

Chapter VI.

Patients as co-researchers? Views and experiences in Dutch medical anthropology

Introduction

In this paper I want to raise questions about developments in medical anthropology in my own country The Netherlands. Is Dutch medical anthropology undergoing changes as a result of a shift in power between the healthcare system, patients / clients and the world of research, in particular medical anthropology? Is there a shift from anthropology *of* to anthropology *in* medicine, to use the old distinction? In her contribution to this volume, Sylvie Fainzang warns us that we should not let ourselves be co-opted by biomedicine, as we have our own anthropological perspective. Another development may be equally – or more – relevant here: the rising power of patient organisations in the negotiations of healthcare policy and research. Patients / clients / care consumers now present themselves as candidates for doing or sharing research that deals with *their* wellbeing. How does this trend affect ‘medical anthropology at home’?

I will first briefly sketch the rise of patient consciousness and then argue that this development dovetails with the central principles of anthropological research. The main body of my presentation will be an overview and discussion of trends in this field within The Netherlands, and how these events affect medical anthropology. In my conclusion I will address why the rise of patient movements did not – or hardly – affect medical anthropological research in Dutch academia.

Rise of patient consciousness

The increased awareness among patients of their rights and their specific experiences *as* patients is well known and has been extensively documented. In 2003 the *British Medical Journal (BMJ)* introduced a theme issue titled ‘The patient’, where a number of distinguished scholars, policy-makers and

practitioners pleaded for more ‘patient-centred’ medicine. The then editor Richard Smith wrote in his editorial:

... being patient centred involves much more than being dedicated and caring. It’s a different way of thinking and behaving, where doctors and patients work together as true partners. (Smith, 2003:1274)

The theme issue explored the meanings and implications of ‘true partnership’ and looked ahead to a time that the journal – a typical doctors’ journal – might be a common enterprise of doctors and patients (nurses are not mentioned). In 1997 *BMJ* invited a patient to join its editorial board. A few years later it started a website about ‘best treatments’ for doctors as well as for patients. Around 2003 *BMJ* appointed a patient editor, Mary Baker. The objective of this theme issue, Smith wrote, was “to help doctors prepare for a world where true partnership with patients is the norm” (Smith, 2003: 1274).

The rise of patient power is of course closely related to the consumer movement. An example of how a consumer organisation develops into a patient, or – more ‘correctly’ – a health consumer movement is the British organisation Involve, which promotes the involvement of consumers in decision-making regarding services and policy.²

The term ‘patient’ is itself a symbol of the passive and powerless position of people who face health or disability problems. Blume and Catshoek (2003: 183-184) criticise the term as misleading (and offensive, I would add). Why should someone be called a ‘patient’, if he / she is deaf or using a wheelchair but hardly ever sees a doctor? Still, even *if* he frequents the doctor, why the term ‘patient’? The patient stereotype is well described by Cayton:

Anxious, weak, perhaps in pain and deprived of clothes, usually cowed into submission by lengthy waiting, and almost always ignorant of what is wrong with us and what will happen to us. We are hardly in a position to be active consumers. You cannot be an active consumer without the power of information. (Blume and Catshoek, 2003: 183)

In the Dutch context, however, terms like ‘consumer’ or ‘client’ are less common. There is some resistance to their euphemistic cover-up and most organisations continue to call themselves ‘patient organisations’.³ The term ‘patient’ almost assumes the status of a self-applied nickname, a *geuzen-*

naam, as it is called in Dutch. For the rest, the patient movement in The Netherlands does not seem to be very different from what occurs in the United Kingdom. The organisations mainly focus on advocacy, furthering the interests of their members and building a more ‘normal’ image and social identity of people with a sickness or disability (cf., Duyvendak and Nederland, 2007).

I will focus here on one of the objectives of patient organisations: to get actively involved in research that deals with *them*. That ambition follows logically from the wish to have their share in decision-making on policy and services and from their growing self-consciousness: they are convinced that they have knowledge that is crucial for carrying out scientific research that ‘normal’ researchers lack. In Dutch we speak of *ervaringskennis* (experiential knowledge) and *ervaringsdeskundigheid* (experiential expertise). It is here that medical anthropology enters.

Medical anthropology

One does not need to convince an anthropologist that the views and experiences of a sick or disabled person matter when studying sickness or disability. That insight lies at the heart of anthropological research. Our insistence on the emic point of view is in fact an invitation to sick and disabled persons to speak about their experiences. Participation, our hallmark, is an attempt to come as closely as possible to the lived experience of those we study. Intersubjectivity is a prerequisite for doing anthropological research (cf., Tankink and Vysma, 2006). Without sharing subjectivity, ethnography remains stale and unconvincing. The importance we attach to the views and experiences of those we study shows in our writing: we favour long quotations and narratives from our informants and repeatedly state that we want to give them a voice.

That concern to capture *their* point of view continues during the writing-up. Many of us show what we have written to our informants and ask for comments and corrections (cf., Stoller, 1985). At the same time, we explicitly demonstrate our awareness that we will never fully capture their views. By using the first person singular we acknowledge that in the end it is still *I* who writes, interprets and draws conclusions. We admit the limitations of our intersubjectivity (cf., Estroff, 1995).

The idea of active involvement of patients (or other interested parties) in the planning, conducting and writing up of research goes far beyond what Fisher (1986) calls ‘collaborating informants’ or what Marcus (1999) terms

‘circumstantial activism’. It also differs fundamentally from yet another methodological concept ‘complicity’ (Homes, 1993; Marcus, 1997, 1998).

‘Complicity’ refers to the engagement of a researcher in a relationship with informants who are involved in dubious or illicit business. A classic, but rather innocent example is Geertz’s entanglement in an illegal cockfight in Bali (Geertz 1973b). It is an affinity that comes into existence in the field and does indeed lead to more intersubjectivity and, therefore, to better ethnography. It does not, however, include the control over each phase of the research, as is envisaged in the patient-induced research. A similar comment can be made regarding the concept of ‘collaborating informants’, which demonstrates the transactional nature of ethnographic knowledge. Using a case by Crapanzano (1980), Fisher shows that the involvement of an informant as collaborator helps him to see his own knowledge as:

... more subtly constructed through the action of others. Our knowledge is shown to be less objective, more negotiated by human interests ... (1986: 208)

‘Circumstantial activism’, coined by Marcus (1999), is also primarily a methodological technique. Its purpose is to improve the epistemological quality of a research. It is a ‘modest intervention’ that helps to conceptualise the problems that are being addressed in the research project (cf., Hine, 2007: 656).

It is no wonder that medical anthropological studies that have been written by patients are particularly cherished. We believe that these authors are in a privileged position to understand suffering and we acknowledge their authority.

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 (1995), Irving Zola (1982) and Robert Murphy (1988).⁴ Murphy 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 discovery of deeper meanings. His reflection starts with an observation 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) has written extensively about his own illness experiences, using them as 'data' that enhance his authority as an author of sickness and suffering. Suffering is what cannot be spoken about (Frank, 2001). He takes the position of a patient who is approached by a researcher. That meeting can lead to feelings of disrespect and insult if the sick person feels he/she is broken down into ethnographically and theoretically interesting fragments. Estroff reports a similar incident (1995). She begins her article with an angry informant who has read her story in the anthropologist's book and feels 'exploited'. Similarly, Kleinman and Kleinman (1991) criticised anthropologists for transforming illness experiences into academic anthropological concepts.

A less known example of a patient who became (or rather remained) a researcher is Gerhard Nijhof, a medical sociologist, who was diagnosed with cancer and underwent surgery. He spent an anxious period in the hospital and had to learn how to live with his disease. Being critically ill was not a matter of being 'patient' but of hard work. The cancer changed his life *and* his sociology. *Ziekenwerk* [Sick work], the short 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, he writes, 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 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 realise that people may remain 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 why 'interrogating sociologists miss so much of what sickness means to sick people.' A sickness such as cancer is mainly surrounded by silence. The contribution by Els van Dongen to this volume is yet another illustration of the authority and cogency that one has when quoting from one's own experience of pain and uncertainty.

Writing from one's own experience enhances the validity and reliability. I speak of 'validity' if my conversation partner (or 'informant') understands my question and if his response is indeed an answer to what I meant to ask.

Knowing with a reasonable amount of certainty that we understand each other and are able to exchange our views on an issue that we both – again, with a reasonable amount of certainty – see in the same way is, after all, a result of intersubjectivity. Such intersubjectivity is built upon and develops during a sequence of meetings and conversations. During a brief and only encounter between an *enquêteur* and a respondent, intersubjectivity is unlikely to occur or – at most – remains an unknown factor (cf., Bleek, 1987).

Similar remarks can be made with regard to reliability, which I understand in its everyday meaning. Are the informant's answers frank and trustworthy? Or does he try to hide information? 'Lying informants' are common; why should someone tell the truth about something that is not the other person's business? And why should he offend the researcher by refusing to give an answer? Giving an 'other' answer may be a more polite and convenient solution in such a situation (cf., Van Dongen and Fainzang, 2005). 'Lying' is meaningful, as Salamone (1977) once remarked. When people lie, it usually means that something important is at stake. Lucky is the researcher who stumbles upon a lying informant. The problem, however, is that one first needs to know when lying or concealment takes place. Again, it is only by intersubjectivity and circumstantial evidence (Geertz, 1973a: 23) that we are able to sense this.

Obviously, where researcher and research subject have a common interest, as is advocated by patient organisations, lying or concealment will be quite useless and misunderstanding (in-validity) less likely.

Finally, taking research one-step further toward policy-making and practical service, only valid and reliable information will produce meaningful and useful suggestions for health – and healthy – care problems. Meaningfulness is crucial because policy needs to take the perceptions and experiences of patients as the starting point, and usefulness is necessary because policy must address the problems of patients (and not those of other stakeholders).

In conclusion, the 'philosophy' of (medical) anthropology seems particularly apt to embrace the active involvement of patients in all phases of a research: in its preparation, execution, analysis and application. Let us now look at how the idea of patients as co-researchers was launched in The Netherlands and how medical anthropologists reacted to this idea.

Discussions and experiments in The Netherlands

In 2001 the Dutch organisation *PatiëntenPraktijk* commissioned Stuart Blume and Geerke Catshoek to write a report about the possibility of in-

cluding patient organisations in scientific research. Their report suggested three strategies to achieve this objective:

- Bring about structures for dialogue between scientists and patient organisations;
- Strengthen the legitimacy of patient participation in research;
- Promote and develop new styles of research (Blume and Catshoek, 2001).

All three recommendations were already common practice in medical anthropology, so the report provided an excellent opportunity to test the principles of medical anthropology and to place the anthropological approach in the spotlight of Dutch healthcare research.

We invited Blume and Catshoek to write a ‘teaser’ for the annual symposium of the journal *Medische Antropologie* (Blume and Catshoek, 2003). The symposium on ‘The role of patients in research’ was held in December 2003. Six months later, seven papers that had been presented at the symposium, plus one that had been added, were published in a special issue of the journal under the title ‘The patient as co-researcher.’ Interestingly, only two of these contributions had actually been authored – or co-authored – by a ‘patient.’ None of them reported on the outcome of a research that had been carried out jointly by professional and patient researchers.

Let us look more closely at some of these publications. The first article (Klop et al., 2004) presented the policy of the national fund for healthcare research, ZonMw, to enhance the interaction between researchers and patients. The article was written by three (non-patient) representatives of the funding programme.

The second article by a ‘patient’ volunteer for the Dutch League of Arthritis Patients Associations (De Wit, 2004) highlighted the obstacles he had encountered when he tried to promote the patient perspective among researchers. Like the first one, this contribution developed ideas on how patients could play a role in research; it did not show any results of such research.

An article by Abma et al. (2004) did report on a research that was carried out in close cooperation between professional researchers and members of a paraplegia association. One of the authors was a paraplegia patient. The article discussed methodological and strategic aspects, rather than the outcome of the research.

The last example is an article that described an experiment with older

people (over 85) who were asked to comment on, and possibly correct, the outcome of a research on 'successful ageing' in a Dutch provincial town (Von Faber 2004). The results of the research, which was a combined qualitative and quantitative study, had been published in a booklet in comprehensible language and large print, which had been distributed among all (almost 600) participants of the research. Out of 320 participants that were invited to take part in the discussion, only 21 responded. I was myself involved in the group discussions and vividly remember the disappointing results of the meetings. We had clearly over-estimated the ability of these older people to critically assess the findings and conclusions of the research. They mainly came to thank us or to ask a question. One man produced a sheet of paper and started to give a formal speech in praise of the research team. Six of the participants had never read the booklet or did not even remember they had received a copy. Others vaguely remembered they had read it but did not know the contents anymore. Our expectations of critical comments proved indeed unrealistic and I began to doubt about the feasibility of some forms of patient-led research. Sometimes, it seems, it is the professional rather than the patient who insists on patient participation.

A few months after the publication of the special issue on 'The patient as co-researcher', ZonMw, the Dutch national fund, organised an 'afternoon study' for patient organisations. About seventy people attended. Five speakers and a lively plenary discussion addressed conditions, possibilities and examples of research projects that involved patients as co-researchers. The meeting produced a list of 21 recommendations to enhance patient-research, most of which were of a practical nature such as training patient-researchers, digital support, communication, and payment.

This type of afternoon study has since been held every year. The meetings have stimulated and inspired patient organisations and individual patient-researchers. A team of patient-researchers and non-patient professionals also wrote a handbook for patient participation in scientific research (Smit et al., 2006). It provides a wealth of practical suggestions on how and where the contribution of a patient-researcher could be most valuable: evaluation of research proposal, patient information, style of interviewing, mediating between researcher and patient population, monitoring of research, analysing data, and distributing results (Smit et al., 2006: 20).

The handbook also contains vignettes with concrete examples of the various possibilities and pitfalls of patient research. Another handbook on patient participation appeared one year later (Abma and Broerse, 2007). The authors are a management specialist and a medical biologist. Two years

earlier Caron-Flinterman, a specialist in Science and Technology Studies, defended her dissertation on patient participation in decision-making on biomedical research. Her starting point was that ‘stakeholders participation’ seemed an increasingly common phenomenon in healthcare research but not in basic biomedical research. The main question of her study, therefore, was to what extent patient participation would be possible in decision-making concerning biomedical research.

More activities and publications could be mentioned here, but I will leave it at this (for a now, somewhat dated, Dutch overview, see Smit 2005). The point I want to make is that after we drew attention to the advantage of having patient-researchers, this idea has gradually drifted away from medical anthropology and moved toward medical and behavioural scientists. Medical anthropologists have hardly played a role in the developments that have taken place since. Why?

Medical anthropological silence

Before I try to account for the apparent loss of interest among medical anthropologists to engage in joint research with patient-colleagues, let me recount one attempt to bring these two parties together. During the discussions on the first afternoon study, I told the representatives of the various patient organisations that some of our medical anthropology and sociology students were searching for topics for their master research. I suggested that I could mediate between them and the students to find research topics that both parties would find relevant and that could be researched in mutual cooperation. They reacted positively. I wrote to 40 organisations explaining my willingness to broker a suitable research topic for the students and asked them to formulate one or more questions they deemed relevant and to name a person in their organisation who was willing to participate in the research. Fifteen organisations responded. Most of them listed a question they wanted to study or indicated that they would decide on a question in consultation with the student. I distributed the information from the organisations among the students and waited for their reactions.

The reactions were minimal. Out of forty students who were planning to participate in this joint research, only one got involved with a patients’ organisation, an association of people suffering from chronic pain. One of the activities of the association was to organise training sessions to help people coping with continuous pain. They wanted to know if their sessions

were successful; how they had affected the lives of the participants; if they had improved the quality of their lives; and if the participants now used less medication for their pain.

These questions were largely typical for most questions that patient organisations wanted to address: practical issues that had direct relevance for their work. I suspect that the students' lukewarm reaction can be partly explained by the practical nature of the questions that the organisations suggested. They appeared uninteresting and too thin for students who wanted to write an anthropological thesis. How could they devote an academic discussion to such simple questions? They rather seemed questions for an evaluation questionnaire.

The student who did connect with a patient organisation eventually wrote a thesis on the expectations people with chronic pain have toward the organisation (Schrama, 2006).

Conclusion: Uneasy bedfellows

Let me now try to offer a few possible reasons why patient organisations and medical anthropologists are less easy bedfellows than one might expect. And particularly: why so little research takes place between anthropologists and patient-researchers.

One reason may be that patients and medical anthropologists have different interests after all. Patients and their organisations are mainly focused on very practical matters – mostly medical and financial ones – that alleviate their problems such as pain and restrictions on treatment. Improvement of medical facilities and medication are probably the most outspoken ones. Research that serves their interests and which they want to promote and influence will therefore be largely in the field of biomedicine. Caron-Flinterman (2005: 105-116) who listed the most urgent problems among patients with Asthma and Chronic Obstructive Pulmonary Disease (COPD) confirms this. Their two, by far most urgent, problems were 'side-effects of medication' and 'hypersensitivity for all kinds of substances.' Social aspects of their problems, such as 'interference with social life', 'inadequate collaboration of healthcare professionals' and 'non-understanding by social environment' proved much less urgent. Their priorities for research largely reflected the above list. The author concludes that the patients 'prioritised biomedical research – research on the aetiology of the diseases and on new and better medication – above research on healthcare, social, or political issues' (p. 112).

Clearly, medial anthropological research is less ‘interesting’ for patients: it does not address their main concerns. Moreover, the social problems that patients did prioritise, hardly interest anthropological researchers. They are often considered too simple and too practical to carry out research that will be appreciated in anthropological circles. Anthropologists may claim that they are led by ‘what really matters’ to the patient (cf. Kleinman 2006) but in actual fact what matters to *them* is more likely to direct them in their research. What matters to them is rich ethnography (good stories) and theoretical innovation. Kleinman and Kleinman remark that:

What is lost in biomedical renditions – the complexity, uncertainty and ordinariness of some man or woman’s unified world of experience – is also missing when illness is reinterpreted as social role, social strategy, or social symbol ... anything but human experience ... Ethnography does participate in this professional transformation of an experience-rich and -near human subject into a dehumanised object, a caricature of experience. (1991: 276)

Instead of capturing their point of view and their experience, anthropologists may thus turn patients into objects of metaphorisation and academic debate and miss the point they set out to make. As a result – and ironically – medical doctors and biomedical researchers may be closer to patients and their interests than anthropologists who have made it their business to be close to them. Or am I now too optimistic about the medical profession?

A second reason, related to the previous one, may be that the idea of co-researching derives more from the anthropologist’s search for epistemological legitimacy and advanced methodology than from the patient’s strife for better living conditions. In other words, anthropologists may be interested in patients who play an active role during fieldwork and in the writing-up period because this produces better ethnography and anthropology. Patients may thus be used for the benefit of anthropological ambitions. It is not surprising then that the co-operation between patient- and anthropological researchers does not really materialise.

Thirdly, some anthropologists will look upon patient-led research with suspicion. Patient-led research is supposed to lead to applied research, which has never been fully accepted in mainstream anthropology. The old adage of non-intervention still holds strong, be it in a more subtle form than before. Small interventions in the everyday life of fieldwork are accepted and have become a normal part of the methodological canon of participatory observation. However, research that has been explicitly

designed to be applied and make the world better is as suspect as it was fifty years ago among the majority of anthropologists.

Even ‘icons’ of critical medical anthropology (such as – in alphabetic order – Baer, Estroff, Farmer, Fassin, Inhorn, Kaufman, Kleinman, Lock, Mattingly, Nichter and Scheper-Hughes), who explicitly state that their research is to change the wrongs and inequality in health and healthcare, did not invite patients as equal co-researchers. Patients and their fellow-sufferers are quoted extensively in the publications but further does their contribution not go.

In conclusion, in spite of a remarkable affinity between the anthropological ‘philosophy’ of patient-centred and experience-near research on the one side and patients’ interest in direct involvement in research on the other, the two parties hardly succeed in actually doing joint research. Anthropologists will have to give up some of their most cherished theoretical and methodological prerequisites to turn their on-paper interests in patient-led research into actual practice. Moreover, they should take into account that there may be more ‘theory’ hiding in the ‘simple’ questions that patient organisations raise than they – somewhat prematurely – assume. I am afraid, however, that only a small and somewhat marginal minority in medical anthropology is likely to take that step: those who already work in practice-oriented organisations and policy bodies, outside academia.

Notes

- 1 This text was presented at the fifth international conference “Medical Anthropology at Home” in Sandbjerg, Denmark. I thank the conference participants, an anonymous reviewer and Rebekah Park for their valuable comments. I also thank colleagues at home, in particular Renata Klop, Cees Smit and Maarten de Wit.
- 2 From its website: “Involve is a not for profit and non-partisan organisation which exists to put people at the heart of decision-making. We believe that better public participation can help solve some of the UK’s most pressing challenges and lead to the genuine empowerment of people. Involve works with organisations in government, the private sector and with the community and voluntary sector to promote more and better opportunities for people to get involved with national and local decisions, services and policy making. Involve provides research, training and practical help.”
- 3 The French speak of ‘*associations de malades*’ (associations of sick people).
- 4 These examples are derived from an earlier publication (Van der Geest 2007).

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