The significance of presence

Personal experience and research among incurable cancer patients

Ellen Kristvik

Is personal experience a productive resource when carrying out a research project, or is it rather an impediment, binding the researcher to her own preoccupations instead of the informants' own concerns? I will pursue that question with reference to a research project on user participation in treatment decisions for cancer patients at an incurable stage. In that discussion, the significance of presence is relevant as a methodological as well as a thematic issue. I will explore how my own experiences as a close relative of seriously ill cancer patients affected the research process. Encounters with three patients with inoperable lung cancer are discussed against the background of the memories of my own experience of the cancer-related deaths of my parents and husband. The discussion shows how personal experience and involvement with the issues at stake directed my attention as a researcher and sharpened my perception of some factors more than others. At the same time, I found myself to be particularly attentive when informants talked from an unexpected point of view. While personal experience related to the research topic did not provide instantly applicable answers in itself, it did contribute to the dynamics of the research process, in promoting questions and exchanges in the researcher-informant interaction that would have been unlikely to have arisen otherwise.

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What is the relationship between personal experience and anthropological understanding? Is direct experience a prerequisite for adequate comprehension? Or is it rather the attainment of a certain distance, actively sought in a real or constructed outsider position that allows for a clear perception and recognition of what is taking place? These questions are related to the topic of *presence* as a methodological issue. I will discuss the possible extension of the classical claim for authority as a field worker 'having been there', to experiences derived from an anthropologist's personal life: to what extent and in what way do my own illness-related experiences have a role to play in how I produce knowledge as an anthropologist? As I hope to show as this paper evolves, the significance of presence is also highly relevant to the theme of the project itself.

Achieving trustworthy accounts of the position of 'the Other', or capturing the 'native's point of view' has been a primary concern for generations of anthropologists. From the early days of the discipline, anthropology has emphasized the crucial role of experience as a source of knowledge, hence the significance ascribed to 'being there' as a claim for legitimization and authority (Geertz 1988). Furthermore, a paramount concern in anthropology is how knowledge about a different cultural context (whether the researcher's own or not), due to the very contrast it may imply, can shed light on another cultural setting and the people who live there.

The issue of true knowledge has sometimes been posed as a question of membership. In a postulated dichotomy between outsiders and insiders, an insider position has been claimed to be necessary for an avoidance of misleading, even oppressive, representations (Stone & Priestley 1996). This has been vigorously asserted not only by proponents from the disabled movement, but also from third world or feminist perspectives, or those related to questions of sexual disposition. A common position or shared experience has then been deemed necessary to be able to make valid statements as a researcher or someone else engaged in an attempt to understand a member of a certain community or category, especially when that implies a vulnerable or underprivileged position. According to this view, only insiders have the right to make a legitimate claim as 'true knowers' (op cit).

From an anthropological perspective, neither the insider's points of view, nor what can be perceived and deducted from an outsider's position, constitute privileged ways of accessing knowledge. Both are fallible and disputable. A scholar's report of an observation made is no 'direct access to truth', nor is someone's personal experience or the account of that. And what is most thoroughly hidden from us is often what is most immediately before our eyes. The moment always escapes us, and can only be understood in hindsight (Strathern 1992).

Some of the dilemmas implied in this are further intensified when the anthropologist directs her ethnographical gaze to her own neighbourhood. Maintaining a distinct division between an insider and an outsider position is more complex in anthropology at home (Strathern 1987; Okely 1992). Is intimate familiarity with the research issues beneficial to the work, or a complicating factor?

This paper is related to an ongoing research project which has a deep connection with my own life. The project on decision-making processes regarding medical treatment for cancer patients in a palliative stage is connected to my personal history in several ways and my own experience has been a motivating factor as well as a point of reference for this ethnographic research. It addresses questions I have wanted to explore for a long time. In some sense it began when I was a teenager, with my father dying in a hospital far away.

Oneself as a stranger

I don't have many material objects left from the time when I lived in my parents' house. The difference in storage space between that house and our new residences was a limiting factor in itself when my sisters and I cleared the home of our childhood. I had to let go of a lot. Among the few things I did keep, however, is a box I hardly ever open. I know it is there, and that is enough. This box contains correspondence between my father and me; two sets of letters separately kept. They cover a period of one year and, at the time of writing this article, were composed nearly forty years ago. The letters from my father to me have been with me since the time I received them. The letters from me to him were kept by my mother after his death. The last letter my father wrote is dated shortly before he died, my last letter to him was written even closer to the day of his death. During the year of his sickness, my father stayed in a hospital in the capital, far away from my hometown. It is especially my own letters that I find difficult to read. When I did try to do that, I stopped fairly soon. They display a disturbing contrast between that seventeen year old girl's stories about everyday life at home, and the way I now think about that time. I don't let go of that box, however. It remains an open opportunity for exploration which I might be more ready to use at a later point in time.

My father spent the last year of his life away from home and his children because of an arduous attempt to prolong his life. Paradoxically, what was intended as a life extension deprived us of a chance of being together during very decisive times. Could it have been otherwise? For a forty-seven year old man, father of four, who had hardly been ill before, was there another option besides going for maximum treatment, even if the chances of succeeding were meagre indeed?

In the cultural context to which we belonged, this was hardly a valid question. Extension of life itself has and had a paramount value, which easily comes to dominate over other concerns also considered valuable, like the actual quality of the life gained or the days that remain. Since then, this development has only accelerated (see Kaufman 2009). Technological development, with its steady advancement in possibilities for extended longevity, creates a momentum in itself; the very existence of the technology makes it difficult to abstain from its application. Researchers such as Aries (1981), Lock (2002) and Hadders (2011) have described the implications this has for relatives of a dying person in terms of an alienating environment at the time of death. Another possible side to this, as my story conveys, is the reduced chances of being together at all in the last stage of life.

Another thing that characterises the story of my letters is the silence surrounding the issue of death. The letter-writing girl does not mention the impending death in what she writes, but nobody spoke to her about it either.

My father did not respond to the treatment. Still, he was kept in the hospital and the treatment continued till the very last stage of his life. Thus, some kind of hope was stubbornly maintained, in spite of the indications of his deteriorating condition. I do believe that it is possible to maintain hope and realism at the same time. But miles and miles away as I was, the consequences of the declared optimism were complicated.

The absence I lived with was double; in addition to the physical distance, I lacked a language that could help me navigate the situation in which I found myself.

My father's sickness was not my first encounter with fatal disease, and it has not been the last. Both of my grandparents on my father's side, who lived upstairs from us when I was a child, died before him. Later I lost other people who were dear to me, too. But my father's death stands out as pivotal. For one thing, those who had died before him had been much older, closer to a natural point of departure from this life. My father was not yet fifty. And though my grandparents were close to me, too, I was not dependent on them in the same way as I was on my father. Another thing that differed, and represented a striking contrast to later experiences I was to have, was the geographical distance between my father and me at the stage when his health was rapidly deteriorating and death was drawing near. I was able to visit my father one month before he died. That is a precious memory, but my recollection of him ends there. In the letters I wrote afterwards, I continued to write as if I could freeze that situation, and keep things as they were at that point. And all through our correspondence my letters kept what to me now seems like a forged cheerfulness and a spurious assurance about everything being fine with me and my younger sisters, for whom I was in charge while my mother was away. Thinking back on it now, I am only too painfully aware of how afraid I was, and how helpless I felt in the face of the challenges involved in taking care of my two younger sisters who were bewildered, like me, and strongly opposed to my attempts to replace the authority of our missing parents. In my letters there is no trace of that. Neither do my letters relate to the steadily weakening condition of my father. I had no clear picture of it. I was not there.

To me this became an indication of a void – like an experience I have had, but not yet captured – and the disturbance that this created was part of what motivated me to take up a project among cancer patients and their relatives forty years later. In the meantime I had said farewell to my husband and my mother, who both died of cancer. But in these cases I had been able to be present, sharing that critical time with them. And I knew something about what that difference had meant to me.

During the three years that passed from the day that my husband got the message about the metastasis of his malignant melanoma, until the day he died, his disease was my main priority. Contrary to what had been the case with my father, I was able to be with him throughout the course of his illness and stay by his side till the very end.

I miss my husband. But it is a different kind of loss than the death of my father. It has not left me with the same kind of void. That I was able to be there, and could say goodbye to him, has been healing, and has made it possible to go on. And when my mother became terminally ill, also with cancer, half a year after the death of my husband, I was grateful that this happened in that order, allowing me also to be present during the last stage of her life. It was tough, but it did not leave me with a hole inside.

Shifting to a researcher's position

The experience of the illness and death of my father was a motivating factor in my decision to go for nursing training, and after that to work within hospice contexts. But that was somehow not enough. After having studied to become an anthropologist, and having worked with what were apparently very different issues among TB patients, shamans and sex workers in Nepal, questions related to the end of life came back to me, as a wish to explore the implications of getting a fatal diagnosis. I was already intent on applying for a research project related to the meaning of cancer when my husband fell ill. His illness delayed that project for several years. But when I finally began anthropological fieldwork among incurably ill cancer patients and their relatives, it was a project with obvious connections to several events in my personal life. It was related to the sickness and death of my mother and my husband, where I had been in the complex role of a relative caring for someone who was fatally ill. But underneath all that, as a more decisive driving force behind the project, and highly influential for the way later experiences were lived through, was the much earlier part of my history: the fatal illness of my father, and my absence during that time.

The fieldwork implied being present when people experienced the turmoil of getting a fatal diagnosis, and going through times increasingly marked by serious illness. I was there when the diagnosis was delivered; I was with them when they came to the outpatient clinic for chemotherapy and when the illness itself, or the side effects of the treatment, sent them back to the hospital. And throughout this process, as often as I could, I talked with them about what they were going through.

My research question, to start with, concerned patients' involvement in decisions concerning their treatment. When no curative treatment is available, therapeutic measures like chemotherapy and radiation may still be applied with an intention of achieving a limited life prolongation by attaining a temporary halting effect on the progression of the disease. But the potential benefit is uncertain and the side effects, not to mention the additional costs in terms of time expenditure and mental energy, may be considerable. I wanted to know how decisions were taken regarding what was to be done. Were patients and their relatives themselves involved in those decisions and, if so, how? To what extent did they want to be involved?

Encouragement of patient participation in treatment decisions does not have a long tradition within the practice of medicine. Until the middle of the twentieth century decisions regarding therapy were mostly left to doctors alone, and the limits of medicine and the issue of death were submerged in silence (Katz 1984; Illich 1976; Glaser & Strauss 1965). But while patient autonomy and self-determination have become better established issues on the medical agenda (Beauchamp & Childress 1989), the relationship between practitioner and user is inherently based on an unequal distribution of knowledge. Patient involvement in treatment decisions cannot be reduced to a legal issue, ensured by simple procedures aimed at obtaining informed consent (Drought & Koenig 2002; see also Kristvik 2011b). Communication with patients about a life threatening diagnosis remains a challenging task that is taken on with different degrees of openness (Taylor 1988; Good et al. 1990; Christakis 1999; The

2002). The freedom to abstain from difficult or impossible choices can also be considered an important right (Bosk 1979: 258-259; Kaufman 2005). The opportunity to talk about a bad prognosis and impending death, however, is not only a prerequisite for informed participation in therapeutic decisions, but also a crucial part of care in the last stage of life (Saunders 1959; Kübler-Ross 1969; Byock 1997).

On the question of understanding: Reports from the field

From my personal experience I knew something about the risk of losing precious time together with a loved one, because of a futile rescue attempt. Was this awareness helpful for the project, or was it rather an obstacle? Did it sensitize me to what might be important for those I met? Or did it dispose me to impose myself as researcher on the data, with an inclination to write about my own preoccupations, instead of my informants' own concerns?

My own experience had led to a feeling of betrayal, a sense of having been let down by the health care system; deprived of a precious opportunity that would never return. I was highly sceptical of the treatment policy that had prevailed at that time, in which the sustenance of hope seemed to be a reason in itself for continuing problematic therapy. Nor was I convinced that things had significantly changed in those respects. I thus entered a field where I was emotionally involved, and had strong opinions, too. There are obvious pitfalls in this, but the question of whether I fell into them, or how deeply I fell, can be seen as an empirical issue. I will therefore discuss it with reference to my encounters with three different patients, who all received the diagnosis of incurable lung cancer while I did my fieldwork in Middletown Hospital.

David: A fighter till the bitter end

David, one of the first patients to be included in my study, was a man who clung to hope till the very end. He was already suffering from severe health impairments (including heart problems and chronic obstructive pulmonary disease) when he received the cancer diagnosis. David reacted to the message with a prompt demonstration of his ability to understand the technical terms that were used by the doctor, and his capacity to match these with more of that kind. His next concern was convincing the doctor about his survival capacity and mental strength, launching into an elaborate story about how he had been at death's edge and still recovered.

David was intent on making it, this time too. He requested, and got a maximum amount of treatment and kept speculating on alternative measures, some of them quite inventive, in case the chemotherapy should fail. At subsequent consultations with hospital doctors, he kept referring to his extraordinary survival capacities. With one exception, which was not well received by David, most of the doctors patiently listened to him, or more or less gently diverted his attention to something else.

When his health deteriorated so much that he had to be hospitalized, David told his friends and family to stay away. He did not want them to see him in such a miserable state. He let me in, however. A few days before he died he complained to me about his increasingly weak legs, and the need to restore his strength through rigorous training. The next time I came I was not able to see him because the nurse was tending to him right then, and when I came back, he had died the previous day. “It was not a peaceful death,” said the nurse I spoke to. The patient had been visibly afraid, and upset about the breathing problems he had had for so long, but which intensified towards the end. David died in agony.

David was a person who made a big impact on me, a person it was highly interesting and challenging for me to talk with. He had been through a lot and his staying power was extraordinary. But it was difficult for me to follow him through the course of his illness; difficult to hear his zealous ambitions, largely unchallenged by the doctors, about getting cured, when I myself had no faith in that happening. It was not my task to confront him with what I perceived to be a more realistic prognosis, but I nevertheless had the feeling that such a confrontation was in prospect, and was something which would become increasingly devastating as time went by. The talk I had with the nurse about the day he died somehow confirmed that, too. It also deeply affected me to know that David died alone, not because of geographical circumstances, but because of the stark denial of his weakening condition – or his insistence on keeping up hope until the bitter end.

Could this anguish at the time of his death not have been ameliorated? Did David really have to die so utterly alone? Was the benefit from his persistent optimism great enough to justify the lack of a coherent attempt to challenge his perception of the situation he was in, and hence help him prepare in some way for what lay ahead?

David’s fate reminded me of my own lack of preparedness for the death of my father. But how confident could I be about the transfer value in that? It was only an assumption that it would be possible for a doctor to get through to David with a more realistic message about his prospects, a hypothesis that was impossible to verify in advance. His vehement reaction to the one doctor who had tried to confront him did not indicate that preparing him for a steadily declining condition was an easy task. The current organisation of doctor-patient consultations at the hospital, in which the doctors continually rotated so that they kept being new to the patients they met, did not make it any easier (see Kristvik 2011a). But even if that system were changed, would David have been more receptive?

Though I had briefly met some of them, my contact with David’s relatives was not close enough to try to meet them after David’s death in order to talk about their perspectives. In many ways David was an extraordinary person and patient. But even so, his coping strategy is one example of something which is indicative for many others, however dissimilar they may be in many other respects. Jon, for instance, was apparently so different, yet his experience further illustrates some of the themes that struck me in David’s story. And in this case, I also had the opportunity to talk to Gro, his surviving spouse, after he had died.

Jon and the abyss of the unmentionable

I was there when Gro and Jon, after a long series of tests and several weeks of investigations, were told about Jon's inoperable lung cancer. What was particularly striking to me at that time was the way feelings were openly expressed. Emotionally loaded as that kind of consultation is, only a few of the patients I had observed in this situation, had actually given vent to feelings of grief then and there. What was more common was a quiet acceptance, – due to numbness, maybe. The questions posed, if any, would typically be of a practical nature. When crying did happen, it was most often by wives in the role of accompanying partners, with the patient himself showing signs of embarrassment, in some cases asking the health workers to provide "something to calm her down."

In this case, too, it was the wife, Gro, who first burst out in tears in response to the doctor's message. "I have been so afraid," she said. But when Jon responded by turning to the nurse, asking for Kleenex, he added: "And some for me too, – when she cries, I start too." Husband and wife cried together. This was not common. The doctor was gentle and sympathetic. Without rushing, he soon turned their attention to the treatment, and the possibilities for positive effects in that.

The course of the subsequent illness was pretty much as could be expected. For a while in the beginning the treatment seemed to have a positive effect. I remember how the couple enthusiastically called out to me when seeing me in the hospital corridor. They had just received the latest test results; the size of the tumours was reduced. Their relief was tremendous.

We kept contact throughout the rest of that year. After the rather short period of improvement, this was a story about a steady decline. In addition to the illness itself, Jon suffered from several side effects of the treatment, and it was sometimes difficult to separate one from another. After a fall in connection with a spell of dizziness his leg had to be plastered and he was bound to a wheelchair. In addition to that, he was repeatedly hospitalized with fluid in his lungs.

"I have not lost my good spirits," Jon kept telling me, when I asked how he was doing. Gro also answered in the same positive vein: "Things are going well." They both expressed a determination to hold on to hope, even when Jon's condition was rapidly declining. Less than two weeks before he died, Jon asked for still another course of chemotherapy. This was granted to him, but his condition quickly declined after that. His body seemed too weak to tackle the strain.

Jon and Gro had been part of each other's life since the time of their youth. They had been through tough times, had taken care of old parents and run a family business together. Gro was there by Jon's side throughout his illness. She kept working for the first couple of weeks, but was given sick leave rather soon. Jon spent most of his time at home, and needed much assistance. When Jon was hospitalized in the final stage of his disease, Gro came in every morning, and stayed till the evening, though she had two hours' drive both ways.

To Gro this was an obvious choice, and she talked indignantly about her reaction when it was questioned:

> "How can you drive over there every single day?" a friend of mine asked, one day as I was about to drive to the hospital. I felt like hitting her then. Nothing else mattered at that time. Nothing else.

Jon and Gro seemed like a close couple, present for each other. But when I visited Gro one year after Jon's death, she was haunted by the thought of the distance that had been there, nevertheless. One thing was the thought of Jon's last hours. He died in the middle of the night and she had not been there. Now, one year later, she still kept worrying about how that time had been and how Jon had actually died. Had he been peaceful, like he seemed to be when she left, or had he struggled in the end?

Another cause of distress for Gro that I learned about on the same occasion was the emotional distance there had been between them, i.e. a lack of expression of feelings of sorrow and despair:

> *Gro*: I didn't cry in front of Jon. But my goodness, how I cried on the motorway! [On the way back from the hospital] And now I think "but why did you not do that?" [Cry in front of him] Some people have commented on that, too. But should I have weighed him down with that, letting him see me in that miserable state? Maybe that is how it should have been? Maybe I should have done just that?
> *Ellen*: Is that what you think?
> *Gro*: Yes, that is what I think. Sometimes. Or? I don't know for sure. There is no recipe for these things. I wanted to spare him. But it is not sure that it was the right thing.

When I then told Gro about how impressed I had been with the two of them giving vent to their emotions in the first consultation, she told me something I had not heard about before; Jon's repetitive withdrawals:

> *Gro*: Throughout that period, after getting the diagnosis, Jon cut himself off, and made a sort of wall around himself. He went off in the car, and parked the car on the hill over there, and sat there thinking. Then he drove back, but kept sitting in the car. I would go out and say "Jon, come on in!" "No," he would say, "I want to sit here. I am going to die," he would say then. This happened during the summer and in the autumn. "But why do you say that?" I would say. "Come on! Nobody has said that!" And I have thought about this; what a silly answer it was. I needn't have said that, that is what I have thought afterwards. Oh, my God! Is it possible to say such a thing?! "Nobody has said that!" I said, you know: "Come on in!"
> *Ellen*: But it is true, isn't it? Nobody had told you that.
> *Gro*: No, they hadn't. But now I think: You should have sat down with him in the car. You should have placed your arms around him, you should have – oh, my God, where was I?! It would have been so simple, just opening that door, – and instead [I said]: "Nobody has said that! Do come in!" "No, I have to sit here. I have to collect my thoughts, I want to be left in peace," he said. And then I thought: "Well, I have to let you do that. I have no choice." So – he became very quiet. He turned inwards, withdrew into himself.

Gro was tormented by what she had done and what she could have done. She accused herself, but was also bewildered about what was right. These were only some of the many questions on her mind. There were also loads of questions of a medical nature: What did the doctors know at what points during the course of Jon's illness, and what had actually taken place, exactly? Guardedly and cautiously she tried to find out whether I could answer: "You are not a medical person, are you?" And when I asked whether she would have wanted to pose her questions to the doctors then, she strongly confirmed:

> I would have liked to ask about – a lot of things! But the doctors, they have finished with this patient. What counts for them are the new ones. So they cannot be bothered about me, that is what I thought. They have finished. But I have thought a lot about going there to ask about what actually happened. I could have brought a photo with me: "Here he is!"

This was the woman who used to tell me that things were fine, and who never posed questions to the doctor while her husband was a patient at the hospital. Now, it seemed to me, she suffered from the consequences of that silence, and the uncertainties about what she had not been told, still preyed on her mind. As a close relative of a patient at the hospital, Gro had been told that she could ask for an appointment with a doctor or a nurse whenever she wanted. She had never done that. Now, afterwards, she spoke about how she would have liked the doctors to be more active, to have called her in for a meeting, instead of leaving the initiative up to her. She would have wanted a clearer message towards the end.

The information process throughout Jon's illness had been mostly indirect. To me that seemed to have created a distance between the spouses, and prevented a deeper sharing between them. That's how I heard Gro's story about the man locking himself up in the car, and her reflections about her own reaction to that. This prompted me to pose a question to Gro that I often had on my mind, but seldom felt free to ask: Would she, looking back on the illness trajectory, have wanted the information, also in the initial phase, to be more direct, so that she could have been more prepared for what happened? But Gro did not confirm my expectation of a positive answer. She hesitated, and then said that the question was far too difficult to answer.

I was deeply affected by Gro's regrets about the way she had reacted to her husband's withdrawal, and was inclined to see her affliction as a result of a flaw by the health care service. As she had not been told about the sinister prospects of her husband's illness in direct terms, she was unable to respond to Jon's distress on an emotional level. But is this a valid line of reasoning? Her remorse can also be seen as an inescapable part of the mourning process, regrets about a lack of presence that to some degree will always be there however close the relationship is, and however tailored the information has been.

Petter's story: A promise kept

My third and last example takes the question of my assumption about information, therapy, and treatment decisions a bit further. This is another case in which I talked to the surviving partner after her husband's death.

His wife Anne cried in the consultation when Petter received the diagnosis. Petter seemed rather embarrassed and stayed quiet and calm. He soon started on a course of chemotherapy, but that was terminated before it was completed because of severe side effects which meant Petter was hospitalized after each dose, suffering from infections and other complications. When tests were conducted that showed no positive effects from the therapy, the course was discontinued, and no further attempt was made. Petter himself appeared to be content to stay at home. "I walk about here in the flat, enjoying the beauty in my surroundings," he told me, when I asked him how he was doing. Petter was no academic, but he was passionately interested in linguistic and historical questions, and had gathered a huge collection of articles and newspaper cuttings, in addition to his own notes. These were spread out on the sofa table, in an ardent attempt to sort them out. On the phone with me he described how he, because of his dizziness, had to carefully choose other points of support when he moved to an upright position from his seat in the sofa, to prevent the papers from being scattered all over the place. I kept contact with Petter over the phone until metastasis to the brain meant he was too confused and had too many difficulties talking for that to make sense any more.

His death notice in the newspaper had a special formulation: "He died peacefully in my arms," his wife wrote. When I talked with her some weeks after his death, Anne told me about this: In the last stage of the disease, Petter would get attacks of stomach pain. By then he had lost the ability to speak, he was clearly distressed and did not respond much to medication. Anne found out that what had the strongest soothing effect on him was her massaging his stomach. And that was what she was doing when she realized that he had drawn his last breath, there in her arms.

On the same occasion Anne told me that allowing Petter to die at home was a promise she had given him at an early stage. To my question about when that promise was made, she said that it happened on the very day of getting the diagnosis.

Anne and Petter had obviously been through a very tough time. Still, I thought of them as lucky in many respects: They had been able to stay together throughout it all, confirming thereby the close bond between them. That, I thought, must have been invaluable, not only for Petter, but also for Anne, and for the possibility of her proceeding with her life.

I remembered the last time I had seen Petter, then hospitalized for side effects of the chemotherapy, and how harassed and distressed he had seemed at the time. Anne and Petter had both been very explicit about their appreciation of their time together at home. It was therefore quite a surprise to me when Anne, in response to what I said about my recollections of Petter in the hospital, promptly said: "I felt abandoned at that time. I felt they were giving him up."

The termination of chemotherapy that to me had seemed a cause for relief and the end of a spell of futile suffering appeared to have been experienced by Anne as a betrayal. Anne had actually wanted it to continue. She was one of the most realistic of the spouses I had spoken with during my fieldwork, perhaps the most realistic of them all. She was the one I had heard posing a direct question to the doctor about the prognosis, through her tears, right after hearing the diagnosis. As is common practice, the doctor had evaded her question, but the promise that had been made later that day indicated Anne knew what the doctor had avoided saying. Or did she? In any case her reaction brought home to me how difficult, complex and far from straightforward this situation is. Anne was realistic, yet held on to hope. Not in David's insistent way, isolating herself in the process. But still...

Should the doctor have asked for her opinion? Would another course of chemotherapy have made it easier for her to go on afterwards – knowing that 'every possible measure' had been tried? Should she have been consulted about when 'enough was enough'? Or was it right she was delivered from the burden of decision-making, and allowed to feel frustrated with the health care system, as a location of her distress in difficult times? The decision to terminate chemotherapy might, after all, be defended on medical grounds, even if a patient's relative had wanted it otherwise.

In lieu of a conclusion: On truth, positions and values

I started off with a question about the relationship between a researcher's personal experience and the acquisition of anthropological understanding. In accordance with the statements initially referred to, this might lead to a search for the criteria and implications of a claimed 'common experience', posed as a question of whether I, as a relative of a deceased father, husband and mother, might claim an 'insider position' with a privileged access to knowledge.

Patients like David, Jon and Petter deeply affected me. It was easy for me to identify with their partners and in learning about their fate, many memories from my own life were evoked. In different ways, the stories of all these patients touched on what were crucial matters to me: perspectives and priorities in the last stage of life, conditions for close relationships and the question of life extension vs. quality of life. The question of how my personal experiences affected my work as a researcher can be considered in two parts: during fieldwork, and in the analysis phase.

In this paper I have presented some glimpses from the fieldwork phase, and my encounters with informants from the hospital. My own involvement with the research issues certainly sharpened my perception of some factors and directed my attention on some more than others. When I posed questions on the basis of my recollections and comprehension of the matters at stake, however, the responses I got were often unexpected. Opening up for that possibility is crucial. Allowing oneself to be surprised is essential for a researcher.

The implication of this for the analysis part, however, is not evident. The objections, or lack of confirmation, of my informants to my own assumptions do not in themselves extinguish the validity of my points of view. But, as I have pointed out in connection with the cases above, I cannot take the reliability of my own presuppositions for granted either. The issue of time is crucial to a project of this nature. Understanding and perception are processes in time, not static events. Talking with the two widows – Gro and Anne – made it possible to discuss the illness trajectories of their husbands retrospectively, yet these conversations were also historically situated. One or ten years later, their perspectives may have changed. One thing that the stories of David, Jon and Petter do show is that treatment decisions for patients at an incurable stage are complex issues with far reaching consequences, issues which cannot be reduced to their medical aspects alone. Making such decisions, and deciding on the role of patient involvement in them, is a demanding interpretative challenge, and ultimately a question of values.

In his famous and provocative discussion under the heading 'Culture and truth', Renato Rosaldo has pointed out that people do not always talk most extensively about or describe most thickly what matters most to them (Rosaldo 1989: 2). Taking this point one step further, none of us has a direct, unmediated access to truth – not even about him/herself (Taylor 1985: 118). We can all be strangers to ourselves, and to a certain extent we all are. The box in my attic is a reminder of that to me.

In this light, the question of insiders and outsiders, and common experience as possible criteria for understanding, needs to be reformulated. Any equation made between people's experiences, even within the same group or community, risks ignoring what may be vast internal differences. It is not necessary to have gone through 'the same' experience as another person to sympathise with him or her (Shweder 1991; see also Wikan 1992 and Van der Geest 2007). As pointed out by McLean and Leibing (2007: 11) the role of empathy in the process of generating knowledge has also been a controversial issue among anthropologists. Anthropological understanding requires more than empathy (see Hastrup 1995: 156) and more than 'being there', too. It cannot be taken for granted that what one 'goes through' is turned into a 'conscious experience'. Living through it is not enough. It needs to be interpreted. That happens within a cultural setting. And interpretations may change.

Closing remarks. Back to the box in the attic

Presence is crucial to anthropological methodology. I have tried to explore some aspects of its significance. It is also a major concern when it comes to the actual theme of this project, and the question of what matters when life comes to an end, for the dying person and those nearby**.** A driving force behind this project, from the planning phases onwards, has been a conviction about the importance of being given a chance to be there when a near and dear person is dying, also at their very deathbed, and the possible long lasting effects of being prevented from doing so.

The box in my attic has remained unopened throughout this writing process. I have no concrete plans to open it either. But as I sit down to wind up the threads thrown out in this paper, I feel closer to doing so than when I began. The intense discomfort about the helpless and evasive language of the letters has decreased with the awareness of this being an outcome of the culture in which I lived, rather than simply my own shortcomings. Encounters with informants in my project have made me further aware of how difficult it is to express emotions in times of crisis such as receiving a fatal diagnosis represents. I cannot know for sure how things would have been without it, but I believe my own experience has sensitized me to the trials that my informants have been going through. And through that encounter, I have become somewhat more compassionate to myself, too.

Note

Ellen Kristvik is a senior researcher at HØKH, Health Services Research Centre, in Lørenskog, Norway. She has a PhD in social anthropology and is also a qualified nurse. She would like to thank Inger Altern, Gry Sagli and Jennifer Gerwing and the participants of the symposium ‘Ethnography and Self-Exploration’ for their fruitful comments. E-mail: ellen.kristvik@ahus.no.

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