

Is it possible to understand illness and suffering?

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The research approach of participant observation implies constant self-reflection. Subjectivity in that context is not seen as a hindrance but as an indispensable tool to understand the other. The sharing of subjectivity – intersubjectivity – creates moments of recognition and the intuition that we have ‘grasped’ the other’s point of view, but those moments cannot be proved right or wrong; they remain contestable. The paper discusses successes and failures of anthropological interpretation using ethnographic examples of illness and suffering. It concludes with a plea for permanent sensitivity.

[subjectivity, intersubjectivity, anthropology, participant observation, illness, suffering, experience, permanent sensitivity]

Trained in the tradition of anthropological fieldwork I have grown increasingly skeptical about the possibility of knowing, that is knowing *people* (who are the ‘object’ of our discipline). Geertz (1973: 29) calls anthropological knowledge (‘cultural analysis’, in his words) “intrinsically incomplete” and “essentially contestable”. I can only agree. It may therefore be wiser to avoid the presumptuous term ‘knowledge’; I prefer to speak of ‘understanding’, or rather ‘interpretation’. The latter term acknowledges the anthropological modesty regarding knowledge. ‘Interpretation’ always carries with it the awareness of subjectivity. An ‘objective interpretation’ is a contradiction in terms.

Anthropological interpretation has its roots in the hermeneutic tradition with its ever-returning circle, the permanent commuting between subject and subject. The research approach of participant-observation implies constant self-reflection or introspection. Subjectivity in that context is not seen as a hindrance but as an indispensable tool to understand the other. The sharing of subjectivity – intersubjectivity – creates moments of recognition, an almost emotional experience or intuition that we have ‘grasped’ the other’s point of view, to quote a classic line from Malinowski. But that moment of recognition cannot be proved right (or wrong); it remains, as Geertz wrote, essentially contestable.

As anthropologists aim at an ‘emic’ point of view, sharing experiences with the other seems the most rewarding approach. At the same time, however, we can never assume that the *same* experience produces the same *experience*. Reflecting on our own

experience to understand the other is balancing between 'ego-centrist' non-understanding and empathic understanding the other in terms of ourselves.

This paper discusses successes and failures, promises and pitfalls of anthropological interpretation using ethnographic examples of understanding illness and suffering. Intersubjectivity is thus put to the test.

Intersubjectivity

What do we mean by 'intersubjectivity'? And what is meant by 'subjectivity', a concept that presumably precedes intersubjectivity?¹ If we argue that intersubjectivity is the secret key to understanding in anthropological research, we should at least agree on what we are talking about. Unfortunately, there is much confusion about 'intersubjectivity' and 'subjectivity'. Authors from different disciplines such as philosophy, psychology, sociology and anthropology seem to have different concepts in mind, or emphasize different aspects when they use the two terms. Tankink and Vysma (2006: 251-256) distinguish three 'traditions' of intersubjectivity: Merleau-Ponty's philosophical perspective, a psychoanalytical and a sociological view (Habermas).

Merleau-Ponty regards the first experiences of child's life as moments of intersubjectivity and such moments form the basis of the child's consciousness and subjectivity. The child's presence in and openness to the world constitute the very essence of being – or becoming – human. Consciousness is, by definition, shared consciousness. Intersubjectivity, somewhat paradoxically, precedes subjectivity, and creates it (cf. Jackson 1998: 11).

In a psychoanalytical context, intersubjectivity relates more to processes of cognitive and emotional communication between analysand and analyst. Processes of transference and counter-transference show the intricacies of what takes place between the psychoanalyst and his/her client. Reflecting upon these processes serves primarily the client's coming to terms with him/herself. That concern is not at stake in anthropological research but similar processes may take place during encounters between researcher and the 'other' in the field.

In Habermas' sociology, intersubjectivity is an epistemological concern; to quote Tankink and Vysma (2006: 255): "How, in a subjective world, do we communicate in such a way that we do not sink into a morass of relativism...?" Or in the words of Jackson (1998: 10), how can I know "... the inner experience of the Other as he or she knows it? On what grounds can empathy, transference, or analogy bridge the gap between you and you?" That existential concern is crucial in the interpretation of field data.

For this paper on intersubjectivity as a tool in (medical) anthropological research, I take my inspiration mostly from debates in philosophy between 'materialists' and phenomenologists, debates that will probably never end. Phenomenologists regard the materialist view as simplification because it "detotalizes reality" (in Le Sennes's terminology, quoted in Luypen 1976: 28). It misses the point that we can only speak about reality in so far as it appears to us. Every experience of the world is a human experience and involves a process of meaning production. To speak about a reality

outside the human experience is a contradiction. The world as we know it, is ‘infected’ by our presence, observation, and interpretation (cf. Bakker 1964: 102-106). As a consequence, subjectivity is not a hindrance to knowing and understanding the other but an indispensable tool to approach that very knowledge and understanding.

The awareness of the necessity of subjectivity in the production of knowledge is largely ignored – or repressed – in the natural sciences where subjectivity is seen as an obstacle to exact knowledge and intersubjectivity as irrelevant. In anthropology, however, particularly in medical anthropology, the two concepts are cherished. It is through our subjective experiences in everyday reality that we know what we are writing about. In Luypen’s terms, when we speak about trees – in any scientific tradition, as botanists, agriculturalists or anthropologists – we rely on earlier experiences with trees (“a blossoming apple tree in the fields”) to have a proper understanding of the topic of our scientific discourse. The direct (‘totalizing’) experience of trees is a precondition for the scientific (‘detotalizing’) approach (cf. Luypen 1976: 98-102).

This insight into subjectivity and intersubjectivity, as indispensable constituents of knowledge, is the soul of anthropological research. Terms and concepts used by phenomenological philosophers to capture the intersubjective momentum – *rencontre* (meeting), *ouverture* (openness), dialogue, participation, presence – are best translated into the anthropological ‘tools’ of participation (sharing of relevant experience) and reflection (trying to make sense of the experience in a shuttling movement between the subjectivity of myself and the other). The ‘other’ thus becomes a ‘you’. Intersubjectivity implies a “second person perspective” (De Quincey 2006).

Participation

The epistemological relevance of subjective experience as a frame of reference is beautifully summarized in a famous line of Heer Bommel, one of the two main characters in *Tom Poes*, created by the Dutch cartoonist and literary author Maarten Toonder: *De gewone ervaring leert anders* (‘The ordinary experience teaches a different thing’). Scientists may make all kinds of claims about people and their behaviour, but sometimes we know from our ordinary experience that they are wrong. The *ervaringsdeskundige* (‘experience expert’)² immediately sees that something is wrong. The researcher was fooled perhaps by his informants or he misunderstood them because he did not have any affinity with their experience. The ‘ordinary experience’ knows better.

Patients and other ‘experience experts’ increasingly criticise researchers for not speaking their language, not picking up the issues that concern *them*, and not providing information and recommendations that are important to *them*. Instead researchers are mostly writing for an academic audience and appear to be much less involved with and close to the people they study than they claim in their prefaces and conclusions. In reaction to this frustration patients demand to participate in research projects that deal with them. A recently published Dutch handbook for patient participation in scientific research opens with the following statement:

Scientific research without active involvement of patients can hardly be imagined anymore. Institutes and funding organisations increasingly request participation of patients for whom the research is meant as an absolute condition. They have now reached the conclusion that 'experience expertise' has been neglected far too long. This growing awareness is a welcome development, which is fully endorsed by patient organisations (Smit et al. 2006: 3; translation SvdG).³

In a brief reflection on her research among caregivers of nursing home patients who refuse to eat, Roeline Pasman (2005) mentions three advantages of intensive participation in research: participation reduces the distance between researcher and the other(s); it leads to the discovery of issues with which the researcher was unaware; and it deepens insight and empathy with regard to the people in the research project. Pasman provides convincing examples to illustrate her view. Nurses and other caregivers are more open towards a researcher who helps them in their work than to someone who critically observes them from the sidelines. That a researcher discovers new things when she participates stands to reason. Pasman cites the example of a woman with symptoms of dementia, who first refuses to eat but a few minutes later cheerfully consumes the food. The experience inspires Pasman to think and construct new ideas. Finally, she feels that she reaches a better understanding, emotionally, of what it means to work in a nursing home by joining the caregivers in their work. She now understands, she writes, what it means if a caregiver tells her – with some embarrassment: "My day has been good if all patients have finished their plate."

But we should not overestimate our participatory achievements. Some anthropologists present a too rosy and too optimistic picture of their participation, especially those who carry out research far away among people from whom they differ considerably in terms of economic status, living style, and health and language, tending to speak too easily of successful participation and intersubjective understanding. *A beau mentir qui vient de loin*, the French say ('Who comes from far can easily lie'). Lorraine Nencel (2005) is honest, however, by describing how her relationship with Peruvian women who engage in prostitution was problematic. She admits that there was hardly any dialogue and concludes that the most significant communication between her (the white, well-to-do researcher with a stable partner) and the women was *silence* (p. 349). And silence is a tricky type of 'intersubjectivity' to interpret. Silence may be the only possible way of speaking when pain and suffering become too much for words. Frank suggests that professional helpers (and I would include researchers as well) should not so much so much listen *to* and think *about* people's stories of suffering, but rather *with* these stories. "Sometimes, thinking the story means listening to silence, to the story that resists becoming a narrative" (Frank 2001: 361). That, however, is hard to achieve and one never knows for sure if one got anywhere near it. *Complete* participation, whether far away or 'at home', is always difficult, if not impossible. Anthropologists should be more modest and reflective when they speak of 'participation' or 'intersubjectivity'.

Let me mention two aspects of participation that should temper the claims by anthropological researchers: participation is always limited and largely non-commit-

ted. Anthropologists take part in only a tiny part of the lives of those among whom they carry out their research. The domains in which they are most interested and which are probably the most crucial are usually excluded from their participatory presence. In the final analysis, most anthropologists have to content themselves with circumstantial evidence, clues they picked up from their presence in other domains of life.

Even more problematic is that participation, *if* it takes place, likely produces another kind of experience than what the people in the community feel. The difference hides in the non-committedness or other-committedness of researchers' participation, which exists only for a certain period and with another purpose. After a certain time, they leave the place and return to their university to write up their data. Their informants stay behind as they are 'locked up' in their lives and have no other choice but to continue what they have been doing before and during the researchers' visits. Alluding to Heidegger, they have been thrown into it and cannot leave it like researchers. That difference deeply affects the participatory experience, both cognitively and emotionally. The existential difference between participation as methodology and everyday experience is little discussed in anthropological fieldwork reflections. In summary, participation is harder and more problematic than may be thought at first sight, but there is no better alternative. The limited intersubjectivity that is created in anthropological research is the best we have. Research that lacks any shared experience is senseless. But how can experiences be shared in *medical* anthropology, in research that tries to understand what sick and suffering people go through?

Participation in illness and suffering?

Remembering his own illness and anxiety, Frank (2001: 354-55) describes suffering as the experience of being "on the other side of life":

Suffering is loss, present or anticipated, and loss is another instance of no thing, an absence. We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be. At the core of suffering is the sense that something is irreparably wrong with our lives, and wrong is the negation of what could have been right. Suffering resists definition because it is the reality of what is not (Frank 2001: 355).

If that existential emptiness resists speaking by the person who passes through it, it seems painfully naïve if any researcher claims to be able to capture and describe that experience. Yet we continue trying to come closer to it.

There are mainly three options for attempting to participate: as patient, as caregiver, or as concerned third party (relative, friend, visitor), which implies three different roles (Van der Geest & Finkler 2004). The last two are relatively easy; the first – the most relevant one – is, however, extremely difficult and tricky. Let us briefly consider each of these roles.

As caregiver

Researchers in hospitals and other medical institutions often join the professional staff; or, conversely, they already belong to the staff and try to combine medical work with participant-observation. Sometimes they present themselves as staff members by dressing like them and moving with them. Obviously, that position will be helpful in research on caregiving but may not be the most suitable if the researcher wants to understand the experiences of patients. Patients see physicians and nurses to some extent as 'the other party', from whom they must hide certain things.

Most examples of participation as caregiver, to my knowledge, focus primarily on the experiences of those who provide care. Pasma (2005), a nurse, attempts to describe how nurses see their work among older people with dementia. Working in a home with caregivers of older people with dementia, Anne-Mei The (2005) acquired a first-hand understanding of the dilemmas and frustrations of that profession, not of being a patient.

As concerned person/visitor

Interestingly, two researchers with medical training, with whom I have been closely associated, tried to get away from their medical role during their fieldwork in a hospital ward because they felt that role to be a hindrance. Eric Vermeulen (2001, 2004), nurse and sociologist, carried out research in two intensive care units for extremely premature children. He felt uncomfortable being treated as a staff member even though his study was focused on how the medical staff and parents reached decisions on treatment of the children.

Shahaduz Zaman (2004, 2005) is a Bangladeshi medical doctor and anthropologist who did his fieldwork in the same hospital where he had received his medical training. His aim was to describe everyday life in a ward of 100 beds, portraying all parties that were active. He felt particularly attracted to the conditions of patients and realized that he should not be identified as a medical doctor in order to win their trust. The staff, however, knew his medical background and occasionally approached him in that capacity. Many patients, too, thought he was a doctor and were confused when he rejected that identification. Both, Vermeulen and Zaman, preferred to be free from the role of staff member to get closer to the patients and/or their relatives.

Most researchers, who aim to gain a better understanding of being sick, assume the role of an empathic person attentive to the worries and practical problems of the patient. They converse with the sick person and his visitors, provide simple services, and observe. The role which they really aspire, of course, is the role of researcher. Els van Dongen (2004), for example, held long conversations with people living in a psychiatric hospital in The Netherlands. She explicitly refused to be associated with the professional staff, and by doing so, managed to build up a rare relationship of shared subjectivity with some of the inhabitants.

In an earlier research among patients in a cancer ward, Anne-Mei The (1999, 2002) moved between two roles: wearing a white coat (in spite of her non-medical sta-

tus), she sometimes walked with the medical staff, but she derived her most precious insights from her presence as empathic and supportive visitor and listener, through which she developed a personal bond with some patients and kept in touch with them after they had left the hospital. Her intimate relationship with the sick people enabled her to draw closer to the experience of being terminally ill. Her own emotions, she writes (1999), allowed her to relate better to the emotions of the patients and their relatives.

As patient

For experiencing the experiences of the *sick person*, however, one cannot content oneself with walking as a doctor, nurse or visitor between the beds; such a researcher should him/herself be a patient *in* a bed. Commenting on The's research, Nijhof (2000) writes:

Who knows best what is going on in the minds of dying people? The person who practices participant observation with compassion? Or the one who is close to the sick person? Or the interviewer who inquires about his recent experiences? Or the person who falls sick himself, who thinks about his condition and writes down what happens?
[translation SvdG]

These are rhetorical questions; everyone understands that the sick person is the best 'equipped' 'researcher' (provided, of course, that the patient is able to reflect on his experiences). Examples of sick people as researchers are, however, scarce. There are two types: real ones and simulators.

I was involved in a small research experiment with a fake patient in a Ghanaian hospital (Van der Geest & Sarkodie 1999). Samuel Sarkodie, a sociology student who assisted me in my research in Ghana, was admitted to a nearby hospital with the consent of the hospital authorities. Sarkodie presented with simulated malaria. The purpose was to enable him, from a patient's bed, to study life in the hospital as closely as possible. Most staff members were also informed about the research. I paid him visits to discuss the experiment and observe the situation for myself and provide supervision in disguise. Sarkodie kept an elaborate diary about the events in the ward. The experiment lasted only a few days and produced little information that could not have been acquired in another way. Moreover, Sarkodie never experienced the patients' feelings, who were really sick (and short of money).

A little known but instructive experiment of a simulated patient role in research is reported by French et al. (1972). Using a wheelchair in accordance with his simulated disability, French was admitted to a rehabilitation clinic in the United States. His observations were, among other things, about the intense boredom in the ward, but the emotional stress of being insincere in his role as disabled person becomes more and more dominant in his 'ethnographic' notes. No longer able to bear it after five days, he revealed his true identity to the others in the ward, ending his research. His co-patients reacted with indignation. A young woman upbraided him: "Who do you

think you are, trying to imitate a cripple. You will never know what it feels like.” Her reproach touched the core of the methodological flaw: a fake illness or disability feels very different than a real one.

My own experiences with illness – fortunately – are very limited, but when I was admitted to a Ghanaian hospital with cholera, I learned a lot about being a patient, even though I was a privileged one. One of my most intensive experiences were the frightening sordid toilets behind the scenes (but they seemed to be much less frightening to my co-patients who gratefully borrowed my luxurious toilet-paper role). Another memorable experience was the religiosity that dominated the atmosphere in the ward. The number of praying and singing people that passed my bed outnumbered that of nurses and doctors. It felt as if the hospital was as much a place of worship as of medical treatment (Van der Geest 2001). I was authentically critically ill, but I realized that my experience was still very different from that of my co-patients, a dominant factor being that I had sufficient money⁴ to pay for the treatment; a few days later, I was safely home.⁵

Well-known examples of researchers who were affected by a serious sickness and used their experience to write more empathically (and more intelligently) about illness are Arthur Frank and Robert Murphy. Murphy (1998) writes about his illness over a period of eighteen years, from the moment the first symptoms of a spinal cord tumour presented themselves, to his being restricted to a wheelchair and becoming dependent on others. This ethnography about one person shows what illness does to social identity. His struggle for autonomy slowly grows into acceptance and finding deeper meanings. His reflection starts with an observation from the time when he still was an outsider to the world of disease and disability. He sees a severely disabled person in a wheelchair and wonders why such a person would want to live. He is unable to grasp that person’s desire for life. When, many years later, he is disabled himself, he remembers that moment and is finally able to explain to himself and his readers how much life still holds for him.

Frank (1995, 2001, 2004) has written extensively about his own illness experiences, using them as ‘data’ that enhance his authority as an author of sickness and suffering. I already quoted his comments about suffering as what cannot be spoken about. In that same article (Frank 2001), he takes the position of a patient who is approached by a researcher; that meeting can lead feelings of disrespect and insult if the sick person feels he/she broken down into ethnographically and theoretically interesting fragments. Similarly, Kleinman and Kleinman (1991) criticised anthropologists for transforming illness experiences into something other than human experience. But meetings between researchers and ill people can also have a wholesome effect if the latter feel real concern and understanding. That experience, moreover, is mutual and seems to me a mark of intersubjectivity.

A less known, but no less convincing example of a patient who became (or rather remained) a researcher is Gerhard Nijhof, medical sociologist, who was diagnosed with cancer and who underwent surgery. He spent an anxious period in the hospital and had to learn how to live with his disease. The cancer changed his life *and* his sociology. *Ziekenwerk*, the little book he wrote about his experiences, is an attempt,

from an insider's perspective, to forge a new kind of medical sociology (Nijhof 2001). For most medical sociologists, however, serious illness is not a personal experience. They conduct surveys or hold interviews and return to their universities or homes to analyse and write their findings. The concepts they use reveal their provenance: the minds of healthy sociologists. Nijhof became acutely aware of this when he fell sick, encountering completely different concepts.

One such concept was 'apparatus security'. Social scientists have written extensively and critically about the 'technologisation' of medical care. Doctors and nurses were said to be busier with machines than with people. The machine became the patient's enemy, or at least his rival. Nijhof had rarely read anything about the sense of security that machines may bring to patients. For *him*, alternatively, the machines *were* sources of trust and security, magical components that kept him alive. When shortly after the operation, a doctor told him the 'good news', that he could leave the intensive care and return to the ward, he was scared. He did not want to be separated from the safety of the machines.

Another new concept is the night as an un-researched or un-discussed factor, unseen in the medical sociology that only seems to be interested in daylight.

I cannot remember that I ever saw the term 'night' in my literature. Sociologists sleep during the night and society is then closed for them. But the night may also be absent in their work because they assume that little happens during the night, that other people also sleep at night. [translation SvdG]

But that is a mistake. One of the disruptions of everyday life brought about by sickness is that the rhythm of day and night is interrupted. "It is not anymore: working in the daytime and sleeping at night. There is no working at all and sleeping takes place whenever sleep comes to you, when you manage to sleep." Getting through the night is one of the most difficult tasks of *Ziekenwerk* ('Sick work'). The television, with its repetitions of day programmes such as football matches, tennis tournaments, and the Tour de France, saved him. His reflections on the night ended in a plea for 'every-night healthcare' (in contrast to 'every-day').

His main 'conversion' as a sociologist is, however, his acknowledgement of the importance of the *unspoken* word. For years he had been studying words, spoken and written ones. Analyses of texts had been his main occupation, but he came to realize that people may keep silent about certain experiences. "Yet, we continue to pay attention to their speaking only... the things about which they don't speak escape us." That is the reason that "interrogating sociologists miss so much of what sickness means to sick people." A sickness such as cancer is mainly surrounded by silence...

Concluding: Intersubjectivity and permanent receptivity

Nijhof's pondering shows what *radical* sharing of experience brings about in research on the meaning of sickness. Participating in sickness cannot be programmed, but when

one falls sick, one may make a 'virtue' out of this necessity. Permanent receptivity is the only possibility to 'apply' intersubjectivity in suffering. Sickness presents itself as – and is –personal misfortune, as an event that obstructs research. Permanent receptivity helps to look through that 'disguise' and to grasp the opportunity it provides to come closer to 'the other'. Frank (2005: 439) captures this permanent receptivity by turning around the well-known counsel that the researcher should go where the action is. We should rather be aware that there is 'action' wherever we are.

The Kleinmans pleaded some years ago for an experience-near medical anthropology but complained at the same time about the inability of anthropologists to achieve this aim. They criticized their colleagues for reducing illness and suffering to 'culture' (Kleinman & Kleinman 1991). In his most recent book, Arthur Kleinman (2006) looks back on his life as psychiatrist and anthropologist and is seized by embarrassment and regret: he realizes that he did not really understand the pain of those who approached him for help. Experiences of pain and misfortune in his own life have since opened the world of others for him. We may call this a growth in intersubjectivity, but that growth will never be complete.

The strength of the anthropological approach, certainly when it attempts to come closer to the experience of pain, illness, and suffering, is not that it can pride itself of capturing exactly what the other experiences. Its strength, rather, lies in its modesty and in the awareness of the incompleteness of the attempt. The anthropologist, who sincerely tries to participate, has done what he can; there is no better option.

Awareness of the subjective colouring of our interpretation is also not an indirect claim of 'true' understanding. The mixture of subjectivities that anthropologists encounter in their ethnographic and interpretive work cannot be simply made 'objective' by 'deducting' their own subjective part.⁶ What we observe, experience, and reflect upon is and remains inherently incomplete.

Notes

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- 1 Even the etymology of 'subject' (from Latin *subjicere* – throw down, put under) is puzzling. In the earliest English texts 'subject' refers to a person under the rule of another, a subordinate. The term is associated with below, inferior, and servant and hardly promised to become *the* term to express human uniqueness and agency. The etymological history of *object* looks more logical.
- 2 "There is no translation of *ervaringsdeskundige* in everyday English, although there are some colloquial expressions for the same sort of concept, such as 'a graduate of the university of life'. In the medical sense there is the concept of the 'expert patient' – usually someone suffering from a chronic illness who may become more of an expert than those looking

- after him. There is an attempt to use these ‘expert patients’ to help other people suffering from the same condition” (R. Rivett, personal communication).
- 3 The call for patient participation in research was the topic of a symposium and a special issue of this journal some years ago (see: Blume & Catshoek 2003 and *Medische Antropologie* 2004) and has led to annual meetings between patient organisations and researchers under the auspices of ZonMw, a Dutch organisation for the advancement of health and health care research (www.zonmw.nl/patientenperspectief). See also: Roxle 2001.
 - 4 Economic inequality between researcher and informant is an underestimated factor in the disparity of experiences. I have tried to point this out during my first fieldwork, many years ago (Bleek 1979).
 - 5 It is paradoxical but no coincidence, therefore, that this essay on intersubjectivity in medical anthropology mainly presents the subjective and intersubjective experiences of others.
 - 6 According to the French poet François Villon, it is even more difficult to know oneself than to understand the other. The (translated) final lines of one of his most famous ballads go:

Prince, I know all things
I know the rosy-cheeked and the pale
I know death who devours all
I know everything but myself.

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