

Instead of Yelling: On Writing Beyond Rationality

I was going to talk about the constitution of desire for what the so called autonomous patient is expected to come up with, is an articulation of her or his will. It is expected to be there mostly oppressed speaking up when given room. But it isn't always there, pre-existing. The typical situation I wanted to start from is that of a doctor asking - "what do you want?" - and a patient saying "I don't know". How else to read this situation than as a failure? A failure of the patient, that is, who should have a will to begin with.

There is a lot to be said about how 'the will' is constituted in a juridical frame while when it comes to 'deciding' about life what is needed is something quite different that, for the moment, I am inclined to call desire.

But this, however, is not what I'm going to further develop now. I haven't been able to work on these questions I was ill for months. Incapable of working. Which brings home a proper message to our session on dis/ability today: all the talking we may do, presupposes and enacts a specific ability: that of a subject who is articulate. A lot of abilities go into being an intellectual. Skills required to investigate. The ability to use words. And first and foremost: a very basic ability. To think, write, read: to work.

Lacking some of these basic abilities for a while, I have, however, done some further thinking both on earlier material, and on earlier research experiences. This has resulted in a series of questions. Questions I would like to share with you for if we tackle them jointly, if each one of us takes them along, the chances that answers may emerge are a lot higher than if I chew on them alone.

The topic I want to address today, is that of suffering. In dis-ability there is a dis. Something amiss. Clashing, giving frictions. Sometimes the dis-bit may well and rightfully be pushed away from the so called patient and shifted onto the so called surroundings (like in: it isn't the paralysed legs that prevent a person from going to the first floor, it is the staircase) but not always. It is a bad strategy for 'dis/ability studies', to always shift out the 'dis'. For whether it comes from elsewhere, or is relational (between person and surroundings) or resides in one's soul or bones somehow somewhere there is a dis. It should not just be shifted, but attended to. What to do with it? Or: what is done with it? The way the question faces me, or the way I face the question, here, now, is as one of method a method of investigation as well as one of writing. What to do with the dis in dis/ability, with lack, with pain, with suffering, when writing?

I'll try to illuminate the problem with personal anecdote. In the late seventies I was a student of medicine and gradually got angry at the way suffering is handled in the caring professions. I realised that, basically, I wanted to react by yelling. By screaming out a revolting, inarticulate, harsh yell. This can't be done in a medical lecture hall, so I went elsewhere, to learn to become articulate. I started to study philosophy. In my philosophy classes we had to read Habermas, who argues that taking up speech is a way of accepting the rules of rationality that come with speech. The only way, then, or so it seemed, of not accepting rational rules was, again, by yelling. However, the followers of Habermas, and most other philosophers as well, exclude those who yell from their *Herrschaftsfreie Diskussion*. Yelling disqualifies the subject.

When a few years later a locally famous Dutch professor suggested that the patient-movement in psychiatry could be strengthened by drawing on Habermas's theory, one of my friends and I

wrote a reaction. She was just then reading one of these huge volumes, and had underlined each time Habermas said in so many words that only the normal can participate: in order to enter the discussion, one has to have finished one's therapy first. We wrote that this made us want to yell but we wrote it, we didn't do it.

Yelling, for all its loudness, doesn't carry very far. But what other repertoires of relating to suffering are there? This is a 'what to do' question. As a way of tackling it, it may help to ask: What is being done?

A first repertoire is rationalist. Rationalism doesn't necessarily deny suffering. Denial may occur but inside and near to the helping professions, and in medical research, a lot of rationality goes round that rather tries to tame suffering. Control it. Ban it through rational interventions. There are, obviously, varieties. Take the treatment of diabetes. A person with diabetes is supposed to balance her food intake, exercise, and insulin dose so as to keep her blood sugar level within limits. Low enough, not too low. Everything can, or so it seems in rationalist mode, be balanced against everything else. Both physiologically (as in a sugar balance) and life wise (as in: which bad life-event to accept in order to gain with good life-event). In decision analysis the latter is made explicit in forms that list the pro's and con's of any given intervention. These forms may ask people to tell what they, personally think is worse, say: dying sooner or living with an amputated leg. Rationalism lies in the supposition that such questions have an answer. That suffering may be countered and if not countered, calculated.

A second repertoire is empathic. This is vehemently critical of the first. It says that rationalists refuse to listen to the pain of those who suffer. The empathic repertoire takes, instead, this pain on board. There are a lot of varieties. In nursing it is done in small, practical manners, such as by holding someone's hand when they get an injection or are otherwise hurt. In medical sociology it is a popular repertoire as well, but differently so. The sociologists involved take the suffering of those they write about on their own shoulders. And claim they understand. Thus they try to give it voice, bending to someone else, listening while, also, thereby, as in all charities, 'othering' this other person. One of the to me worst version of the repertoire is where it becomes soothing. Smothering the suffering away by too much understanding of it.

A third repertoire is clinical. It is typical for the medical tradition. It implies: leaving an open space for the suffering of the other. Like this textbook on 'Clinical Medicine' that I consulted, that tells to medical students: if, at the end of an interview, the patient cries, you have done well, since you have given the patient space for his or her emotions. Do not leave the room. That is the advice there is nothing about how to listen, or about what to say. There is nothing about touching. Just do not leave the room and let the patient be. Don't probe into it. This repertoire has been taken up in the social sciences, too. There it lies in the acknowledgement, the acceptance, of a lack of knowledge when it comes to the suffering part of the sites, situations and people in health care that one writes about.

There must be more repertoires. But let us, for now, have a closer look at these three: the rationalist taming and tackling of problems, the empathic embrace of suffering and the clinical mode in which suffering is given room. All three can be adopted by social scientists or others who, like most of us assembled here, write about medicine and dis/ability. In which repertoire to write?

In order to establish a proper insulin dose rationalism may help. But it will never get close to the dis of disability, for it only tries to chase this away. It cannot begin to resemble yelling. When one is having a wound stitched, a nurse who holds one's hand may be wonderful. But empathic sociologists, while pretending to help others, risk, or so it seems to me, to mostly

please themselves, for being ever so good. On moral high ground. The method, the style, that I have so far been parasitic on, is the clinical one. What I like about it, is that it does not claim to know and thus does not risk to disown the suffering one come across. It leaves suffering being other, other to talk, to our talking, to our texts.

But the clinical repertoire has its limits. These strike me all the more now that I am no longer primarily studying doctors, but, instead, the way people with diabetes are taught to take care of themselves. For in that process they are taught to be clinical not just towards others, but as a way of relating to themselves, to their own suffering. Calm, but not heartless. Do not leave the room.

But what does it mean to not leave the room, when one might need to cry oneself? The clinical repertoire is not made or meant to be used for/by a suffering subject. It has been developed for doctors. Just as the rational repertoire fits in with, say, research and the empathic one with the work of nurses. In none of these repertoires does the subject talking coincide with the subject suffering. This mimics the way the body is investigated in pathology: the body doing the cutting is never the body being cut. Likewise: the subject speaking is never the subject suffering. It may be the same person at some other point in time. But it is not the subject of the text.

One can, as if by definition, not be rational and suffer at the same time. Empathy is an attempt to bridge an alleged great gap towards the suffering of the other: what is there to bridge if the relation is to oneself? And doesn't empathy with the suffering self, in as far as it is possible, become an emotionally draining complaint or an entrapment in the role of the victim? The clinical way of dealing with one's own suffering, finally, is not impossible but it doesn't really touch on the suffering. It is not exactly (like the rationalist mode) cold. But it leaves a blank space for suffering. Which may end up becoming a black hole.

So what other repertoires might there be? How might the subject of the text engage, actively, practically, with suffering other than by taming and chasing it, other than by taking the suffering of others upon her shoulders, other than by respecting it by leaving it be?

This is the question of method I want to pose. I have no answer to offer at this point, but I think it is a question we urgently need to explore and experiment with. And maybe it helps to take up this question in parallel with another, equally urgent one. A question that may help us to not get stuck in the ever so seductive position of the victim or the self-satisfied saviour. That is the question how cruelty might be articulated. What is it to make others suffer, to be the actor of their suffering or, again, that of ourselves? How may active cruelty be made present, presented, in a text?

Another list. For apart from repertoires of relations to suffering, there are textual modes to take into account here.

One is the classical, obvious one: description, depiction, representation. There are a lot of representational styles involved from medical text-book photos to those of the famous Benneton advertisements. What do they do, how do they make suffering be and disappear again? A lot of the STS-lessons about the production of truth need be taken on here, and adapted, for suffering is never an alleged plain truth but, always already, in different modalities, a moral fact.

Two is enactment. Here the yelling I began with fits in. What ways are there of doing suffering that hold better on paper? Uttering grief. Raging. Denouncing. What more? There are poems, novels, letters to the editor and a lot more to explore.

Mode number three is a devilish one, it is to provoke suffering in the listener/reader. Remember when Stefan Hirschauer wrote about surgeons operating on genitals: quite a few of his readers felt this in their own private parts. Which emotionalities do texts make space for, or allow, or induce? Which kinds of suffering may be evoked and to what further effect? And might this be a place where the subject who articulates suffering and the subject who engages in cruelty meet, cross over?

Representing, enacting, provoking. The list surely deserves further exploration. I plan to take it with me into the hospital so as to learn from the way patients handle the issue. How do they transport their own suffering to doctors and nurses and what does this do for them? For just as one may be parasitic on the rationalism of researchers, the empathy of nurses or the doctors' clinical style, one may try to learn from various modes and modalities of engaging with the dis of disability that patients use in a medical setting where (in contrast with most other places they inhabit) they exist in and through their suffering. But something changes. When we, as ethnographers, sociologists, philosophers, no longer lean on the styles of the helping professions, the comfortable position of the one who helps is lost. Patients come to the hospital in order to be helped and that informs the way their suffering is brought into play.

Should we seek help ourselves as well?

I don't think so. By whom? There is nobody for us to call upon. But I do know that as a part of the method I am after, it is crucial to refuse to help or to pretend to do so. No asking for help, no promising of it. How then to engage with the morality implied in the dis of dis-ability? For suffering is a non-good I do not want to get romantic about it, as if, finally, it were 'always good for something, somehow'. No. How to face the non-good and how to allow oneself to be faced by it? That is the question.

Enough for now. And while usually one ends by saying, 'any questions?' it makes more sense on this occasion, to end by welcoming your answers.

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