

“The mortality of human beings is at 100 per cent”, Prof. Raymond Voltz, the head of the palliative care unit being part of my field sites, humorously pointed out in late 2013. However, what it actually feels like to die is hard to grasp by looking at statistics and probabilities, or by asking non-dying persons what they think about dying. Nevertheless, contextualizing the situation of the research participants as well as the field sites with a few instances of quantitative data will help to get a better picture of how dying usually takes place in Western Germany. Subsequently, the organizational and institutional backgrounds of dying processes taking place in Germany will be sketched. This will be followed by a discussion of the methodological approaches used for this study. My personal occupations with dying in general and how they reflected on research are elaborated afterwards, as well as more general ethical reflections on fieldwork with dying persons. The advantages and challenges of doing fieldwork within one’s own culture, and applied strategies for resolving challenges, form the final topics of this chapter.

2.1 Research context

An exitus can take place anytime. Fatal sickness can strike anyone. However, the research participants of this study – like most persons in many cultures (Schröder 1986) – did not think about this possibility all the time.¹ Although dying usually

¹If they do, they are likely to be categorized as paranoid or hypochondriac, both regarded as pathological conditions and demanding therapeutic intervention (Dr. Z., personal communication, September 2014).

comes as a shock for each dying person as soon she is affected, is not a statistically rare event. In Western Germany, the main field site of this study, about 1% of the population is in a physically terminal condition (Hutter et al. 2015). The condition of dying can endure from a few days up to several months.

The terminally ill research participants included in this study were among the 43,000 persons dying in the metropolitan region of Cologne, Bonn, and the surrounding areas each year. From a population of ca. 82,000,000 people, about 860,000 exituses are reported in Germany each year. Around 4,300,000 people live within the metropolitan region where fieldwork was mainly conducted. Supposing that 1% p.a. of them die, that means that statistically, about 43,000 persons die within the area where I had my research focus every year. Amongst the most widespread causes of exitus are cardiovascular illnesses, accounting for about 41%, and forms of cancer, accounting for about 26% (Hutter et al. 2015). The dying research participants partaking in my study mostly suffered from more than one illness that finally led to exitus. They had various forms of cancer, chronic late-stage obstructive pneumonic disease, sometimes exacerbated by additional infections, and/or different organ insufficiencies. Yet generally, they all shared one condition: they were dying pre-exitally, and they were initiated into this situation by having received a terminal diagnosis.²

About two thirds of all exituses are preceded by a phase of terminal illness, only one third of exituses in Germany happen suddenly (palliative care expert Raymond Voltz, personal communication, 10.8.2016). There are no exact numbers about how many persons out of all reported death cases in Germany knew about their terminal condition before exitus. But many persons dying of cancer, cardiovascular illnesses, et cetera have lived with cancer, heart problems, et cetera before the particular illness reached a non-treatable stage. In these cases, the illness's evolution into a terminal condition most likely was monitored in regular check-ups, and the terminal diagnosis has been communicated at some point in the context of illness-specific monitoring. Scholten et al. (2016) give an overview of how many death cases in Germany are to be assumed as eligible for palliative care retrospectively based on the death reports of 2013. For persons who are dying and drew or could have drawn on palliative care, they estimate an amount of 40.4% of all reported deaths in the age cohort from 30-39 years, the percentage rising with higher age, up to an amount of 80.3% of all reported deaths in the age

²The initiating moment of a dying process falls together with having received a terminal diagnosis in Germany: See chapter 3 of this thesis.

cohort of 80 years and over. Given the fact that only persons in a terminal condition receive palliative care, and that each patient is informed about her terminal condition if she is capable of comprehending the content of such a diagnosis, it is reasonable to assume that up to two thirds of the total German population, about 547,000 p.a. live with a terminal diagnosis at some point in life. Furthermore, the study of Scholten et al. (2016) implies that – as the German population is ageing – the number of persons who are diagnosed as terminally ill is likely to rise during the next decades.

Spaces of research

All dying research participants were either

- dying in their homes, the homes of relatives, or care homes, supported by palliative home care; or were
- in inpatient palliative care; or were
- living in hospices with palliative treatment opportunities and palliative home care doctors coming in.

The fieldwork was carried out wherever the dying research participants chose to meet me: The actual field sites included homes of dying persons, homes of relatives of dying persons, palliative care units, various hospices, care homes, hospitals, general practitioners' consultation rooms, and also transitional spaces like trains and cars. Since it was not unusual that the dying research participants changed their places of dwelling during their dying processes, or went for consultations to clinics or doctors, I seldom met any given person within only a single spatial context. Additionally, I accompanied some research participants in transportation service cars, to parks, cafés and other public or semi-public areas.

Many research participants visited palliative care units for treatment adjustments at least once during their dying processes, even when they did not spend most of their dying processes within inpatient care. Germany's first specialized palliative care unit was founded in Cologne, and the University hospital of Cologne still hosts one of the largest palliative care units in Germany, currently with 15 beds. In this location, I spent much time, and I was temporarily working as a care assistant there for some weeks. Attached to the unit is a specialized palliative home care team (SAPV), assisting dying persons at home or in care homes and hospices in terms of supplying medication, care, and advice. Additionally, the unit supplies a multi-professional consultation service, called in by other units of the hospital when patients are soon likely to need palliative care. About 400 persons receive palliative care within this specific unit per year, and in total the

combined inpatient and home care services of the unit care for about 2,700 persons per year. The average time of stay is about 10 days – not meaning that patients die after 10 days on average, but that they either die or move to stay elsewhere after their palliative treatment has been adjusted to their needs (including medication, care, technical equipment, etc.).³ The dying persons included in this study who were staying at the palliative care unit mostly left the unit before exitus: To return home, to move back to their rooms in a nursing home, or to move to a hospice.

Biomedical supply for dying persons

Within the field site of Western Germany, the medical care and medication adjustment is ideally supplied by doctors with a special training in palliative care or in clinic units with a specialization in palliative care. Not all areas in Germany have an optimal supply in terms of palliative care yet, but the German government published a law in 2015 aimed at making palliative and hospice care ubiquitously available (BMG 2015). For 100,000 inhabitants of North Rhine Westphalia, where all of my German research participants lived, an average of 12.3 home and inpatient palliative care doctors were at the disposal of dying persons in the end of 2015. There were an average of 5.2 doctors having a special training in palliative care and helping persons who are dying at home, in hospices, or in care homes (Bertelsmann foundation study 2015). Currently, an average of 17.9 home care hospice services is available per 1,000,000 inhabitants in North Rhine Westphalia. In the city of Cologne (1,000,000 inhabitants), where most of the research participants of this study died or were treated at least once throughout their dying processes, there are four inpatient hospices, ten home care hospice services, one specialized children's hospice service, and a total of 120 doctors with a specialization in palliative care – both for home care and inpatient care (Palliativnetz Köln 2016).

These numbers mirror the relatively comfortable situation of dying persons in Western Germany, compared to e.g. South China, where I conducted contrast research. The German research participants all had access to qualified palliative care support. It is not yet the case that each person who experiences an exitus in North Rhine Westphalia is cared for by palliative care professionals beforehand; and not every terminally ill person needs or wants palliative treatment. However,

³See Palliativzentrum Köln Festschrift (2015).

most dying persons have the chance to receive specialized care – concretely: They can die without pain, and if there are no family members willing or able to take care of them, the social services and health insurances organize caring arrangements for the dying persons. All insurance policies pay for palliative care, and every citizen of the Federal Republic of Germany has health insurance.⁴ So, instead of struggling to get adequate treatment and care, the research participants were able to experience dying with all basic needs covered.

2.2 Research participants

As mentioned above, all dying German research participants were living or treated in the cities of Cologne, Düsseldorf, Bonn, and in the rural areas around the city of Siegburg and the region of Bergisches Land. They were suffering from cardiovascular illnesses, respiratory and lung diseases, or different kinds of cancer. Most were diagnosed with more than one condition.

All dying research participants were receiving medication against pain, and many also relied on panic-reducing drugs in situations of intense psychic stress. Mostly, the medication was adjusted in such a way that it did not affect the perceptions of the dying persons severely and permanently. However, it could at times cause side effects like tiredness, apathy, aggression, changes in personality, and the like. My research concentrated on moments when dying persons felt well enough to meet me, and when effects and side effects of drugs did not change their psychic and mental capabilities in a way that clearly influenced actions, evaluations, considerations, and social interactions. As biomedical and medication aspects of dying are not the main topic of this study, I focus on how dying persons felt, talked, acted and appeared when their experiences were apparently not decisively influenced by medication. Data out of other situations or border situations was mainly left out, and is marked by explanations if it is included.

The span of time during which participant observation with one person was possible ranged from five weeks up to one and a half years. The dying persons spent their final weeks in institutions with curative aims, in hospices, in care homes, or in their own homes or those of close relatives. All participant observations took place between 2013 and 2015. The Ethics Committee of the University of Cologne approved the study (approval number 14-166).

⁴For details of the economic aspects of palliative care in Germany, see Marckmann et al. (2012).

Four main groups of research participants were included:

a) *Key informants*

The main set of data was collected through participant observation with 16 key informants diagnosed as terminally ill. Originally, there were 19 persons I accompanied. However, three informants’ data was left out at the wishes of their relatives.

Most quotes and examples reported in this thesis stem from key informants, i.e. the dying processes I became most familiar with. To contextualize longer quotes, I will add important information about the particular person’s age, job, and relational or familial status in brackets below.

Table 2.1 provides an overview of gender, age, relationship/familial status, and occupational self-description of key informants at the first time of our meeting:

TABLE 2.1 Research participants

Total: 16		
	Female: 9	Male:7
Age:	32	47
	43	49
	62	57
	66	58
	68	75
	72	82
	72	88
	72	
	86	
Familial/relationship status:		
	Female: 9	Male: 7
Married/in relationship:	5	2
Divorced/single:	4	3
Widow/er:	-	2
Mother/father:	7	6
No children:	2	1

Occupation

The female key informants worked as taxi driver, housewife, teacher, consultant, nurse, or introduced themselves as pensioners. The male key informants worked as engineer, lawyer, bar owner, carpenter, salesman, public official, or introduced themselves as pensioners.

b) Interviewees

I checked the results gained from my close participant observation using semi-structured interviews. These interviews took place with 20 dying persons who were not the same as the key informants. The interviewees only met me for some hours on different days, so I did not have closely shared everyday experiences with most of them, as was the case within the participant observations. The check-up interviews were characterized by referring to phrases and impressions common to many key informants, and I asked the interviewees whether they shared these experiences (and if not, what they experienced instead).

c) Short-term contacts with dying persons

I included information from short-term contacts with 25 additional dying individuals in order to gain holistic information about the treatment and management of dying patients in the field. During my cooperation with the palliative care unit and the palliative home care teams, I met dying persons whom I did not ask to be informants, but with whom I had informal talks in my role as a temporary care assistant.

d) Non-dying participants: Contextualizing dying

The participant observations were framed by meeting with the informants' relatives and friends, mostly with the dying persons establishing contacts between us. Usually, I met most of the persons who were regarded as significant others by the informants at least once. In addition, I interviewed and had informal conversations with medical professionals caring for the informants.

The non-dying individuals were chosen according to their significance within the lives of the dying informants, who usually introduced them to the author. Mostly, as I became part of the dying process, relatives and friends had a great interest in getting to know me, sometimes experiencing me as a helper in looking after the dying person, often having little chats with me before or after I entered the room of the dying person close to them, and sometimes even being a little jealous or irritated that their dying close one chose to talk to me about personal things. All participating non-dying persons knew that I was studying the dying informants' everyday experiences, and understood that it was the dying persons' perspectives were the focus of this study, and not they themselves as relatives or friends, or their own non-dying persons' perspectives on the dying process.

Relatives and friends, especially those that I met quite regularly in the room of a dying informant, nevertheless shared many of their current issues or thoughts with me. In these situations, I encouraged them to speak out what came to mind in these cases, had conversations with them and included these conversations in my field notes. All non-dying persons knew and verbally agreed that I could include our conversations in my field notes, and that they could refuse to continue talking at any time, as well as asking me to stop noting down our conversations.

Persons, not patients

This study included participating persons – not participating patients. In the following paragraphs, I will explain why dying persons are not introduced by naming their particular diagnoses in the context of this thesis.

The terminally ill research participants experienced themselves as coming at their lives' ends – not that much as dying of e.g. the fourth stage of chronic obstructive pulmonary disease. At the same time, a usual conviction within the so-called Western world is that people die because of biomedical conditions (see chapter 3 for a closer look at this phenomenon). For non-dying persons, it is quite ordinary to use a phrase like “she has terminal liver cancer” when actually meaning “she is dying”. However, a cultural anthropologist is not supposed to unreflectedly prioritize and repeat categories used to describe persons who hold a different self-image, especially if the latter is in the focus of study. Additionally, describing biomedical illness categorizations or symptoms in detail would mean following cultural conventions of seeing dying persons mainly as ill people: This could veil transitional characteristics within pre-exital dying that are not intrinsically connected to a certain illness or symptom, but rather to the condition of consciously approaching exitus.

Therefore, I am going to present dying persons as they introduced themselves to me during research: As mothers, husbands, young women, lawyers – with attributes reflecting social embeddings and individual characteristics. Information about specific illnesses will be only included when it is necessary for understanding the sketched situation, or if it was important for the dying person herself. The dying persons will only be called ‘patients’ if a biomedical view of them is paraphrased, or if it is intended to highlight the specific feature of being an ill patient within a biomedical or institutional context.

Not introducing the dying persons as patients does not mean that therapeutic biomedical interventions were not part of their lives. With their having received a particular diagnosis, all research participants were possessing the “therapeutic citizenship” (Nguyen 2010) of being a terminally ill person. According to Nguyen,

ill persons can or cannot possess “a biological citizenship, a system of claims and ethical projects that arises out of the conjugation of techniques used to govern populations and manage individual bodies” (Nguyen 2010: 126). The research participants did all possess this stateless citizenship in terms of being able to claim biomedical assistance. They were covered by health insurance, as nearly all persons in Germany are; they were categorized as being in a terminal condition because of a specific physical condition by their practitioners and their health insurance companies; and they were treated according to the biomedical recommendations for a person who is suffering from that particular illness. All dying persons received a comparable kind of individualized treatment: Anti-pain drugs, caring assistance, and helpful devices were offered to them according to their individual needs. At the same time, even two persons suffering from the same illness could need and receive two totally different treatment approaches: Just because two persons suffer from liver cancer, they do not necessarily have similar requirements, and they do not necessarily die in a similar way. As the dying participants’ biological-biomedical citizenship was not a regular topic of struggle, and as illness categorizations did not generally equalize all persons’ treatment experiences just because they were diagnosed with the same illness, it seemed unnecessary to stress the therapeutic citizenship of being a patient or to emphasize diagnostic categorizations in the experience-focused context of this study.

Apart from reflecting how the dying persons conceptualize themselves, describing dying persons without characterizing them in terms of their illnesses has another advantage: Leaving out specific illness descriptions enables the reader to take the dying persons’ perspective, without creating distance by describing specific illness symptoms or visible illness signs that most readers do not have or know, and which might provoke feelings of alienation. The reader should imagine dying persons as people with reasonable and valuable voices that deserve to be heard.

Additionally, the confidentiality and anonymization rules I agreed to when I asked the Ethics Committee for approval are generally better met if I do not make individual persons all too recognizable by mentioning their exact illness histories.

Conditions of participation agreement

As I guaranteed to the Ethics Committee of the Medical Faculty of the University of Cologne in order to be allowed to include some of their patients (approval number 14-166), all true names were replaced by different names that could not be traced back to the persons I was in contact with. I have also endeavoured not to discuss outstanding and unique biographical details that are not necessary for

the reader to be able to understand quotes or sketched situations within the following text. This makes it harder to re-identify research participants. Following the Ethics Committee's request, the original tapes and notes clearly related to certain persons' identities (e.g. voice tapes, photos, word-by-word-protocols containing clear names, etc.) were destroyed after being analysed, so they cannot reveal the identity of any informant.

Together with many of the participants, I decided that their true ages and occupations could be mentioned. Sometimes I replaced exact job positions, because a few research participants did not want them to be mentioned. In these cases, I inserted occupational titles similar to the ones they actually had: I.e. jobs which require a similar educational background, and broadly compare to the participant's real job in terms of income, reputation, and status positioning within German society.

The research participants were all asked to agree to be accompanied by me, and the aim of the study was revealed. Concerning the purpose of my research, they knew I was interested in how terminally ill persons live, how they feel, and how they think about dying. All participants received this information verbally and set out in writing before joining the study: The former giving them a chance to discuss the research plans and potential meetings with me directly, the latter providing a document for looking up details and sharing it with close ones. When a positive response from a potential participant reached me, written consent was documented during our next meeting. For this purpose I used different texts approved by the Ethics Committee, addressing the different requests for the four different participating groups. The agreements were individualized according to the informant's preferences in terms of potential appointment dates, frequency and length of visits by me, et cetera. All dying persons were repeatedly informed that the exact focus of the study could develop and change during research, depending on issues that were important to them.⁵ Thus, the research participants became used to the idea of being an active part of explorative research. Many dying participants reported that being regarded as experts on the emic perspectives on dying, rather than having to follow a fixed research agenda, was one of the main reasons why they agreed to let me take part in their lives.

The initial participation agreement could be revoked at any time if an informant did not feel good about being part of the study anymore. I communicated

⁵Following the idea of tracing issues that are relevant to the research participants instead of imposing the researcher's own presuppositions and interests; see e.g. Davies (2008).

that I saw each agreement rather as a process that might involve renegotiations, instead of taking a single written ‘yes’ as a binding and irrevocable obligation (see also Davies 2008: 56). I also guaranteed that research would be stopped in any situation suggesting that it would be inappropriate to continue. Incidents which would have led to stopping participant observation, or leaving out already collected data, included situations which obviously implied that being part of the study was harmful to a dying person and/or her social surroundings – e.g. intense stress reactions, emotional instability, increased physical weakness in reaction to meetings with me –, or situations in which relevant non-dying persons did not support the study or had serious problems with participant observation. To ensure transparency, dying and non-dying participants were encouraged to ask me for fieldnotes and quotation examples, if they wanted to know more about my way of working or about the content of past conversations. Some persons were very interested in reading and re-discussing, others were not.

It did not happen that any informant asked me to stop participant observation generally. In three cases, relatives and one doctor asked me to exclude data from participant observations they were part of, after the particular informant’s exitus. These requests were posed having read quotes of a dying person they were close to: Some relatives and one doctor felt that information, stemming from my communication with a particular dying person they were close to, could influence their renommée or their family lives negatively. Only sixteen key informants are therefore included in this study, rather than all nineteen persons I worked with. Out of the shorter encounters with non-key informants, all of the data could be used.

2.3 Methodology

The main methods used during fieldwork with dying persons, which will be presented in detail within the following subchapter, are methods that classically guide anthropological fieldwork: Participant observation, informal talks, ego-centred network analyses, and semi-structured interviews. In terms of participant observation, I place a special emphasis on sensory ethnography (Pink 2009). Concretely, I tried to approach the experiences of dying persons in terms of my own direct sensory experience (e.g. by simulating bed-rest care, consuming special high-nutritional meals together with dying persons, and the like). I co-worked on a palliative care unit to understand more about the spaces of institutional dying in Germany. To explore the biomedical and legal conditions of dying in Germany, I had various expert talks with experts in law, biomedicine, psychiatry and psy-

chotherapy, nursing and hospice care. To sharpen my view of cultural specificities of dying in Germany I undertook contrast research with terminally ill persons in the Pearl River Delta, People's Republic of China.

Participant observation

Participant observation (De Munck 2009; Hauser-Schäublin 2009) lies at the heart of this study. As dying persons and their perspectives were the main focus, sharing their everyday lives was necessary to understand dying from dying persons' perspectives.

The first step was to identify key informants who were willing and able to share their everyday lives while dying. Accompanying them took place on a long-term basis – in this context, meaning: until the end of a person's dying process. The key informants had to be verbally responsive at least during the first weeks of participant observation, not experiencing permanent exhaustion and emotional distress, and not suffering from dementia; they had to possess the capacity to understand what participant observation means, and they had to be able to potentially agree with participating in the study.

As the aim of the study was to gain first-hand insights into the experiences of dying persons, investigating ways of dying in Germany with persons who did not meet the criteria mentioned above was not possible. Dying processes and exituses which could not be investigated by repeated participant observation, or communication with the persons concerned, included e.g. punctual death by stroke, victims of fatal accidents, and persons who were suffering from dementia and from a terminal disease at the same time.

Though excluding the groups just mentioned, a fairly large group of dying persons was still potentially accessible for long-term participant observation. They were initially approached in various ways, including through proposals of doctors of the palliative care unit I worked with, through contacts established by persons from university or hospice care that knew about my research aim, through recommendations by other research participants, and through recommendations via personal contacts. First contacts took place in hospices, at dying persons' homes, at their relatives' homes, in palliative care units, and in care homes. All persons labelled themselves, and were identified by others, as dying. Nineteen key informants could be observed and accompanied; however, in three cases, relatives asked me not to include their cases in the study after their respective exituses. Thus, only sixteen persons are included as key informants.

Shortly after proposing to participate in the study and signing the agreement, the key informants' age, familial/relationship status, family history, and (former)

occupation(s) were identified. Usually, the informants began to tell me these things when I asked them to introduce themselves a little.

Ego-centered network analysis (Schnegg 2009) was carried out to examine whom the informants understood to be an integral part of their dying processes. Questions to examine this included asking with whom the informants shared the information that they were dying, who cared regularly for them, who visited them or called them regularly, whom they felt close to, and simply noting who participated in everyday life and central decisions that I witnessed during participant observation. Each dying person was accompanied by an average of five significant others throughout the dying process.

The long-term participant observations turned out to produce very rich data. After having known the informants for at least some weeks, one person even for more than one-and-a-half years, my key informants shared personal thoughts and feelings quite freely and pointedly. One informant I was very close to, Johanna, sometimes reflected on the intense dialogues we had after quite a short span of time, saying: "I don't have time to waste". Talking straight and clearly while demanding a high degree of attention and truthfulness from me as a researcher were characteristic of the relations between my key informants and me. All informants were very aware of the limited time they had left, and thus did not hesitate for long to debate whatever was important to them once they built up trust.

The informants were free to choose when we met, and mostly their daily condition and moods decided what topics we discussed, or whether we discussed anything at all, rather than simply sharing some cookies over a coffee, listening to the radio, or watching birds in the garden. Most informants asked for the option not to stick to certain fixed dates for my visits. This was so because their condition often changed from day to day; maybe new doctors' consultations were needed, and sometimes they had to move from one place to another, so the intention to see them on regular days at a fixed time turned out to be inappropriate. Instead, most liked it best to receive a brief phone call every other day, and then would decide whether they would like to meet personally, or whether they just wanted to talk on the phone or to write emails, or rather preferred to be left alone. The longer the relationships lasted, the more comforting the dying informants reported the participant observation to be. Hopefully for many of them, it was as Mona told me: "not like yet another appointment", but rather an option for just being and doing as each person wanted, "without being judged".

Besides spending time with dying persons in different spaces, I also worked as a temporary nursing assistant at the palliative care unit of the University of Cologne for some time at the beginning of the study. I did this to get a better feel-

ing for the environment some dying persons live in for a certain time. During this time, I became involved in the staffs' everyday interactions with dying persons. I also witnessed various situations of informal talk about dying persons – what Mattingly defined as storytelling in clinical contexts (Mattingly 1998), contrasted with biomedically informed official “chart talk” (Mattingly 1998: 273). The stories that were told about, and together with, dying persons provided many hints at topics that became important during the participant observations, too: Issues of making and refusing decisions, situations of lack of and offering guidance in a situation when clear advice becomes rare, and the like. As a temporary nursing assistant, I had the opportunity to attend many situations that palliative care consists of, as diverse as doctors' talks with dying persons, music therapy, and palliative care in care homes and dying persons' homes. Spending time with professionals caring for dying people was crucial to inform my understanding of the biomedical implications of being told that a disease is incurable, as well as for understanding how dying is framed within an institutional framework specialized in care for the dying. The doctors and therapists of the unit – to varying degrees – explained their everyday proceedings to me, and shared their perspectives with me. This happened partly when dying persons were with us (e.g. during consultation hours) and partly without any dying person present (e.g. in the staff rooms).

Finally, I also conducted contrast research in the Pearl River Delta. This contrast research was intended to sharpen my view of cultural specificities of dying in Germany. Furthermore, the contrasting experiences helped to reflect upon pre-suppositions and biases that otherwise could have remained unexplored. A closer description of the content-related gain from this contrast research is given below (subchapter 2.5).

Sensory ethnography: Sensual and sensitive participation

Influenced by Pink's (2009; 2010) conceptualization of sensory ethnography and Edvardsson's & Street's (2007) argument for embodied ethnography in health care settings, I tried to explore not only verbal, but also non-verbal and sensory dimensions of dying as well as I could. Smelling what the informants smell, hearing what they hear, seeing what they see, and (at least to a certain degree) feeling as they feel, was one ethnographic vision that inspired this study. Practically, I spent many days and nights with dying persons, trying to adopt their perspective by always holding my face at the level at which they had theirs, sharing what they heard, saw, and smelled from this perspective, and sometimes giving them haptic support, like holding hands when exitus took place. When possible, I shared the same meals that dying persons ate, instead of eating my own food in front of

them, the diversity of meals ranging from completely mashed dishes that were easy to swallow to special high-calorie drinks.

When I worked as an intern on the palliative care unit, I had the chance to gain haptic and olfactory impressions of caring processes. Additionally, I gained insights into everyday medication and care proceedings that dying persons deal with. Bringing dying persons food, giving them massages and changing their laundry, assisting when a catheter is implemented, and staying with persons just before exitus until they passed away, allowed me to share some of the most intimate moments of different dying processes. Also, having lunch with the nurses, sharing early shifts and chatting during coffee time created an atmosphere of shared sensory experiences which made it easier to relate to biomedical staff. On these occasions, the palliative carers helped me to understand their approach to dying persons, which is rooted in a biomedical and psychotherapeutic concept of dying, and shared elements of their year-long experience with dying persons with me.

Furthermore, the nurses of the palliative care unit allowed me to lie down in a bed of the unit and showed me the perspective of the person who is cared for. Through this, I got in touch with how it feels to be moved by a carer, how it feels to be fed, and how perceptions of space and danger can change when somebody maintains a rather static position within a caring bed. Being in a bed for a longer span of time requires thinking beforehand about where to place things next to oneself (which may be needed in the following hours). Lying in a bed without the option to leave it easily makes this bed one's private space: I noticed that I felt disturbed when somebody sat down next to me on the bed without asking beforehand, and people entering the room unexpectedly became a disturbance that I felt delivered to. At the same time, a restriction of movements can come with a certain dependence, practically and emotionally, towards those persons who visit: Given the fact that it is a more or less restricted group of people visiting a bedridden person, the social world grows pretty small, as well as the potential for unexpected events. For a bedridden one, interpersonal contacts with persons who are more mobile than herself can even evoke feelings of hierarchic imbalance, the visitor having the choice to come or leave as she likes, the bedridden person feeling delivered to a visitor's preferences in terms of social interaction. While physical care by professionals was something I could feel comfortable with quite quickly, the relative impossibility to effect or avoid interpersonal contact caused much more insecurity and unease for me personally.

These perceptions also deepened my understanding of how crucial my physical positioning towards the research participants was for establishing an eye-level relationship, allowing me to build an atmosphere of mutual trust. As Bourdieu (1991) describes, the positioning of persons within a space can reflect hierarchies,

but also grounds them. Concretely, when somebody is lying in a bed and somebody else enters the room and does not position herself on a similar level to that of the reclining person, this prompts a certain kind of communication by creating a gradient: The one who is standing and able to walk around is likely to be the one who is leading the communication, while the one who lies down is likely to take on a more passive, dependent role. When I was lying down in a bed myself, I experienced how quick movements of a person walking around me could make me feel uncomfortable, as I had to follow the person with my eyes. I also felt how discomfoting it was if someone entered the room, stood beside the bed, and talked down to me: Unintentionally, this person would make me feel somehow inferior. As a result, I chose to meet my informants by bringing our faces to one constant level, sitting down next to their beds or in front of their beds most of the time. This rather static positioning of myself in the dying persons' rooms enabled them to turn towards me or away from me, and it prevented them from having to talk up to me.

When it came to the point that dying persons were no longer able to communicate verbally, exploring new ways of understanding with them became necessary. Research did mostly involve talking with research participants, as many informants and interviewees had hours of being awake and were ready to communicate verbally. However, when exitus drew nearer, I often had to switch to observing nonverbal impulses like mimicking gestures, and small movements of the body, as well as to touching hands and holding shoulders, in order to communicate and to get a feeling for the mood of the dying persons. The research participants and me would listen to music together, and I would sometimes hum or sing for some informants as I would have done for persons I accompany as a terminal carer. But most of all, noting mimicking gestures and atmospheric changes carefully while being with my dying informants was my crucial task during their very last days and hours.

Besides being receptive to sensory dimensions and noting down noises and smells in addition to words and actions, working with dying persons also demands sensitivity from a researcher. I was not only a researcher doing sensory ethnography as well as I could, but I was also required to do sensitive ethnography. Developing a sense of when silence was appropriate even though I had many questions was crucial for the dying persons: If an intrusive researcher were to be too insistent with people who may get tired or weak very quickly, e.g. by pushing the dying persons to talk more or for longer than they feel able, most dying persons would not have let that researcher enter their lives ever again. It was important to accept when informants burst in tears and laughter empathically, instead of trying to stop it somehow and thereby signalling to the emotionally moved per-

son that her behaviour was not acceptable in some way. Trying to understand the perceptions of dying persons, getting closer to their perspective, and accepting emotional attachment to them, while not letting a stream of anticipated pain of separation and empathy wash me away, was crucial: Not only to balance my own feelings, but also to avoid burdening dying persons with the additional pain of making them feel that I could not deal with the condition they were unavoidably in. Sensing when it is better to simply sit beside a person instead of seeking communicative exchange, and uncomplicatedly helping with simple things like giving a dying person some tea or helping her to sit up in her bed when nobody else could do it at that moment: Retrospectively, these two ways of contributing to bearable dying processes were amongst the most important competences during my research with dying persons.

Checking up: Interviews, conversations, and analysis

Besides doing participant observation, some qualitative interviews (Schlehe 2009), most of them semi-structured or unstructured, were carried out after a longer period of participant observation with each key informant. These topic-centred conversations mostly served to check whether I had taken note of important issues in the key informants' lives correctly. Additionally, the interviews provided opportunities to hint at other aspects of dying processes which the informants might see as important, but which I might not have investigated more closely because I did not witness them during participant observation.

To gain a more general understanding of the conditions of pre-exital dying in Germany, I had extended expert talks and informal exchanges with persons who are professionally occupied with dying in Germany. The most important background information was given by Prof. Dr. Wolfram Höfling (National Ethic Council, specialized in law science, University of Cologne), Prof. Dr. Raymond Voltz (first chair holder for palliative care in Germany, University of Cologne), Dr. Klaus Maria Perrar (senior consultant, palliative care unit, University hospital of Cologne), Martin Wiegand (head of nursing, palliative care unit, University hospital of Cologne), and Beate Meurer (coordinator of the hospice home care service for the inner city of Cologne).

Furthermore, I spoke to non-dying persons close to dying persons included in this study: Relatives, friends, nurses, doctors, physiotherapists, psychotherapists, priests, music therapists, morticians, social workers, and hospital case managers. However, the data collected with non-dying persons were always related to a specific dying person's condition. The conversations with non-dying persons were mostly oriented towards issues which were relevant to the dying person we both

knew, and therefore developed context-dependent instead of being carefully pre-structured.

Check-up interviews

When the period of participant observations seemed to have produced sufficient data for me to be able to extract general ideas about dying processes in Germany, I met with 20 dying interviewees who were not identical with the key informants. This took place after analysing the greater part of the participant observations with the key informants. The additional interviews were conducted to check whether the results of the close participant observations were true for many or rather only a few other dying persons.

Before starting the check-up interviews, I reviewed the field notes from the participant observation. By structuring them, it already became apparent that certain cultural concepts might play a decisive role regarding how dying processes could be shaped in Germany; specifically autonomy (*Autonomie/Eigenständigkeit*) and serenity (*Gelassenheit/Ausgeglichenheit*). So these two dimensions of dying processes became important topics for interviewing, along with others such as issues of residence and care, physical and emotional specificities in dying, etc. I decided to shape the interviews in terms of stories and events that I witnessed with key informants. Example stories and example events were picked out of the field notes.

After having chosen these topics and drafting the loose structure of the questionnaire I intended to ask, semi-structured interviews were conducted. The interviewees were not only asked if they shared similar opinions or experiences to those that I described based on my work with the key informants, but they were also encouraged to show me whether and how they experienced those issues differently (or maybe whether they did not think those issues were pressing to them). Most parts of the interviews were carried out in a narrative way, to enable the interviewees to tell their own stories, if their experiences were divergent from the inputs I had received from the key informants. Interviews usually started by asking how the interviewees were feeling, later weaving contextualized questions into the dialogue. For instance, if data from some key informants suggested that there might be issues in having no guidance in how to eat well to keep one's body as healthy as possible, this topic was brought up in an interview framed as an anecdote. Telling this anecdote as a trigger input into the communicative flow was intended to elicit a response from the interviewee that might indicate whether she was familiar with similar issues, and if so to what extent, or whether she had different topics that mattered more to her. Concretely, a semi-structured interview

might contain elements such as: “I talked to somebody who is in a similar situation to yours. He is a bit annoyed that he does not know whether he should rather eat healthy food, or eat as he wants... you know, he likes cakes very much. Have you ever had similar issues?” Answers could be as diverse as “Absolutely. I’ve decided to eat more fish, it helps with cancer”, or “Yes, somehow. You want to do something good for yourself, but on the other hand, it’s like you don’t know how long you can still have this cake...” or “I wish I could eat anything nowadays; I have no appetite at all”, etc. Using this as a point of departure, follow-up questions, affirmative encouragements for them to keep on speaking, or simple repetitions were offered in response in order to get to know more (e.g. “Oh, fish; to reduce the metastases? How does that help?” or “So there are two ways to deal with that...” or “No appetite at all?”).

Additionally, stories of how their dying started were collected – simply by asking how the interviewees thought that dying started. This was mainly intended to explore whether dying actually started with the communication of the terminal diagnosis from the viewpoints of the interviewees. As there were many overlapping parts within different narratives about receiving the terminal diagnosis, I chose to combine parts of different stories. I created an initial rough sketch of a culture-specific narrative about the disruptive biomedical experience (Shimazono 2003) of being initiated into the dying process (see subchapter 3.2).

Final analysis

By reviewing the data from the check-up interviews and re-reading the field-notes from participant observations, it became clear which issues were shared by many dying persons. Afterwards, the most important opinions, issues and ideas of research participants were arranged into categories that form the structure of this thesis. The theoretical concepts used to make sense of the data were partly concepts that I already considered to apply before analysing the field data (Shore 1996, Turner 1967). Partly they appeared suitable just after fieldwork had started (Johnson-Hanks 2006).

When revising the notes, it became apparent that there were striking commonalities among the stories about being initiated to the dying process – something I already noticed during research, as I mentioned above. Receiving a terminal diagnosis turned out to follow a less flexible and less heterogenous cultural convention than other aspects of dying. Therefore, it made sense to continue with accumulating an abstract, ideal-typical narrative (Shimazono 2003) out of various stories about the initiational talk between the doctor and then-dying person. Contrarily, the endings of dying I witnessed were very personal moments. If I had the

opportunity to witness those situations, I was often involved practically by helping the research participants. Each single ending of dying had its own character, depending on the person dying, the non-dying persons around, the biographical and spatial setting, and the like. Instead of accumulating those (often very touching) moments, which would have lacked the respect for the dying individuals in my opinion, I picked one particular description of how a woman ended her life in my presence. This episode contains many aspects that were relevant for many persons when they ended their lives, and therefore seems to be informative enough for the purpose of this thesis.

Surprisingly enough, one topic that I expected to be a major issue – pain management – was not as important for dying persons as it was for non-dying persons around them: Not because they did not fear or experience pain, but because it was usually managed properly by the treating physicians. As the dying persons involved in this study usually had a lot of information on how palliative care and pain drugs could prevent hurting and panicking, they seemed to be quite sure (and experienced) that they did not have to die in pain. In front of me, they did not mention fear of pain extensively or often. Mostly, pain was a topic for the dying participants when they discussed individualized pain relief strategies with a doctor. This was different for non-dying relatives and friends: They tended to talk a lot about how they wanted a given person – or themselves – to die without pain. For the dying persons, however, being sure that pain could be relieved immediately made this topic a minor issue in everyday life. This illustrates general differences between dying and non-dying persons that may evolve during dying: What is a major fear of non-dying persons (dying in pain) does not have to become a major fear for dying persons. Incidents like these reminded me how important it is to adjust the research framework and drop topics that initially seem to be important, but later on turn out to be of minor concern to the informants.

2.4 Research ethics and personal reflections

Within the context of this study, dying persons were willing to share a substantial part of their clearly limited life spans with me. Their willingness to participate at all is something that cannot be balanced out in any way. Ethical research with dying persons demands the capability of dealing with possible feelings of staying behind with a certain debt, and it requires the capability of feeling and expressing adequate grateful humility: The researcher remains without the comfort of saying ‘thank you’ and meeting again after the research, and there is no chance to repay what the dying informants invested in this research – literally their last days.

Considering this, ethical issues are obviously relevant when a researcher asks persons if she could become part of their last weeks of life. Before and during fieldwork, it is necessary to reflect on responsibilities and moral standards that meet the requirements of dying informants. Additionally, moral standards of institutions like medical Ethics Committees have to be integrated into the research.

Furthermore, any researcher should reflect her private experiences with dying carefully before and during research with dying persons. Personal entanglements with dying should not arise in the field unpredictably, and they should not affect dying informants and interviewees. In this study, various instruments were used to consciously deal with personal entanglements: A private emotional diary and professional supervision within a peer group of other persons working with dying people proved to be an adequate support in my reflecting and dealing with personal experiences and emotions connected to dying and exituses. The next paragraphs are dedicated to exploring these, and further personal and ethical challenges that arose in fieldwork with dying persons.

Dying persons – especially vulnerable?

As Fluehr-Lobban (1998) explains, ethics have to be considered at every stage of anthropological research. When it comes to dying persons, this seems to be especially important: As they do not have much time left, it is a major aim in research not to cause any unnecessary trouble or harm to them during their last weeks. Behar (1996) notes that fieldwork is carried out in “a mode of knowing that depends upon the particular relationship formed by a particular anthropologist with a particular set of people in a particular time and place” (Behar 1996: 5) – this also means that the well-being of the informants and the researcher herself and the quality of the data alike depend on the degree of sensitivity and reflexivity the researcher is able to show in everyday fieldwork.

A repeated concern about possibly doing harm to any of the dying informants accompanied my preparations before meeting the first dying persons in the context of this study. Possibly provoking a sad or troublesome situation just before an informant's exitus would take place, meaning that I maybe created bad last moments in life for somebody, was my biggest nightmare during the preparatory weeks. Additionally, before I started research, I imagined that I would face many situations in which research might not be appropriate: Maybe because the informants would prefer to spend their time with relatives and friends rather than with me, or maybe because they would be very sad and I might intensify this sadness by asking about their feelings, and the like.

During research and after having finished the study, however, my view on the potential harmfulness of anthropological research with dying people has relativized. Research with dying persons is not especially dangerous *per se*. To imagine that any researcher with a considerable amount of empathic common sense would have the capacity to play a decisive part in negatively shaping the last days of a person would be to underestimate the degree of self-care and agency enacted by informants: Seeing oneself as generally equipped with the power of harming dying persons turned out to be a kind of negative hubris, a topic of the researcher herself, rather than a real and constant danger for dying persons. Instead, dying persons tended to feel relieved when they could talk about their own feelings without being judged (see also Haslbeck 2005).⁶

Appleton (2004), a palliative care nurse with additional anthropological training, describes perfectly well why it makes little sense to see dying persons as especially vulnerable *per se*. Similarly to what she mentions with respect to her own work, I also met many informants who were eager to communicate about their feelings: Participant observation and interviews can be a relief because they offer time to talk, instead of being just a potential burden. Though only two of the dying research participants had a rough idea about cultural anthropology and the method of participant observation, even persons who had never heard of fieldwork before seemed to feel perfectly fine with developing their own interpretations of this method with me. We agreed that each meeting would take the shape the dying person wanted; the frequency of meetings and the places where we met were totally up to them and their conditions, and they were encouraged to refuse to talk about topics they would not feel comfortable with. In this sense, I think that research with dying persons turned out to be no more or less ethically problematic than any other anthropological focus would have been.

Even when dying persons are not able to communicate verbally anymore, they are often quite competent to evaluate whether they wanted somebody to be with them or not: By facial expressions, muttering sounds of agreement or unease, and by expressing unrest or the need for quietness with small movements and gestures. To assure the research participant and oneself that the researcher will notice these nonverbal signals, it is crucial to create an atmosphere of attendance for dying persons' feelings already before they can no longer communicate verbally. A good basis for creating an attentive research setting is to leave space – from

⁶Similarly, Rosenthal (2002) and Heimerl (1999) report positive effects on the subjective well-being, if persons in existential crises are encouraged to talk about what bothers them.

the first meeting on – for all kinds of emotions and ideas a dying person offers, and to ask for feedback in terms of researcher's interpretations ("do I understand you correctly, that you feel XY?") as long as verbal answers are possible. A dying person has to feel that she can act in whatever way she likes, and that the researcher relates to her verbal and nonverbal signals in a respectful way, without judging or devaluating feelings. If learning how to read a particular person's perceptions and emotions is a key concern of the researcher from the first meeting onwards, it becomes easier and easier to follow what a dying person might want to communicate, even if she cannot speak anymore. Besides, it becomes nearly impossible to provoke harm, if the researcher maintains her attention toward the dying informant. With background knowledge from accompanying dying persons as a hospice volunteer, and with ordinary common sense and empathy, research with dying persons turned out to be unexpectedly comfortable for all concerned parties.

Ethics Committees and participant observation

The potential informants I wished to approach were pre-exitally dying persons. Pre-exitally dying persons are also biomedical patients in Germany. Thus, the medical faculty's Ethics Committee of the University of Cologne was responsible for evaluating my study and, potentially, granting me access to dying patients. Anthropological studies like mine, however, are rarely presented to medical Ethics Committees.⁷ At the same time, Ethics Committees generally apply the same criteria to evaluate studies like mine, as they would apply to decide about biomedical studies containing e.g. drug testing or chemotherapeutic interventions. While Ethics Committees are used to being approached by researchers with a biomedical background, my research design was clearly an unusual request.

The communication with the Ethics Committee which had to approve my study was friendly and polite. I did not feel that they were sceptical about anthropological approaches in general, though anthropologists are still rare within biomedical surroundings in Germany. But generally, there could be a certain potential for difficulties when biomedical experts are the ones having to decide whether an anthropological study, containing methods and aims totally different from what they usually approve, is reasonable, necessary, and responsibly carried out.

⁷Further thoughts on the interrelations of Ethics Committees and anthropologists are presented by Riessmann & Mattingly (2005), Dilger (2015).

Regarding the decisions of Anglophone Ethics Committees as to whether and when research with dying persons should be carried out or not, Appleton (2004) reports the following impression from her own fieldwork: "It appears that there are certain assumptions underpinning research ethics generally and the research approval process in particular. Firstly, that dying people are a vulnerable group, who should not take part in research and that many health and social care professionals see it as their role to protect patients from researchers at the end of life. Secondly, that it is in the participant's best interests to remain anonymous and for confidentiality to be maintained in research. Finally, that the participant will be untouched or unchanged by the experience of taking part..." (Appleton 2004: 261). These assumptions were also partly implied by the Ethics Committee I worked with.

Within my own research, I made sure that all persons included in this study were willing and able to decide for themselves. Beyond personal agreement, it made sense to involve a third party – the palliative care unit's doctors – in the initial search for research participants within the palliative care unit, for the doctors knew many dying persons and could estimate if these persons would be suitable study participants. This method of approaching informants, mediated by physicians who could protect labile persons from joining the study, completely met the expectations of the Ethics Committee. In cases of informants and interviewees who were not provided by the palliative care unit, however, there were no gatekeepers involved. Instead, I followed a mutual estimation, worked out by both the potential participant and me, whether the persons I approached were stable enough to become part of the research. When I submitted an addition to my initial study design to the Ethics Committee, saying that I would like to start including dying persons who were not patients of the palliative care unit, the Committee was initially not sure about who had to be asked to agree with my informants' and my mutual decision to work with one another – the question if some doctor could be involved to potentially protect vulnerable patients came up. However, after explaining that it might be hard to justify in front of dying persons why a doctor should decide about her patient's private appointments, and after guaranteeing to make sure to consult professionals each time I noticed lability of a research participant, I was encouraged to go ahead and include dying persons without defining a third party to be asked for approval. This shows how inherent logics of medical Ethics Committees might not always meet the realities of anthropological fieldwork, simply because they are not designed for anthropologists. However, potential differences in evaluating how dying persons should be protected could be resolved satisfyingly by keeping up a dialogue with the Committee and resolve

unclear issues, based on a mutual willingness to understand each other's perspectives.

To all the persons included in this study, anonymity was guaranteed. This was required by the Ethical Committee for good reasons. It is necessary to protect dying participants from being all too recognizable, and anonymization also protects non-dying family members from the unwanted revealing of personal moments. However, some dying persons would rather have liked to be quoted with their real names ("that is something that stays. Sad that we cannot print my real name", Karl said more than once). Just as Appleton (2004) mentions, anonymization is not necessarily what research participants would like for themselves. So retrospectively, I would suggest that the duty of anonymization rather should have been replaced by a demand that anonymity be offered, but leaving it up to the participant to remain recognizable within the study or not; this would surely meet the desires of dying persons.

Leaving informants untouched or unchanged is something that is hardly commensurable with participant observation. When a researcher is supposed by an Ethics Committee to intervene as little as possible in the informants' lives, gaps show up between reasonable requirements for participants observation on the one hand, and reasonable requirements for medical contexts on the other hand (which medical Ethics Committees foremostly are concerned with, resulting in a transfer of medical ethical standards to anthropological contexts when a medical Ethics Committee is involved in anthropological research). Leaving the informants untouched or unchanged was not what they expected from me, or what I expected from myself as a researcher and as a human being. Though the dying persons' lives would have been different without my presence, I took great care that my being there did not make their lives worse – I aimed to be an enrichment of their dying rather than a burden.

Having finished the research, I agree that most requests by Ethics Committees have a positive and protective effect on potential dying informants. As well, anthropological studies profit from being sensitized towards ethical dimensions of fieldwork with dying persons. Demanding a careful description of research design, and demanding that a comprehensive description of the study is handed over to potential informants, are examples of biomedical Ethics Committees' requests that may also be absolutely reasonable in medical-anthropological research contexts. However, there are certain regulatory logics which can conflict with the aims and methods of anthropological studies.

Professionalism and emotional involvement

Doing participant observation with dying informants means growing close to persons, letting them become part of one's own life, and grieving for them once they have died. Woodthorpe (2011) argues that as a research focus, dying makes it – and should make it – impossible for any researcher to cut off feelings of intense involvement when working with persons at the ends of their lives. I agree that this is true, and that it should be so. I cannot imagine any kind of qualitative, productive research reflecting the views of dying persons that would not involve personal attachment and mutual sympathy, resulting in the researcher being sad when informants are dead.

However, it is not appropriate to confront informants with one's own compassion regularly: The situation of sitting beside the bed of a person who is dying, and who surely has the more severe problem with her dying than oneself as a researcher can possibly have, forbids that one make one's own sadness about dying persons' conditions a major and constant topic. From my experience, dying persons have enough issues to deal with – the last thing they need is a researcher who whines about the mortality of human beings, a researcher who is obviously destabilized by meeting dying persons, or a researcher who gets even more exhausted than the dying person herself is about her own dying. Fieldwork with dying persons requires finding a proper place for the researcher's own compassion, sadness, fear, and anger.

To deal with this issue, I chose to rely on psychoanalytically inspired, self-ethnographic approaches proposed by Nadig (2004) to disentangle my personal emotions and experiences and prevent them from leaking into everyday research, bothering informants, or producing biases and presuppositions. Concretely, it worked pretty well to keep a diary parallel to my fieldnote book: This diary did not contain observations and quotes, but was rather reserved for personal impressions and responses. Using this diary, I took some time at the end of each week to re-read what I had noted down as personal impressions and feelings during the previous days.

When I re-read episodes that made me sad or insecure or that I simply wanted to debate, I had the chance to receive professional supervision and engage in informal exchange with my colleagues in voluntary terminal care. This supervision opportunity meant a lot to me: It offered exchange with persons who know what it is like to see sometimes three dead bodies per week – of persons one had been close to. The supervision group could offer profound advice on how to deal

with situations that made me feel insecure. Additionally, within my preparation course for terminal care work, which lasted about one year and was very intense, I already had a certain degree of preparation to help me to find a good way of handling empathy and professional distance towards dying persons.

Personal entanglements

It has been explained elsewhere (Davies 2008; Berrenberg 2009) that it is necessary for cultural anthropologists to disclose any personal entanglements with their research topics. A researcher who serves as her own measuring instrument has to explain what calibrates her individually.

Furthermore, disclosing the researcher's private experiences with her research topic gives the reader the chance to get to know a crucial participant in the research and writing process: The researcher herself. Unveiling personal entanglements with the research topic helps to make the epistemological process comprehensive and transparent, instead of suggesting completely objective and dispassionate fieldwork without any personal involvement (Kempny 2012; Stodulka 2014).

To enable the reader to embed my research, it is necessary to mention that my voluntary work as a terminal carer provided me with opportunities for exchanges with regard to different cases of dying with other hospice volunteers. Exchange with other persons who deal with dying persons very often was important, as it created a regular opportunity to reflect on my own feelings, and a regular opportunity to feel completely understood within a community of people who shared parts of my work. Furthermore, having known dying persons as a terminal carer before starting to do fieldwork with dying persons certainly inspired how I approached research participants: Some years of exploring the perspectives of dying persons as a terminal carer preceded the years of research. Being a trained hospice volunteer gave me many opportunities to get to know different hospices and care homes as well as curative hospital units, which served as a pre-research source of information on how dying can also be embedded institutionally and spatially.

An additional episode that seems important is my personal, though very marginal and temporary, closeness to the experiences of dying persons. As I received a wrong diagnosis of being potentially terminally ill during the planning my research, I had a slight idea of what it might feel like to be dying for some weeks. This episode of considering myself as dying for a certain span of time was some-

thing I revealed to some potential informants. The personal involvement with dying I had, and the willingness to share it, motivated some potential informants who were initially skeptical about my research to meet me, often accompanied with comments like “so we know what we’re talking about, in a way” (Hermann).

I also had relatives – close and less close – who died either during research or before it. I was doing research in South China when my grandfather, a person who I was very close to, died. That I could not make it to his funeral, because the Golden Week in autumn made it practically impossible to get out of the PRC in time, was personally hard for me. Paradoxically, working with dying persons rather seldom reminded me of my grandfather. I rather experienced grief when I was not working; when I met terminally ill people in China, I could focus on them instead of my own loss fairly well. I interpret this effect as follows: Fieldwork provided a balance between occupying myself with dying, which I certainly aimed at when my grandfather died, and yet occupying myself with dying without putting my own sadness first – self-pity is not an option when working with Chinese persons in severe pain and without adequate medication.

That I was able to work with dying persons despite my personal loss hints at crucial differences between witnessing dying processes of persons one is privately close to, and witnessing dying processes of persons whom one got to know when they were already dying. While I certainly grieved for informants I felt close to, I could nevertheless turn my experiences with them into something productive instead of being paralyzed by touching memories or overwhelming sadness: The dying informants allowed me to be part of their dying processes with the aim of turning these experiences into something meaningful. Having this in mind made it rather easy for me to work with quotes and experiences connected to deceased persons I personally liked. In contrast, if I had been asked to write about the dying processes of close relatives, I am not sure I would have managed to look at these in terms of academic categories and purposes. For example, narratives about my grandfather dying would have felt too close to me personally for me to analyse and theorize while I was still personally shocked and hurt that I could not make it to his funeral. The stories I heard about my grandfather’s dying, after a temporal distance of many months from the actual event, now remind me of certain characteristics of dying processes of my informants: What had seemed absolutely unique to me in my grandfather’s dying process when it had just happened, is exactly what now reminds me of what I experienced with dying informants during my research. Balancing closeness and distance, apparently, is a crucial factor for working with and studying dying.

2.5 Fieldwork in the native culture and contrast research

The next paragraphs will discuss the characteristics of being a native researcher in contrast to being a researcher abroad – while questioning whether the difference between these two ways of doing anthropology is really that immense. Concretely, I will describe what benefits came with being a native when working with dying persons in Germany; what challenges I had to face; and to what extent the challenges, mainly biases and unreflected presuppositions, were met. Impressions from research with terminally ill persons in the Pearl River Delta will then be briefly presented: This contrast study was conducted to sharpen my ability to identify cultural specificities in Germany. Finally, issues of cultural distance and closeness that became important within native fieldwork with dying persons in Germany will be discussed.

General considerations

Working as a cultural anthropologist was traditionally associated with being a professional stranger (Agar 1996): Anthropologists used to be working on and among peoples who were most possible distanced to the researcher herself – in terms of language, habits, living space, and worldviews. Cultural anthropology developed its focus on ‘other’ cultures during colonial times: Historically, the clear distinction between ‘us’ (researchers) and ‘them’ (strangers who are researched) reflected a common perspective in the native cultures of many cultural anthropologists. Today, anthropologists are not simply the ones studying ‘others’ anymore (Peirano 1998), but belong to a discipline whose area of study is “the study of humans” (as the American Anthropological Association states – n.d., <http://www.americananthro.org/>): No matter whether these humans live in Samoa, Manhattan or Solingen. What persists from the tradition of anthropology as the science of ‘others’, however, is the aim to ground a basic understanding of cultural phenomena in taking for granted as few presuppositions as possible, sometimes by looking for the greatest possible distance (of any kind) between researcher and researched as a methodological pinch (Stagl 2002). Furthermore, the tradition of anthropologists as persons regularly confronted with the incommensurability of their own presuppositions with other persons’ worldviews still makes cultural anthropology especially sensitive to the ethnographer’s position in the field, her influences, and her biases (Kempny 2012). In the very moment an ethnographer enters any kind of field, she knows that she changes it, that she

may produce misunderstanding, and that she may misunderstand her informants. By coping with these situations over months, she can hope to gain a certain understanding about the people she does research with. While she takes her native interpretative system with her anywhere she goes, she is trained to be careful to notice any occasions when this interpretative system collides or agrees with the interpretation system of the people whose lives she enters (Kempny 2012: 41): In situations of clashing or agreement, cultural specificities show up. This noticing of interpretational specificities can happen in a completely unknown culture – but may also occur in the researcher's native culture. A shared cultural background can produce very different interpretations of one and the same situation, and different cultural background can also produce surprisingly similar interpretations of one and the same situation.

To consider native and non-native research conditions as completely opposed would be to underestimate how diverse intracultural variation can be, and how strange persons of one and the same culture can be to one another. Accordingly, similarities in status, gender, familial constellation and occupation can produce similar perspectives between people with completely different cultural backgrounds. Borders between 'us' and 'others' can be drawn referring to cultural backgrounds, but can also be bridged by communalities between persons that are not based on a shared culture. Therefore, a binary opposition between native and non-native fieldwork, or a devaluating of the one in contrast to the other, would simplify the multiple dimensions of researcher-researched relations in cultural anthropology.

Specificities of native anthropology in Germany and native medical anthropology

Sökefeld (2002) mentions that, in comparison to other countries, German anthropology still has a fairly intense bias towards native anthropologists – especially if they are Germans doing research in Germany. While a native cultural anthropologist in India or the US, to give just two examples, is not immediately urged to justify why she does not work in a more geographically distant area, this is different in Germany. German anthropologists who spend much of their research time at home are likely to be asked first why they are not somewhere else, instead of first being asked what topic they are researching. They have to explain their reasons for being so close to their native culture.

Reflecting on this special situation within German anthropology, Sökefeld (2002: 93) unveils it as a failure to think about fieldwork at home as something completely opposite to fieldwork abroad: In fact, both try to illuminate various ways of being in and making sense of the world. I agree with him to a certain

degree. What makes cultural anthropology unique can be carried out anywhere generally: Cultural anthropologists draw on selected persons' and groups' perspectives with the aim of understanding their worldviews, as well as the embedding of these particular perspectives in larger frameworks of practices, meanings, and concepts. Cultural anthropologists are trained to possess the capacity of looking for and noticing what persons do, and why; they investigate these issues by pursuing close relations with their informants and their perspectives, while ideally identifying and leaving out their own presuppositions and biases as much as possible. The reflective, bias-conscious establishing of long-term relations makes it possible to develop a deep understanding, to describe processes and changes, and to report on everyday life instead of artificial, momentary experimental set-ups. Where exactly this is done, and whether somebody decides to do this job by facing the risks and benefits of working as a native or as a non-native anthropologist, is not what is basically important for good anthropological fieldwork.

Medical anthropology in particular has a long tradition of investigating persons and practices within the native geographical and cultural background of the researcher. For example Kalitzkus (2003) and Lock (2000) published famous studies on the borders of living and dying within their native cultures. It is questionable whether a non-native anthropologist would have gained as many insights as they did without e.g. knowing about the legal systems and public debates on organ transplants or without being familiar with hospice movement developments. Regarding this, it seems justifiable to conduct a cultural anthropological study first with dying persons within one's own culture.

Additionally, as Van Dongen & Fainzang (1998: 247) describe, medical anthropology applies a slightly different notion of sameness and otherness than other anthropological areas: It is not the native culture that is the main focus when separating informants into 'we' and 'other', but also one's own state of being healthy as a researcher working with unhealthy persons. In the case of dying persons, a non-dying researcher who is confronted with dying persons is in a situation of otherness. Being severely sick can divide the everyday experiences of a sick person from those of a healthy person, probably as much as a different enculturation could (Van Dongen & Fainzang 1998) – and the same goes for being in the process of dying.

Contrast research in the Pearl River Delta, PRC

Nevertheless, researching dying in only one culture – native or non-native – does not allow comparative contextualizations. The aim of this study was not just to describe dying in Germany as well as possible, but also to highlight the particu-

larities of dying in Germany. Therefore, contrasting experiences within a different culture seemed to be the ideal way of identifying such particularities. Additional contacts with a similar group of informants – specifically, biomedically diagnosed terminally ill people – were on my concrete agenda. So, to prevent the study from overlooking cultural specificities of pre-exital dying in Germany, and to reflect on my own possible biases as a native researcher, a shorter contrast study in the Pearl River Delta (People's Republic of China) was conducted in the summer and autumn of 2015. In this context, I worked partially on my own and partially with a native assistant. My assistant continued to meet some of our informants after my husband and I were expelled from the PRC in late autumn of 2015,⁸ and continues to inform me about their and their families' condition until today.

Meeting Chinese persons who were suffering from a terminal disease in hospitals and at their homes prevented me from taking for granted especially one specific condition of pre-exital dying which I had experienced in Germany: The ontological impact of a physician's terminal diagnosis. My contrast study informed me about the lack of facticity that terminal diagnoses possess for some Chinese persons: For many of my Chinese informants, a terminal diagnosis did not mean that a dying person or a loved one necessarily and inevitably approached exitus. Instead, a terminal diagnosis rather resulted in intensified struggling for more competent health carers and good medicine. This interpretation of a terminal diagnosis was far from the impact of terminal diagnoses in Germany, and it showed me how biomedical advice and biomedical facticities are assigned special importance by dying people in Germany.

So, in the Pearl River Delta, pre-exital dying of the kind I was looking for happened not to be a widely shared condition of persons diagnosed as terminally ill. For persons who knew about their terminal diagnoses, an important issue was struggling to gain a cure elsewhere. The terminal diagnosis was often interpreted as a lack of competence on the part of those who reported the terminal diagnosis, not as a factual truth, even if renowned clinics and physicians pronounced the terminal diagnosis. Ideas that a terminal diagnosis may constitute a limited

⁸The exact reasons for this were not explained to us. It happened supposedly because I found informants besides the ones that state hospitals allowed me to see under the supervision of hospital management staff. I looked for informants besides those the hospital officials presented to me because the fieldwork allowed by hospital managers included being watched by officials during fieldwork. The presence of the officials resulted in informants being afraid to tell me anything, because they feared that their saying a wrong word about their treatments could lead to their receiving worse treatment.

perspective from an incompetent source, and not a perhaps previously hidden truth unveiled, were different from the ideas and actions provoked by a terminal diagnosis in Germany. The informants in the Pearl River Delta may have been suffering from an incurable disease just as the German informants were, but they did not necessarily identify themselves as dying because of this.

Furthermore, the emphasis on the perceived duty of and right to information about incurable diseases is something that differentiates German from Chinese approaches to dealing with terminal diagnoses: A Chinese doctor is not very likely to communicate a terminal diagnosis directly, and might rather try to hide it from the person concerned. While a German doctor will regard it as her duty to communicate a terminal diagnosis, particularly in such a way that it becomes clear this diagnosis means the person concerned has to die (Borasio 2012), a Chinese doctor might rather interpret it as cruel to confront a terminally ill person with her nearing exitus.

After having done fieldwork in China, the special characteristics of dying pre-exitally in Germany became fairly clear. In contrast to Germany, pre-exital dying as the result of a terminal diagnosis is not the usual way of dying in the Pearl River Delta. Furthermore, it is far from ordinary for people in the Pearl River Delta to be the first one to be informed about their own dying, or to be asked about their favourite arrangements for the last few weeks. For many persons, high-quality health care is even impossible to access – an exitus following a terminal diagnosis by a rather low-quality physician, then, is likely to be regarded as happening out of the blue, or to be ascribed to a lack of professional abilities on the part of a doctor.

What was impressively different, besides differences concerning dying and terminal diagnoses, was what participating informants requested from me: No Chinese informant asked me to read to them any text I wrote about their situation. German informants, contrastingly, demanded rather exact explanations or examples of how I work. Furthermore, many Chinese informants liked me to accompany them on their visits to doctors because they supposed a ‘Western’ woman would shorten the time they spent waiting in the queue to see the doctor (and even improve the treatment); during fieldwork in Germany, it was less usual for me to be invited to an appointment with a doctor, and my presence was seen more as a kind gesture towards me than as an improvement for the dying person concerned.

This is just a short glance at some of the insights from research in China, which are not the main topic here. Nevertheless, these comparatively different cultural interpretations of a terminal diagnosis may illustrate the extent to which observation of the differences between two cultures helped to sharpen the findings of the thesis.

2.6 Summary: Reflections on fieldwork with dying persons

Methodologically, the study is oriented towards classic methods of participant observation, conversations, interviews and expert talks, with a special emphasis on sensory ethnography (Pink 2009). Four main groups of research participants were included: Key informants, interviewees, short-term contacts, and non-dying persons who were either relevant to dying participants or had expert knowledge of dying in Germany. Though dying persons are usually regarded as especially vulnerable, a sensitive and reflexive approaching of dying participants allows to avoid stressful experiences potentially caused by partaking in an anthropological study. Being involved in research about dying can become a positive experience for terminally ill persons. This is also the case for the researcher, while a close monitoring of personal emotions and entanglements with dying is key during research with dying persons.

While the experiences from China helped a lot to reveal particularities of dying in Germany, the close participant observation with dying persons in Germany nevertheless remained the core part of the study. Approaching dying persons as a native speaker was helpful because dying persons, obviously, do not have much time or eagerness to be language teachers or habitual coaches. Doing anthropology within my native communication contexts also allowed me to understand many nonverbal nuances of communication: I am sure that this sensitivity made it possible to prevent the German informants from being unconsciously emotionally hurt, or misunderstood, by me.⁹ However, geographic and

⁹How unfavorable it is to get severely ill persons' nonverbal intentions wrong can be demonstrated by relating an episode from my fieldwork in China: without my native assistant, I would not have interpreted the courageous smile and happy photograph-showing of my first Chinese informant appropriately. After one conversation, I told my assistant I was surprised how this informant managed to fight so hard for any option of a cure despite doctors telling her she was incurably ill (which she, however, did not interpret as "I have to die soon, there is no doubt"). My assistant had a totally different perception: by showing photos of her granddaughter, our informant was telling us clearly that "This lady badly fears possibly leaving her granddaughter behind. Everyone can imagine that there will be nobody taking care of her granddaughter as soon as grandma is dead. That's what she told you." My native assistant regarded the informant's smile as "incredibly sad", and advised me to ask indirectly and carefully about her feelings. In the later course of research, it became apparent that I would have hurt the ill lady's feelings badly if I continued to ask about her feelings at those times when she showed pictures of her granddaughter.

cultural closeness does not necessarily make a dying person's perspective easily accessible even for a native researcher. Dying persons in Germany have sometimes brought me to the borders of my understanding capacities. As Van Dongen & Faizang put it, "just as distance is not a guarantee of objectivity, familiarity is not knowledge" (Van Dongen & Faizang 1998: 247). While I had shared cultural influences with my informants in Germany, this did not mean I knew what it means to be continually and inevitably dying. In this sense, I was a native anthropologist and yet was not: Both being attached to and being detached from dying persons' experiences influenced my fieldwork.

Retrospectively, there were multiple facets during research in Germany which made me an outsider on certain occasions: I turned out to be a stranger as a cultural anthropologist within surroundings where most people had never heard of cultural anthropology. I was clearly different from dying persons as a non-dying person. I was different from non-dying persons because I had to face a terminal diagnosis myself once. I was a stranger as a woman, as a young person, as an academic, and a stranger in biomedical contexts – which basically provide two fixed role repertoires: One for patients and close ones as being in need of medical assistance, on the one hand, and one for staff as providing medical assistance, on the other hand.

At the same time, I belonged to the dying persons as one who "went through this, too" (Niklas referring to my wrong terminal diagnosis). I belonged to the dying persons because I focused on their perspectives, and paid less attention to relatives', doctors', friends' and nurses' views. I was in command of the German language, like anybody around me during fieldwork in Germany. I had ideas about what would seem appropriate and inappropriate behaviour within different social contexts in Germany. I could interpret non-verbal behaviour quite well, and I was able to develop immediate empathy for my informants' situations because I was a native to the emotional contexts and concepts they were situated in.

Concludingly, and maybe just like any cultural anthropologist, I was a partial insider, and a partial outsider (Jahan 2014).

From the next chapter onwards, it is not research on dying persons that will be the centre of attention, but dying persons themselves. What exactly it means to die pre-exitally in Germany, what the shared convictions about pre-exital dying are, and how dying persons are initiated into the new situation of dying will be topics of the following paragraphs. I will relate the concept of vital conjunctures (Johnson-Hanks 2006) to dying persons' concrete experiences, and explain why it seems to grasp dying persons' perspectives better than conceptualizing dying as a life stage, or in relation to a stage model. The subsequent chapter deals with conditions of care and place of living – conditions of dying that dying persons are often able to choose, and which can turn out quite differently from what they imagined them to be.

Anthropology of Dying

A Participant Observation with Dying Persons in
Germany

Menzfeld, M.

2018, XXI, 273 p., Softcover

ISBN: 978-3-658-19825-1