Reflections on Ethnography in Medicine

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Abstract

After conducting many years of 'classical' ethnographic fieldwork among refugees in Cyprus, I started field research in hospitals, community settings, and medical schools in Belgium, England, and Cyprus. My collaborations with clinical and biomedical scientists have led to an ongoing dialogue about ethnographic fieldwork and ethnographic writing. I discuss, through some ethnographic vignettes from my own research journey, some challenges that academics who work in medical research units may face in their engagements with ethnography. Stefan Beck's work speaks to researchers from different social, biomedical and clinical disciplines. I show that ethnographic work, such as that by Beck, raises the profile of social scientific work in medicine and demonstrates the potential of ethnography in medicine.

Keywords: Anthropology, Stefan Beck, medicine, ethnography, social sciences, biomedical sciences, interdisciplinarity

In Memory of Stefan Beck

It was a shocking blow when Stefan's wife, Gisela, called us from Australia, in the first week of spring 2015, with the devastating news of Stefan's death. His untimely loss coincided, for me, with the start of a large study on death and memorialisation.¹ Stefan's death and my research for this project have since been intertwined and I am grateful I can 'memorialise' Stefan and his work through my contribution in this special issue. One of the many messages in the online Book of Condolence for Stefan Beck read: 'He was good to think with'.² It was posted by Jörg Niewöhner, Stefan's friend, colleague and long-term collaborator (see his contribution in this issue). It saddens me that I am not able to 'think with Stefan' in person anymore. I fondly recall conversations in our Kaimakli garden near the jasmine tree, brought by Stefan and Gisela, or over lunch at the *mairko* Mattheos, in the heart of old Nicosia, which Stefan frequented.

¹ An interdisciplinary study, funded by the UK's Arts and Humanities Research Council, on dying, death and memorialisation: *Remember Me. The Changing Face of Memorialisation*, more on http://www.hull. ac.uk/rememberme (last accessed on 18 May 2016).

² See obituary and condolences on https://easst.net/article/obituary-stefan-beck-1960-2015/ and the complete online Book of Condolence on https://ethnoserver.hu-berlin.de/kondolenz/ (last accessed on 18 May 2016).

Stefan Beck was both a friend and a truly inspirational fellow anthropologist. I feel academic kinship with Beck for three reasons. Firstly, he was a scholar who thought deeply about anthropology, and social science more broadly, and especially how social anthropology intersects, or could intersect, with other disciplines. Beck was working across different fields and it is his engagement with medicine in particular that strongly resonates with me. For six years or so, influenced by both professional and biographical events, I have focussed my research on the social and cultural dimensions of health and illness. Secondly, Stefan Beck wrote in multiple languages, his native German and English, and worked in different academic traditions (see, for instance, Beck 2008, in which he writes about German-speaking cultural anthropology). As required from an academic who worked for a decade in Belgian academia, I experienced the joys and struggles of writing in more than one language and being embedded in a disciplinary tradition that differs from British social anthropology. Finally, Stefan Beck conducted multiple ethnographic studies on Cyprus and has been instrumental in establishing a medical anthropology hub on the island (Amelang et al., 2011; Beck, 2005, 2008, 2011). I started my academic career with a long-term ethnographic study of refugees on Cyprus (Dikomitis, 2012).

It was a biographical event that sparked my interest in studying medicine. When I was pregnant with our daughter, and still inexperienced in all things related to pregnancy and childbirth, I was confronted with contrasting discourses. What follows is one example about how childbirth was differently perceived by our Belgian and Cypriot gynaecologists. I asked our gynaecologist in Nicosia for his advice on giving birth. He said to us:

We are not barbarians here. We do not let women suffer. Without any doubt you should ask for an epidural. In fact, I recommend a C-section. This is best as it is painless and has the best outcomes for mother and child.

When I returned to Belgium at the end of that summer to start teaching, I asked the Belgian gynaecologist the same questions. She said something along these lines:

You are here in the best hands. We try to do everything natural here. If you insist, you can have an epidural, but not a caesarean unless it is absolutely unavoidable. We don't cut women open if it is not necessary. It is always best to let nature run its course.

I wrote an extensive research bid on cultures of pregnancy and childbirth (Béhague *et al.*, 2002; Ivry, 2009; Johanson, 2002; Sargent and Bascope, 1996; Walsh, 2006). I was especially interested in the turn toward the 'natural', or 'traditional', and the views I encountered around 'de-medicalisation' in pregnancy and childbirth, but also around breastfeeding and childhood vaccinations. I never obtained sufficient funding

that would allow me to carry out long-term fieldwork in this area, but by that point medical anthropology had caught my attention! I started research on the socio-cultural dimensions of health, illness and the organisation of healthcare.³ My venture into the field of medicine came with some unexpected joys, but also with its own challenges.

When I was conducting 'classical' ethnographic fieldwork I did not encounter many scholars who considered 'the social and cultural' of insufficient importance to be studied at length or in-depth. I did not have to defend why I thought an ethnographic approach was the way forward. I was not in need of the kind of encouragement that my doctoral students, who work at the interface of social and medical sciences, often seek from me. I conducted my fieldwork and wrote up my ethnography, rather blissfully, as an anthropologist among anthropologists. My colleagues and collaborators were all scholars who shared the same 'academic world view' and who did not question my methodology or critique the narrative style I used in my writings. However, my collaborations, in more recent years, with clinicians and medical scientists have led to an ongoing dialogue about ethnographic fieldwork and ethnographic writing.

My contribution to this special issue is simple enough. I do what anthropologists do as a matter of course: I use precisely the incidental every day of my academic life to discuss some of the practical challenges I faced around ethnography in medicine.

Medical Anthropology

There is a large ethnographic literature of medicine. Medical anthropology includes a wide range of topics and specialist areas, including work on the socio-cultural aspects of health and illness, the organisation of healthcare, the social nature of biomedicine and public and global health. To name but three examples of recent work with superb ethnography: Elizabeth Davis' (2012) ethnographic study of psychiatry in northern Greece; Karen Nakamura's (2013) ethnography of mental illness in Japan; and Alice Street's (2014) ethnographic account of how biomedical practitioners work and struggle in a public hospital in Papua New Guinea. In addition to ethnographies of medicine, there are many ethnographic accounts of medical education and medical students (see Atkinson and Pugsley, 2005, for an overview of this ethnographic tradition). The classic is Howard Becker's *Boys in White* (1961), followed by contemporary work by, among others, Rachel Prentice (2013) who turned her attention specifically to the

³ This included a study on the evolution of mental healthcare in Flanders, a project on health inequalities in the north of England (Dikomitis, *et al.* 2014), an evaluation of the use of electronic risk assessment tools in primary care (Dikomitis, *et al.* 2015) and different studies on primary headaches (Dikomitis, *et al.* 2013; Ahmed, *et al.* 2014; Dikomitis, *et al.* 2015).

training of surgeons. This sub-field also includes two monographs by medical doctors who became anthropologists: Simon Sinclair (1997) conducted participant-observation in a London medical school, and gynaecologist Claire Wendland (2010) worked among Malawian medical students. The fast-growing body of ethnographic work on medical topics has, on the whole, been produced by anthropologists, social scientists and clinicians who received anthropological training (and who often take up positions in universities' Anthropology departments). The most well-known of such clinicians-cummedical anthropologists are Arthur Kleinman (1980, 1988, 2008) and Paul Farmer (2001, 2004). Stefan Beck (2008) was particularly inspired by Farmer's activist research agenda for medical anthropology.

Stefan Beck, in turn, was an inspiration to many social scientists working in the medical field. I highlight below some of his many contributions to the field. Beck (2008, 2011) collected rich ethnographic data around a social gathering of Cypriot organ donors and recipients of bone marrow grafts. He conceptualizes the relationships between these donors and receivers as 'biosocial relationships', which have 'the potential to engender new visions of the social, new visions of the self, and new visions of the biological' (Beck, 2008, p. 26). In a next paper, Beck (2011) focuses on one such biosocial relationship. He puts forward a compelling ethnographic account of a young Turkish Cypriot man who saved the life of a young Greek Cypriot girl through the man's anonymous donation of bone marrow cells. Beck analyses the relationship between the donor and the recipient through the 'biomedical platforms'⁴ of bone marrow transplantation and immunophenotyping. Such bone marrow donations create a biological and a social relationship, which can also be heavily invested with political meaning, which is the case here. Indeed, in combining resources, patients, NGOs, volunteers and biomedical experts create a new type of 'body cosmo-politic', which can confront the 'state-centred type of biopolitics' (Beck, 2011, p 115). Beck was engaged in a cross-cultural comparative study on genetics in Cyprus and Germany. Through his ethnography Beck (2005) demonstrates the influence of biomedicine on concepts of health and how biomedicine can also determine marriage strategies as was the case in Cyprus. Throughout his work Stefan Beck analyses the complex relationships and interconnections between the social and the biological. The thread that binds his multiple studies is a strong engagement with ethnography.

In what follows I will discuss some of the challenges that academics who work in medical research units face in their engagements with ethnography.

⁴ The term was introduced by Peter Keating and Alberto Cambrosio (2003) to analyze the transformation of medicine into biomedicine since the 1950s.

Ethnography in Medical Research Environments

I strongly believe in the importance of such ethnographic research, perhaps increasingly so in this era of growing disinvestment in anthropology. I have witnessed, in Belgian and British academia, the gradual disappearance of Anthropology departments (now often only small 'units' in larger schools) and the withdrawal of several Anthropology degrees. If the discipline is not expanding but contracting, it seems paramount that researchers find a way of *doing* ethnographic fieldwork and writing ethnographically outside these disappearing departments.⁵

I am specifically concerned here with ethnographers who work outside the welcoming homes of Anthropology or Social Science Departments. These include academics conducting ethnographic work who are employed in medical schools or medical research environments (such as clinical research centres or hospitals). Medical fields, both in and outside academia, habitually have very different epistemic traditions in which, often, a positivist paradigm dominates, and where quantitative social research methods are still privileged over qualitative approaches.

What follows is a short account of some of the challenges I faced with regards to methodological issues when I conducted 'hospital ethnography'6 in a psychiatric hospital in a provincial town on the Belgian-French border. My informants were no longer Cypriot refugees who, on the whole, always welcomed me and liked the idea of me 'writing a book' about them. In fact, I do not recall discussions about the particularities of the ethnographic method with my Cypriot informants. My methods were not questioned or critiqued. The Turkish-Cypriot Kozanlılar laughed when I insisted on getting up at five in the morning to get the fresh goats' milk from the shepherd, and they were grateful for an extra hand when making cheese and going to the local markets to sell the bread we made. They all knew I was an academic and was planning to write a book, and although they might not have been familiar with the term 'ethnography', they understood it as Ruth Behar (1995:3) defines it, 'a strange cross between the realist novel, the travel account, the memoir, and the scientific report'. Things were very different in the hospital. I was confronted with complex ethics procedures to gain approval from different ethics committees. I was asked, time and again, what exactly it was that I wanted to do. Why was it important that I should do the night shift as well? Surely,

⁵ There is indeed a growing body of ethnographic knowledge being produced by non-social scientists. For instance, Ball and Ormerod (2000) discuss how ethnographic methods can be applied in engineering design and Maginn (2007) highlights the potential of applied ethnography in urban regeneration partnerships. See also Pelto's recent book on applied ethnography (2013).

⁶ The journal Anthropology & Medicine devoted a special issue to 'hospital ethnography' (see Long, et al., 2008).

many claimed, I could get *all* the information for my research during the day. And why did I want to spend a week with the cleaners' team, or in the kitchen? Did I *really* want to talk to the porters? What could they possibly have to say about the reforms in mental health care, or about staff's perceptions on the evolution of psychiatric care? 'But they are all staff of this hospital and some have worked here for decades,' I argued. 'Cleaners, cooks, porters and administrators are part of the social structure of the hospital. If I want to write about the complex culture of a mental health institution I need to spend time in that social setting, with as many people who live and work there and observe, and where possible participate, in their everyday lives.' Can you not just ask people about their lives? My replies always paraphrased Blommaert and Dong (2010, p. 3, emphasis in original):

People are not cultural or linguistic catalogues, and most of what we see as their cultural and social behaviour is performed without reflecting on it and without an active awareness that this is actually something they *do*. Consequently, it is not a thing they have an opinion about, nor an issue that can be comfortably put in words when you ask about it. Ethnographic fieldwork is aimed at finding out things that are often not seen as important but belong to the implicit structures of people's life. Asking is indeed very often the worst possible way of trying to find out.

Ultimately, I was granted permission and I started fieldwork. Many of my informants in the psychiatric hospital, however, were highly educated individuals who had been trained to think about the world in a particular way, and consequently some had strong views on how I should conduct my research and what the end results would be. A survey and a quantitative approach would surely be more professional? More scientific? More true and more objective? 'But there is no such thing as objectivity,' I objected, and I tried to explain, while I politely accepted print-outs of a large numerical dataset of hospital admissions. It was the first time that I needed, and wanted, to explain that ethnography is a social form of research, that it is predicated on my personal commitment, and that I was really committed to sharing the everyday life with staff and patients. It was a different kind of trust that I needed to earn in this medical environment. With the Cypriot refugees I had also been confronted by issues of acceptance because of my ethnic background, the fact that I was a *Greek* Cypriot refugee's daughter (Dikomitis, 2012, p. 29-33). This time it was my professional background, and specifically my methodological approach, that was questioned and not understood.

At present, there are only a few studies on how medical and social scientists relate to each other. Albert *et al.* (2008) examined the perceptions about social sciences through in-depth interviews with 31 biomedical scientists who are members of peer review committees at the Canadian Institutes of Health Research.⁷ The majority of their respondents questioned the rigour of social science methods and the validity of data collected via those methods. Quantitative methods were perceived as more 'objective' and 'reliable' and their respondents argued that qualitative studies need a quantitative element for data verification (Albert et al. 2008, p. 2526). The research team describe that most of their participants had limited, and occasionally inaccurate, knowledge of social sciences. My experiences in the medical field echo this. One example is how medical students think about social sciences. I examined this through fieldwork in one medical school, where I was teaching optional health sociology and medical anthropology courses. The students showed great enthusiasm, but simultaneously expressed concern and unease with the material and 'the way social scientists think', as one student put it. After long-term participant-observation among medical students, I obtained a good insight into both the formal and the hidden medical curriculum. Institutional slang is one of the areas through which a hidden curriculum can be ascertained (Hafferty, 1998). The term 'fluffy stuff' is a good example of such slang used in the medical school where I conducted fieldwork. Here is how students understand it:

Fluffy stuff: the aspect of medicine that is repetitive and easily understood using common sense. E.g. patient has been diagnosed with cancer – how does that make them feel? Obviously awful. Or what are the social effects on an elderly lady who has broken her hip and is now not as mobile as she was before? She is not as independent at home so she may need help doing this she used to do, which might make her depressed and even embarrass her or she may even need to go into a home and lose all independence, etc. These are very easy to understand, obvious and often self-explanatory topics. (Charlotte)

The fluffy stuff is something that is a bit more common sense where you can sort of talk about it without researching it. (Ashak)

The 'fluffy stuff', according to my informants, includes learning content from the medical humanities, sociology, psychology, professionalism, ethics and public health.⁸ My data show that sociological knowledge is perceived as 'common knowledge' which 'you can Google' and it is always left to last, by clinical tutors to teach it and by students

⁷ Biomedical scientists usually hold a high status in the health research field. See Clarke (2001) and Clarke *et al.* (2003).

⁸ An editorial in the *British Medical Journal* (1980) was entitled 'More anthropology and less sleep for medical students' and it reflects on a possible place of anthropology in medical education. The (unnamed) author divides the subjects in the medical curriculum into two distinct categories: the 'lions and tigers' (including surgery, anatomy and physiology) and the 'alleycats' (including psychology, sociology, epidemiology, statistics, anthropology). Social sciences have now been more robustly integrated in the undergraduate medical curriculum (BeSST, 2016), but it is still unusual to find medical anthropology as a stand-alone core subject.

to study it. This understanding is reiterated by each new cohort, and, worryingly but not surprisingly, is also very much alive among staff in medical research environments. Such staff includes, in addition to social scientists, academics from different scientific cultures who engage in distinctive research practices: basic scientists, clinical scientists, epidemiologists and medical educationalists. I believe it is fair to conclude that the majority of scholars working in medical academic units do not have a robust understanding of ethnographic methods. This is evidenced by the regular contributions in medical and clinical journals which outline the basics of ethnography – sometimes in sweeping generalised terms – and highlight ethnography's potential for medical research (see, for instance, Dixon-Woods, 2003; Goodson and Vassar, 2011; Greenhalgh and Swinglehurst, 2011; Pope, 2005; Savage, 2000; Reeves *et al.*, 2008; Van der Geest and Finkler, 2004).

But where does that leave the social scientists in medicine, and especially the ethnographers among them? The same Canadian research team subsequently examined perceptions held by social scientists working in medical research units (Albert and Paradis, 2014; Albert *et al.*, 2015). They conclude that most social scientists working in Canadian medical schools and medical environments perceive themselves 'misfits or outsiders in their work environment' (Albert and Paradis, 2014, p. 380):

For most of our participants, being in medicine implies something similar to moving to another country, a country with its own rules, expectations, value system, and legitimate strategies to establish reputation. For all participants in our study, adaptation was necessary. For some, adaptation was successful, for others it failed. (Albert and Paradis 2014, p. 381)

Sociologist Maria Tsouroufli (2012) paints an even bleaker picture of her professional experiences in a British medical school – which she describes as a 'war zone' and 'battleground'. She felt marginalised as a feminist academic and as a social scientist with expertise in qualitative methodology: 'I was told that as a social scientist I should understand that most things were a matter of perception and I should not get upset' (Tsouroufli, 2012, p. 474).

I do not experience working in a medical research environment in such a negative way, although I have changed my research practice. The main difference is that I now mainly work in a research team, whereas before I carried out all research activities on my own. The main challenge for me, however, concerns the writing style of my academic work. I always had time and space to write ethnographic narratives and that has changed and is, for me, the major challenge now that I work in interdisciplinary health research teams.

Writing Ethnographically

During a professional development event at a medical school we were asked to list our priorities to develop our careers. I explained that completing my second ethnography was my top priority. After all, during my time in a social science department it had been drilled into me that monographs were essential for academic promotions. At that event, however, I was told by a very senior academic that I should revisit my priorities. 'Books, certainly ethnographies, are not valued in medical schools. Books are things you write on Saturday mornings.' This view was echoed by many biomedical and clinical scientists present at the event. Since then I have not written another book. I focussed on journal articles and research reports. Much of my research time has also gone into the writing of bids for external income, research protocols, ethics applications and study materials. Indeed, in many countries, there is an encroachment of the science publication and research model on a large number of disciplines.⁹

The publication benchmark in medical research units is set by the massive productivity of biomedical scientists and epidemiologists who write 10 to 15 papers per year. The standard template of such journals do not allow much space for writing articles in the narrative style characteristic of such ethnographic texts 'that everyone can read'.¹⁰ Clinical and medical journals generally adhere to a fixed format with set sections which are on average each 600 words long: 'Background', 'Methods', 'Findings', 'Discussion', 'Strengths and Limitations of this Study'. This template is increasingly being used in social science journals too, especially in those journals that focus on quantitative research. Anthropology is, in that respect, more situated on the boundaries of social sciences and humanities. Albert and Paradis (2014, p. 382) suggest that many social scientists in medical schools shift their academic production:

Several have had to compromise or dilute their work to fit the dominant publication model in medicine, that is articles in the range of 3,000-4,000 words, characteristically without theoretical grounding or substantive literature review and discussion.

An additional challenge is that ethnographic studies rarely find their way into clinical, medical and healthcare journals. It remains indeed challenging to publish such research in leading medical journals. The recent debate around the rejection policy of the *British Medical Journal* (BMJ) is a good case in point. The BMJ rejects, according to

⁹ Of course, also academics in social science departments are increasingly engaging with these different writing genres: administrative texts, audit forms, feedback reports, to name but a few. A recent collection (Wulff, 2016) explores the wide range of writing genres anthropologists are expected to master. One reviewer pointed out that books are increasingly devalued also in the humanities.

¹⁰ I refer here to Kristen Ghodsee's (2016) recent book, *From notes to narratives: writing ethnographies that everyone can read*, in which she explores the craft of ethnographic writing.

Greenhalgh *et al.* (2016, p. i563), qualitative research on the grounds of 'low priority' and 'unlikely to be highly cited'. The BMJ's editorial team responded to Greenhalgh and colleagues as follows: 'We do not prioritise qualitative research because, as mentioned in our information for authors, qualitative studies are usually exploratory by their very nature and do not provide generalisable answers (...) We have chosen to focus our efforts on quantitative research that reports outcomes that are important to patients, doctors, and policy makers' (Loder *et al.*, 2016: i641).

To conclude, I have used anecdotal evidence in this reflective piece to highlight some of the challenges that social scientists in medicine, who are engaged with ethnography, may face. There is of course much more to explore, especially about the different ontological and epistemological views researchers in medical research units hold and how these views may acts as barriers to the full acceptance of ethnography. It seems essential that social scientists in medicine join efforts to ensure that ethnographic research acquires more visibility and scientific authority in the medical field. For me, it is precisely scholarly work such as that by Stefan Beck that raises the profile of social scientific work in medicine and demonstrates the potential of ethnography. Beck's research speaks to researchers from different social, biomedical and clinical disciplines precisely because it goes beyond what Beck (2008: 17-18) called 'fashionable interdisciplinary conversations'.

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