis of *migraine*, for example, is purely based on the words of the patient by applying internationally agreed artificial criteria (IHS, 2018). The same is true for entities such as *fibromyalgia*, *visual snow* or *epicrania fugax*. One can call these: "invisible illnesses," as Franssen does. The essay illustrates the ambivalence created by complaints that are expressed by patients but for which no structural or otherwise objective cause can be found. The ambivalence

provokes a both medical ("not true, as there is no objective abnormality") and literary ("words to be believed, but no evidence") approach. The need for the latter is implied when one of the CFS patients in the essay states: "if they can't find it in machines, it doesn't exist."

Here, the relation between literature and medicine at points resembles the relation between law and literature. One pivotal analogy is captured by the Latin phrase *Quod non est in actis, non est in mundo*: "What is not officially registered, is not in the world." The phrase helps us to reflect on 1) the official or non-official status of documents in their relation to 2) the singular status of the world or the plurality of worlds. We will deal with both in the context of the diagnosis of CFS.

As for legal documents, Cornelia Vismann (2008) noted that the English terms "files" and "records" are captured in German by one term: *Akten* (cf. Latin *actus*).¹ Yet in English, "files" connote the materiality of what has been registered, and "records" the function of what has been registered. This distinction helps us to distinguish more sharply, first, between the status of literary documents and medical ones, to then establish a

better possible relation between the two, also with regard to self-care. As for the singularity or plurality of world(s), this has principal ontological and epistemological implications. Law has to restrict itself to one world, namely the legally defined one: a matter of ontology. The restriction is needed to be able to establish what counts as medically true or real: a matter of epistemology. Likewise, whereas literature, with the different genres it uses, always connotes a multiplicity of worlds, any medical diagnosis will have to restrict itself to one. It is only within this one world that possible or alternative explanations for any illness can be canceled out, to arrive at the proper diagnosis. What are the implications for self-care?

THE STATUS OF DOCUMENTS: GENRES AND THEIR IMPLICATIONS

Franssen distinguishes between illness narratives or medical case histories, on the one hand, and quest narratives, restitution narratives, biographies, memoirs, and autopathographical writing on the other. The former are based on medical interviews and tests. They transform into the medical files that contain the medical case histories. Their status very much resembles that of official legal documents, which fill the archives that form the heart of the legal system. As for the official medical files, these not only fill the archives of the medical system but could be taken up in the legal archives without much need of translation. If documented illness narratives and medical case histories are genres in their own kind, then, they have a radically different status than the literary ones.

The literary genres among themselves, moreover, have a distinct and different status too. A quest narrative belongs to the oldest forms of narrative we know of, that often has an allegorical meaning. A restitution narrative can be the description of a healing process, but as such often has spiritual or symbolical connotations. If some authors describe CFS as a “biographical disruption” this connotes the coherence and consistency that marks a life plot that becomes disrupted. With memoirs we deal with personal, subjective, ruminations that do not need the coherence and linearity of a life plot. With autopathographical writing, finally, we deal with a rather recent genre

that does not aim to write the history of one’s personal life but of a disease that marked one’s life.² This rather colorful and diverse collection of genres, then, has “an important role in health care.” They do, no doubt, in the domain of self-care. Medically speaking, in the absence of more precision, we have to do with descriptions by patients themselves.

The fatigue that is so characteristic of CFS, medically speaking, is an a-specific or vague complaint, just as headache or dizziness. Here we can agree with Franssen when he states that “self-narratives are unreliable” because they are “the product of a process of selection, interpretation and appropriation.” As such they have low epistemological status. On a general plain, however, “these memoirs have come to function as sources of insight for lay readers” for they have the capacity to capture “the true essence of what this disease feels like.” It can indeed be the power of fiction, in whatever kind of genre, to capture more truly what is the case than any official document can. Yet this truth is another kind of truth than the one captured in official legal or medical files. It is not that the one is more true than the other. It concerns radically different kinds of truth, just as the way in which medics educate one another on the basis of cases is different from patients informing one another.

Franssen predominantly falls back here on the work of Anne Hawkins whom he quotes in saying that pathographical or autopathographical writing “returns the voice of the patient to the world of medicine . . . and it does so to assert the phenomenological, the subjective, and the experiential side of illness” (Hawkins, 1993). This generic shift appears to confuse different worlds.

MEDICAL WORLD: EPISTEMOLOGY VS ONTOLOGY

The contemporary discussion whether CFS is somatic or psychogenic can be contextualized by comparing the issue with earlier historical medical discourses. For example, multiple sclerosis was long thought to be psychogenic, but at the end of the nineteenth century structural lesions were found at post-mortem and at present there is no doubt that it is an auto-immune disease with

objective clinical and radiological signs (Reich, Luchinetti, & Calabresi, 2018). Hysteria, with the typical *arc en cercle*, was once thought to be a typical female psychogenic affliction, but in recent years it often proved to be a paraneoplastic syndrome (Pollak, 2013). A gastric ulcer was long attributed to stress and personality characteristics, but in the late eighties a bacterial cause (*Helicobacter/Campylobacter*) was discovered and an effective treatment established (Graham, 1989). The examples serve to illustrate how there is a constant dynamic between epistemological and ontological issues. Depending on what medics claimed to know the ontological status of illnesses was defined. Depending on what they came to know, this status changed. This dynamic, however, took place within the medical field itself. If we bring in literature, the entire dynamic changes.

When Franssen calls for diagnoses that give patients “an unequivocal, clear-cut explanation for what the patients has to endure” this is a matter of epistemology, as the term *explanation* suggests. It is important for both medics and patients that they understand what the origin of a disease is. Yet Franssen also claims that the diagnosis has to do justice to any patient’s *experience*, and this is a matter of ontology. Experiences cannot be proven, they connote how subjects perceive a world. Any medical diagnosis is asked to do something, here, that takes it outside of the limits of the medical world, as when it is taken up in the “quest for a deeper understanding of the meaning of illness.” The confusion between the two becomes marked when Franssen states: “I focus on “diagnostics” as a process of translation of medical symptoms and experiences in linguistic signs, as well as on the shifts that this translation brings about.” Symptoms would be in the ball park of medical epistemology, with its own modes of diagnostics. Yet experiences, though important, bring in the multiplicity of worlds and as such exceed the domain of the medical proper.

Franssen’s defines diagnostics as a matter of translating bodily symptoms and experiences into language. This is a fundamental point, and a problematic one. The problem with illnesses such as migraine and CFS is that the only information doctors have depends on how patients report, in language, on their affliction (Haan, 2020). This

needs to be transformed into a diagnosis, through the selection of relevant information found in one text, that is then used to construct another one. Epistemologically speaking, the problem is hermeneutical or semiotic. Ontologically speaking, doctors have to turn an unknown, invisible, unstable “something” into a thing that has the status of a well-defined real. This problem can only be solved if we get back to what we began with. If CFS happens to be, and is proven to be, a neural disease, like an organic psycho-syndrome, this disease then determines behavior, experience, and symptoms. This will not invalidate literature about the issue, with its potential for self-care. It will remain equally important. Yet the split that has become explicit, then, between medical explanation and literary representation exists today as well.

NOTES

1. The quote is pivotal to Vismann’s study *Files: Law and Media Technology* (2008). The original, German version is from 2000. The Latin phrase, as Vismann notes, is probably medieval in origin (56).

2. Jeffrey K. Aronson (2000) not only notices that the genre is relatively new, but also gained such popularity in the last decades that he speaks of a “deluge” (p. 1600).

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