

Chapter Four

Standing at the Doorstep: Affective Encounters in Research on Death and Dying

Abstract

Sensitive moments in ethnographic fieldwork, such as family conferences where continuing or discontinuing treatment is discussed, or when sitting by a dying person's bedside with family members, call into question the positionality of the researcher and research ethics. I frame the discussion in this chapter through the metaphor of the doorstep, which came to symbolize the process of negotiating proximity and distance, involvement and detachment. I consider how we, as ethnographers, can prepare for, navigate, and reflect upon fieldwork encounters that require a particularly sensitive approach. I reflect on how I navigated ethnographic fieldwork on the end of life with dementia by elaborating on my own attunement to interlocutors and situations, discussing also some of my own discomforts. Illustrating more general implications of doing research in a delicate context such as the end of life, I emphasize the importance of building relations of trust, which allows for the creation of more depth and openness in conversations. Participant observation at the end of life can evoke the sense of intruding in people's most intimate moments, but can also strengthen the relationship precisely because this moment is shared. Highlighting the difficulty of having to inquire about future losses, I make clear how, similar to family members and professional caregivers, I engaged in anticipating the end of life of residents.

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Anthropological writing about death has to be, if not an ice-axe to break the sea frozen inside us, at least an ice pick to chip at the conventional forms of representing and narrating the encounter of the anthropologist with death.

— Ruth Behar, *The Vulnerable Observer* (1996, 86)

Introduction

Ethnographic fieldwork, it could be argued, is always an emotional endeavor (Davies 2010) replete with unsettling encounters, and moments when anxiety and joy coincide. While the reflexive turn in anthropology sparked lively debates on fieldwork ethics and the positionality of the ethnographer, these topics should be further considered from perspectives that take the emotional aspects of ethnography seriously. This chapter addresses how emotions feature in the ways we, as ethnographers, position ourselves as moral actors in the field. It does so by taking the values ascribed to emotions and the emotional components of moral value seriously (Lutz 1998) and by taking a close look at the researcher's attunement to interlocutors and situations during ethnographic fieldwork.

I address these specificities in the context of ethnographic research on death and dying, though the discussion is also pertinent to ethnographers working in other settings that are, to a greater or lesser extent, emotionally charged. Researching death and dying has been characterized as a sensitive endeavor (Borgstrom and Ellis 2017; Woodthorpe 2011), yet few authors have addressed their own emotions while doing research (e.g., Pool 2000; Visser 2017; Woodthorpe 2011). “Emotion and the personal involvement of the researcher are undervalued in social scientific studies of death,” Pool (2000, 16) writes, underlining that emotions play an essential part in the research process as the researcher interacts with their interlocutors. This also became apparent to me during eighteen months of fieldwork—in three different nursing homes as well as during individual interviews in the private sphere of the home in the Netherlands—where I focused on the moral constructions surrounding the end of life with dementia, by scrutinizing

ideas of a “good” death, dignity, and suffering. Sensitivity, awkwardness, intense intersubjective bonds, and ontological questions of human existence were at the core of this ethnographic endeavor.

With this chapter, I will not attempt to answer the question of how to do research on death and dying, but rather aim to demonstrate the need to come to a better understanding of the affective states that come with ethnographic encounters. Thinking of ethnography and ethnographic writing in Brodtkin’s words, as a way of “linking our stories to larger stories” (2011, 21), my aim in describing some of my own experiences is to relate to ethnography as a practice, tradition, and personal passion. I would like to underline the importance of writing about and through emotions, in line with Bellah’s statement that “knowing in the human studies is always emotional and moral as well as intellectual” ([1997] 2007, xxxi). Negotiating, for example, the insider–outsider position that is inherent to participant observation and through which my positioning in the field with regard to the people I am with is formed, cannot be seen as a purely intellectual process. This is to say, that deliberating over the extent to which ethnographers can engage in certain topics, with certain people, and in certain situations is not only a matter of moral considerations which have been debated extensively in anthropology, it is indeed also a deeply emotional matter.

Emotions are intrinsically related to value and morality. On the one hand, moral judgment is often expressed in words which describe emotions, pointing to the importance of emotions in how moral claims are communicated and negotiated. On the other hand, morality and emotions are intertwined in the sense that “morality requires emotion because affect provides the motivation for taking particular moral positions towards events” (Lutz 1998, 76–77). Here, I build on Lutz’s approach to explore and reflect on the intertwining of emotions and morality in how we navigate and position ourselves in fieldwork. How, then, do the emotions we experience motivate moral considerations in the field, and how can the researcher’s moral positioning become emotionally expressed? Writing about the emotional layers of ethnography, I find, requires the ways in which ethnography moves us to be taken seriously. In *The Cultural Politics of Emotion*, Ahmed writes that

“emotions involve (...) affective forms of *reorientation*” (2004, p. 8, emphasis added). “Being moved” through the emotional force of an ethnographic encounter also means moving toward or away from people and situations, and can become a sign to do things in a different way or even withdraw. Emotions, then, are central to ethnographic encounters and the negotiated positionality of the researcher.

In the following text, by reflecting on my ethnographic fieldwork in nursing homes in the Netherlands, I will demonstrate some of the emotional and moral entanglements that came with researching death and dying. I go on to show how my own movement through fieldwork—my own *attunement* to situations—has been formed via emotional encounters. As Throop writes, “the ethnographic encounter is an encounter that is often defined by the recurrent frustration of the anthropologist’s attempts at achieving an intersubjective attunement with particular interlocutors” (2012, 85). I understand attunement here as informed by emotions and morality, and as referring to the way I, as a researcher, relate—emotionally, morally, physically—to my interlocutors and fieldwork itself.

I found attuning especially important due to the levels of intimacy, taboo, and the sensitive nature that the topic of death and dying is often charged with. Being there with bereaved family members saying goodbye to a loved one, I took part in what I considered to be intimate moments. The rawness of the confrontation with death, and the profound absence of presence visible in the inactive body of the deceased, was sometimes also accompanied by uneasy relief to suffering (Lemos Dekker 2018). The confrontation with death and loss oftentimes triggered grief and sorrow related to previous experiences of loss, finding family members and professional caregivers grieving past and present losses in a moment of emotional entanglement. Moreover, it also stimulated the realization of finitude, both in interlocutors and myself, and with it the anticipation of losses to come. While witnessing the end of people’s lives during fieldwork, I realized it was always the end of *a* life; that the dying person in front of me had unique meaningful relations, personal habits, and ideologies. I reflected on and fantasized about how their life used to be, a life filled with dreams, emotions, and perhaps secret desires, and was

struck by the complexities of a being coming to its end. This rawness, our responses to loss, to be left in nothingness, and “the sense of death as no longer abstract possibility but present actuality” (Fairfield 2015, 14) provided the context and matter of my research, as well as the lens to think through the emotions that accompanied it.

While a part of what happens in death will remain incomprehensible, as ethnographers we look at and explore death through its manifestations and affects—we study the social and cultural structures surrounding death, its rituals, the experiences of grief, anticipation and loss, and how relationships are made and unmade. I will elaborate on this by reflecting on the emotional and moral entanglements in my own navigation through the ends of residents’ lives in Dutch nursing homes. By using the plural form “we,” here I position myself in a larger community of ethnographers. This is not so as to generalize my experiences, but to serve as a reminder that the experiences I share may speak to others’ concerns and can be seen in line with central methodological debates within anthropology, of proximity and distance, the limits of empathetic understanding, and moral considerations in doing fieldwork.

Participating in the End of Lives

“Being there” in a nursing home meant spending hours sitting in the living room, drinking coffee, or staring out of the window with residents. Marveling at the color of the leaves and life outside alternated with moments of shared boredom. I took part in meetings between the general practitioner and family members wherein the well-being and treatment options of residents were discussed. From time to time, care workers would ask me if I could lend a hand by, for example, taking a resident to the hairdresser, which was located on the ground floor of the building. In the afternoons, I often walked through the nursing home hallways with residents, passing the coffee corner with the birdcage, the photographs of the market, the antique clothes dryer, and again the coffee corner with the birdcage—over and over again. During these walks, residents would recount parts of their lives and talk about their work, their families, and memories. Sometimes, these were entire stories,

sometimes fragments, and sometimes sounds that made no sense to me mixed with words that encouraged me to interpret and read between the lines.

When the end of a resident's life drew nearer, I spent most of my time sitting at their bedside, sometimes with family members and sometimes by myself. At the bedside, family members shared with me stories about the dying relative, who she was and the life she had lived. While I could not engage in dialog with the person with dementia herself, I could listen to the stories told by family members and the professional caregivers caring for her. Often, the dementia had advanced to such a level that verbal communication was challenging or in some cases impossible, especially when morphine (administered to manage pain) had reduced consciousness even further. Thus, I wasn't able to know how the person with dementia experienced the process of dying, how she was facing the end of her life, if she was afraid or not, and which values mattered most to her. As such, I tried to get to know the residents of the nursing home and their family members and to establish a connection as much as possible, before the process of dying started—so I would be a familiar presence for them and they for me at the end of their lives.

Once, after spending a couple of hours with Anna²⁵ in her mother's room, she took a book from the shelf and sat down beside me at the coffee table. It was a printed photo album that showed pictures of her mother, both from the past and from the present in the nursing home. Together, we browsed through the pages and talked about her mother's life. She characterized her mother as a proud woman who cared about her appearance. The next morning, Anna changed her mother's earrings, applied eye-shadow, and dressed her in a pink shawl. Her mother, who was in her final days, was bedridden and her eyes were already closed. Anna mentioned that pink was her mother's favorite color. Gaining insight into the lives being lived in the nursing home and the histories that went with them helped me to understand what mattered to the person with dementia and their family at the end of life.

²⁵ I have anonymized interlocutors' names for reasons of confidentiality.

Participating in the end of people's lives also came with specific complexities. I learned that the specific context of the end of life of people with dementia requires a thoughtful approach to establishing contact. The researcher must take a careful step closer and rely on nonverbal communication, such as physical contact, body language, and facial expressions. Often, when I visited a dying resident, the question of whether it was appropriate, emotionally and morally, at that time to enter the room arose. As a result, in an unexpected way, the doorstep became a metaphor for my engagement with sensitivity, proximity, and distance, and being respectful. Although a physical doorstep is often absent in nursing homes to allow for wheelchairs and beds to make their way through the building, there is a clear, symbolic border—a door, a line between different colors on the floor—between the semipublic space of the nursing home hallway and the semiprivate space of the resident's room. The doorstep came to symbolize the emotional and methodological negotiations of involvement and detachment. How close are you allowed, how close do you dare to go, and how close is close enough to be empathetic? And what distance is enough to be respectful?

One occasion in which these questions arose was three days before Mrs. Van Doorn passed away. I was sitting at the kitchen table waiting for the doctor to arrive when her son Henk entered the unit. He sat down next to me and said to me, "This is not what one wants." Upon which I asked, "What would you want?" He answered, "That it would be over soon." He told me about the death of his father years ago, but then added, "*This* is completely different, she is screaming from pain and suffering." We looked at each other without saying anything more. When the doctor arrived, the three of us walked to the room where Mrs. Van Doorn was lying in bed. I waited at the doorstep as they entered the room. The doctor lifted the blanket and uncovered Mrs. Van Doorn's left shoulder to check if the morphine needle was still in place. It was a small needle with plastic tabs on either side—I now understood the name "butterfly needle." Henk asked the doctor, "How long?" And the doctor replied, "Before she dies? That is difficult to say. I do see that her functions have decreased and she could die of that, but still it is hard to predict." In the meantime, Henk's sister Marta who I had briefly spoken

with that morning arrived. While greeting everyone with a smile, she entered the room and took a chair to sit by her mother's bedside. Just before he left, the doctor told them this was all he could do for now, and that he would be back to check up on Mrs. Van Doorn later in the day. Then, Marta looked at me and said, "Come in, take a chair," and pointed to a chair by a small table in the corner of the room. I took the chair and placed it at the end of the bed.

When Marta asked me to come sit with her by the bedside, she accepted my presence and involvement. I had waited at the doorstep, because I considered this a deeply personal experience. I was anxious about imposing in such a personal moment. Waiting for interlocutors to invite me in became one of the ways I was able to negotiate my position as outsider and insider. I also hoped that my reserved attitude would demonstrate respect.

I constantly negotiated how to approach moments that might be experienced as private or sensitive. I find it hard to describe what sensitivity precisely entailed or what it meant to have a sensitive approach. For me, it was about being attuned to the emotions of the other and myself in the moment, being able to sense the emotional interactions and what matters most in that specific situation. It was about seeing and listening, as much as about voicing the things I was not sure about.

One afternoon, after Anna and I had spent several hours talking by her mother's bed, I was just about to go home when the general practitioner informed me that there would be an unexpected family meeting with Anna's brothers and sisters. We walked back upstairs to the unit where the family was waiting and the general practitioner asked them if it was all right if I was present during the meeting, to which they agreed. After looking for a place to sit down in the living room, which was too crowded with residents, we moved to a table in the hallway. At first, I decided not to take place at the table but sat down on a chair by the wall to seem less obtrusive, upon which Anna said, "No, come and join us, you are also a part of this." While taking a seat at the table, I experienced an increased self-awareness—as if my expressions, how I moved, and my presence all mattered at that moment. As I took my

notebook from my bag I felt the need to place it open in front of me, an attempt at being transparent toward the family, making visible what I was writing and what I wasn't. I could see that Anna and her family were somewhat agitated and restless, as well as very serious in that moment, and being there as a researcher I did not want to cause more harm. In this way, attuning to my interlocutors and the situation was both a moral consideration and about the emotions I experienced and those that I perceived in others. My response—taking out the notebook and placing it in front of me—was a form of self-discipline borne out of a deep concern for transparency, which resonated with Rabinow's remark that the anthropologist is required to be aware of the codes of conduct and should control herself, adapting to the situation, accordingly ([1977] 2007, 47). In this way, attunement was also expressed by holding back, standing waiting, and not wanting to impose my own presence. Being moved, emotionally, was closely related to bodily movement in deciding how, and to what extent, to engage in interactions. There is no blueprint for encounters like these, but I tried to conform to the setting and the person in front of me.

At the doorstep, a range of emotions and deliberations came together. Respecting this cultural boundary between outside and inside, or as was my intention, also meant respecting the private sphere of the family witnessing the final moments of the life of their mother or father, husband, wife, or sibling. Also when there was no actual doorstep, there could be "doorstep situations" that entailed emotional and moral thresholds, such as in the meeting described above where I considered whether, and how, to sit with Anna and her family at the table. It was a point at which I considered my own invasiveness in the moment, and whether my presence was accepted and appropriate. It was a threshold, perhaps more for myself than for the people I was with, which highlighted my own discomfort. Would I dare to step over my own worry of being invasive? This deliberation, however, could not take too long, or it would acquire a voyeuristic character. In this sense, the doorstep presented a clear choice: step inside and fully engage, or walk away. Doing otherwise, standing outside while peering in, was not an option. And thus, I entered.

We are sitting all around her while she is lying in bed. She, Mrs. Van Doorn, is dying. On her nightstand an old photograph, of her first husband I am told. Mrs. van Doorn was born on the 3rd of September, 1919 in a rural area in the south of the Netherlands. She was the oldest of fourteen children. She started working at the age of fourteen and met her first husband at nineteen. They married and had seven children, of which two passed away at a young age. Mrs. van Doorn knew many losses in her life, she lost her husband in 1982, and later another son and two grandchildren. After many years she met Martin, with whom she enjoyed traveling and with whom she lived together before moving to the nursing home. Next to the photograph, a plastic cup with water, with a small stick with a green sponge on the end, to keep her mouth moisturized. She gasps for breath, while we, her daughter, granddaughter, son, the spiritual counselor and I fix our eyes on her. We look at her and at each other, but not for too long. It is as if we fear we might miss something, her final breath, or whatever comes. No sounds are entering the space except for Mrs. Van Doorn's breathing. We talk in a low tone of voice, almost as if speaking under our breath. The daughter Marta, who is sitting next to the bedside and has her eyes still fixed on her mother starts moving on her chair and clamping her hands together, while she says "no not yet." She seems to panic, while the pace and rhythm of Mrs. Van Doorn's breathing becomes slow. Then, a long pause, we hold our own breath and wait. Will this be her last one? No—a new burst fills the air and her daughter startles. Then, once more, a deep breath and Mrs. Van Doorn has passed away. Marta holds her mother and presses her lips on her forehead while her sobbing becomes louder. While at first we were all sitting and the room was filled with tension, now there is movement, we are holding each other, shedding tears and saying our condolences. Besides the sadness, tension has given way to a kind of relief. (field diary, author)

Awkwardness, Sensitivity, and Intense Bonds

While sensitively balancing distance and proximity often resulted in in-depth connections, it was at times also paired with awkwardness, and sometimes also resonated with humor. One Monday morning, I entered the nurse's office and asked cautiously if any of the residents' condition had worsened or if anyone was dying. I was aware of my own discomfort

in posing this question, and I tried to convey this consciousness in the manner of asking. Perhaps, reflecting on this now, what I was trying to do was to soften the question for both the nurses and myself. Although it was not as if I wished anyone would die, I feared my asking would give that impression. Still, I had to ask, first because I could not visit every individual room (the nursing home consisted of fourteen units with six residents each), second because I did not have the knowledge to assess someone's condition—perhaps the person was just staying in bed for a day—and third because knowing someone's condition had worsened or if the person was dying required a different, more modest and sensitive approach while entering their unit. In her response, the nurse joked: “Well, that’s a nice question to begin with on Monday morning!” Both my own discomfort in asking and the nurse’s response, although with humor, implied that death should not be asked for. Even though death and dying are part of everyday life in the context of the nursing home, it remained a topic of conversation that could evoke discomfort or giggly responses. This resonates with Howarth’s observation that in modern societies, “death is confined to medical or scientific discourses; anything outside of that is taboo or viewed as “pornographic.” [Death] has been removed from the public realm and placed firmly within the private sphere of the family and individual” (2007, 16).

As such, I feared the people I met would perceive my interest in death and dying as voyeuristic, as if I was looking at something one is not supposed to look at, invading another’s intimate and personal sphere, and thus feeling inappropriate (e.g., Visser 2017). For example, after spending a month or two in the nursing home, professional caregivers started associating me with the topic of death and dying. This was valuable since it often created a space wherein professional caregivers would start talking about the subject themselves, reflecting on past experiences and current situations, or at times would approach me to tell me when a resident’s condition had worsened. But being related to the topic of death and dying could also feel troublesome given the morbid nature of it, even if it was packaged with humor. Once, upon arriving at a unit, one of the professional caregivers who saw me entering exclaimed, “Uh oh, who’s dying?” and we both laughed at it.

I have also removed myself from encounters with family members, sometimes because I sensed they were unable or unwilling and at other times due to my own discomfort. During one cold morning in December 2015, I arrived at the nursing home, finding team manager Isabelle in an afflicted state behind her desk. In a high trembling voice that was unusual for her, she told me Mr. Langedijk had fallen in the bathroom only a few minutes before and had died. She looked at me in panic and continued in a rushed tone, “They [the care workers] found him in the bathroom, but we don’t know what happened. If he died and then fell, or if he died because of the fall. They are so confused and upset.” Together we walked toward the unit. Upon arriving, the care workers were busy attending to the needs of the other seven residents for whom they had to care. Nicole, one of the care workers, told me she had already notified the family; they were on their way. Her face was red and I could see that she had been crying. About an hour later, Mr. Langedijk’s daughter and her husband arrived. Isabelle briefly introduced me. We shook hands and I expressed my condolences. Isabelle continued talking with the daughter about what happened. Without being able to pinpoint exactly why, I felt slightly uncomfortable in the situation. When Isabelle had finished, she returned to the nurses’ office.

Mr. Langedijk’s daughter, her husband, and I stood in the empty corridor just outside Mr. Langedijk’s room. On their faces, disbelief and shock, but also something which I cannot quite describe, it was not quite anger, but a certain sternness. As the conversation progressed, my initial feeling of discomfort increased. Both my questions and their answers became shorter. I wanted to end the conversation and leave the couple to themselves. I thanked them for their time and expressed my condolences once more.

Reflecting on this encounter, I have tried to dismantle what it was that made me stop: Was it the look on their faces? Their manner of talking and interacting with me? Or was it my own discomfort in asking questions at a moment where I assumed they could be out of place or inappropriate? The moral and the affective were inextricably interwoven in this situation. While it was difficult in these instances to pinpoint the specific reason, it became clear to me that, as Stodulka writes, “as

embodied products of researcher-researched interactions, emotions may either motivate or discourage further engagement” (2015, 86). Considering that emotions move us (Lutz 1998; Ahmed 2004), they move us toward actions and toward others, but they can also move us away from a specific person or setting. Whether to withdraw or engage is a moral consideration as much as it is driven by emotional experience, and whether and how we attune and make sense of them as affectively aware anthropologists.

At other times, as was the case with Mrs. Van Doorn’s family, intense bonds emerged, perhaps precisely because I was not part of the family or a member of staff, and because I had the time to be present and listen. My position as a familiar stranger at times facilitated discussions about sensitive topics which might have been harder to talk about with family members or others who had a personal stake in the process. Many interlocutors explicitly told me they appreciated my presence and our conversations. Some expressed their gratitude for me being there while I expressed I was the one who should be thankful. One evening, I was preparing to go home to have dinner when Marta asked, “But you are coming back, aren’t you?” That evening I had dinner in the nursing home’s cafeteria and quickly returned to the unit, not wanting to disappoint her. Creating a space to discuss death openly was oftentimes valued and experienced positively by interlocutors.

Hence, researching death did not only bring awkwardness and discomfort. Engaging in conversations about death and dying, going beyond discursive taboos, also enabled in-depth connections, even if doing so required working through the discomfort. Having such encounters that allow for vulnerability and trust fostered meaningful relationships. In some cases where I did not know the family before we spent time at the bedside, the relationship was forged in *that* moment. Being present at such a defining moment in one’s life strengthens a relationship precisely because this moment is shared.

However, I also noticed there were limits to how vulnerable I could be, and how much emotion could be shared. Several times I felt the need to suppress my own tears while standing at the bedside with grieving family members. Why did I do this? Did I not want to appear vulnerable?

Or did I feel it was not my sorrow to express? Reflecting upon this now, from behind my desk, I feel the loss belonged to the family, as if there was a certain legitimacy to feeling it. They were the ones losing a loved one. Can we then, even if we allow ourselves to be vulnerable, understand the grief and pain of others? While I could understand their suffering because they were losing a loved one, and could also feel sad because I was witnessing a person dying, at the same time there was a distance, as it was not me who was losing someone. I understood the pain but did not experience the loss (e.g., Pool 2000). Such limitations in understanding interlocutors' emotions have been discussed by Rosaldo ([1989] 2004, 2014) who describes in his classic essay "Grief and a Headhunter's Rage" how he only learned to understand "rage" among the Ilongot after experiencing the loss of his wife in an accident during fieldwork. He writes that only after experiencing a loss of his own could he appreciate the "powerful rage Ilongots claimed to find in bereavement" (2004, 168). Helpful in engaging such limitations is Ahmed's (2004) point that feeling sad about another's pain is a form of alignment with the other, but a form that works by differentiating between the other and the self. This is about recognizing my own emotions instead of equating them with those of interlocutors. My emotion emerged from seeing someone dying and was mediated by witnessing the family's sorrow and my own ability to empathize with what it means to lose a loved one. But, obviously, I did not feel the same loss.

A Final Note on Writing about Death

I had to figure out how to observe and participate in the process of dying, to learn at which moments I could be present and when it was time to withdraw. However, the preoccupation with sensitivity does not end with fieldwork. For me, ethnographic research is as much about writing as it is about the encounters I experienced. Doing this, however, requires a return to emotions, picking up the ice-axe Ruth Behar called upon. In writing about death and dying I have sought to transfer the charged nature of loss into words that do justice to the complexity of encounters

and emotions. I have tried to convey the difficulties and strong connections I encountered, as well as the discomfort and gratitude I felt during my research, to explore how emotions feature in the ways we, as ethnographers, position ourselves as moral actors in the field. This brings to the fore a togetherness of contradictory emotions, impotence, awkwardness, and humor that enabled connections while researching the end of life.