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Organization and Agony. Transfigurations of Dying in Multi-Professional Palliative Care

Introduction

One of the main characteristics of modern societies, which differentiates them from archaic or stratified societies, is that they mostly consist of organizations. It is the emergence of organizations that allows an ever-increasing division of work through specialization. We spend most of our lives within them, from beginning to end: In Germany, 98 percent of births occur in hospitals.[1] We then go to schools and universities. Nearly all workplaces are characterized by a high degree of specialization. The ›circle of life‹ not only begins in organizations—it is also very likely to come to an end in an organization.[2] The fabric of modernity is inextricably intertwined with organizations.

This chapter is dedicated to a specific part of the ›circle of life‹: death and, more precisely, the dying process, which is characterized by its high degree of liminality between life and death. The perception of the dying process has undergone significant changes during the course of modernization. One major component was a paradigm shift when it comes to awareness of dying.

Dying patients were usually kept unaware of their situation. In hospital settings, doctors, nurses, and even relatives avoided talking about dying. Patients didn't know about their impending death, thus were unable to make any preparations or any decisions about what might come after their death. This is what the sociologists Barney G. Glaser and Anselm L. Strauss famously called the »closed awareness context«.[3] According to Glaser and Strauss, the more desirable situation is an »open awareness context«, where information about the patients' situation is evenly distributed. This should allow the patient to be in charge and to participate

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[1] Ramsayer, Beate: Die physiologische Geburt, Hannover 2020, p. 29.

[2] Saake, Irmhild: Wir sterben heute in Organisationen. Und die sind wichtiger als gedacht., in: AVISO – Magazin für Kunst und Wissenschaft in Bayern (2020), No. 4.

[3] Glaser, Barney G./Strauss, Anselm L.: Awareness contexts and social interaction, in: American Sociological Review 29 (1964), No. 5.

in decision-making. The Swiss-American psychologist Elisabeth Kübler-Ross even developed a five-stage model outlining the path to acceptance of dying.[4] This model suggests that every patient will eventually make up his or her mind and achieve open awareness. However, the research following the publication of Kübler-Ross' »On Death and Dying« was quite skeptical about open awareness: it cannot always be achieved, since patients regularly refuse an open conversation about their situation.[5] Studies also show that it depends on the actor constellation whether patients display open awareness or not, and whether open awareness is needed for the provision of care.[6]

The second component of this major shift in paradigm was that medical care for the dying was replaced by so called ›total care‹. Corresponding to the concept of »total pain«, developed by Cicely Saunders in the 1960s,[7] palliative and hospice care is supposed to not only care for a dying patient, but for a ›whole‹ person (as in ›whole person care‹[8]). Medical care, focused on physical pain, was replaced by ›comprehensive‹ or ›holistic‹ care. Apart from physical pain, spiritual, social, as well as psychological pain are also treated by palliative and hospice care. To achieve this total, comprehensive care, multi-professional teams were established. In German hospice and palliative care,[9] those typically consist of specifically trained palliative care physicians, palliative care nurses, social workers, various therapists, pastoral care workers, and volunteers.

The goal of the following chapter is to demonstrate what happens when multi-professional ›comprehensive‹ care is put into practice. Using two case studies as empirical examples, this chapter reveals the multiplici-

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[4] Kübler-Ross, Elisabeth: On Death and Dying, New York 1969.

[5] Richards, Naomi et al.: Awareness contexts revisited: indeterminacy in initating discussion at the end-of-life, in: Journal of Advanced Nursing 69 (2013), No. 12.

[6] Saake, Irmhild/Nassehi, Armin/Mayr, Katharina: Gegenwarten von Sterbenden. Eine Kritik des Paradigmas vom ›bewussten‹ Sterben, in: Kölner Zeitschrift für Soziologie und Sozialpsychologie 71 (2019), No. 1.

[7] Saunders, Cicely: The symptomatic treatment of incurable malignant disease, in: Prescribers Journal 4 (1964), No. 4.

[8] McKee, Margaret et al.: It takes a whole community: the contribution of rural hospice volunteers to whole-person palliative care, in: Journal of Palliative Care 26 (2010), No. 2.

[9] In the German discourse the differences between palliative and hospice care are usually emphasized. Palliative care is supposed to denote the medical care aimed at improving the ›quality of life‹ of the patient. However, hospice care refers to so-called ›holistic‹ care, which encompasses the family and friends of the patient. For further information: Radbruch, Lukas: White paper on standards and norms for hospice and palliative care in Europe: part 1, in: European journal of palliative care 16 (2009), No. 6.

ty of perspectives that is generated by just one single patient. The underlying assumption is that the revealed differences in perspectives are not completely determined and at the same time not entirely random. Building on Stefan Timmermans' concept of »death brokering«, which focuses on all medical activities rendering deaths culturally acceptable,[10] I want to highlight that these death brokering activities in multi-professional settings are not limited to medical activities. All professions that take part in death brokering participate in rendering deaths culturally acceptable. Although the empirical data is not suitable to corroborate this point, I would like to assume, drawing upon the results of other studies, that »culturally acceptable« holds different meanings for different professionals. This means that there is no single, unified, common ideal, but rather distributed ideals across multiple professions. To conclude, it is further argued that cultural acceptability could be more precisely described as the patient undergoing a transformation, where each profession transfigures the agony of the patient in a different way, where suffering takes on different meanings. This ambiguity of meaning further emphasizes the situation of liminality at the end of life. This, however, is not the fault of the organization but a normal, expected and unavoidable effect, which makes them so efficient and pervasive throughout modern society.

Analysis of Actor Constellations

This chapter is about a specific part of a larger study.[11] It is focused on the different actor constellations and different perspectives that emerge from these constellations. The term ›actor constellation‹ denotes all the relations around a single patient in a multi-professional environment: patient-relative, patient-physician, patient-nurse, patient-therapist, among others. Several patients were interviewed, followed by interviews with all professional and non-professional individuals (e.g. relatives and volunteers) who provide care for this specific patient. All of them were asked

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[10] Timmermans, Stefan: Death brokering: constructing culturally appropriate deaths, in: Sociology of Health & Illness 27 (2005), No. 7.

[11] DFG-Project »About ›Dying Well‹. Actor constellations, normative patterns, different perspectives«; Project #343373350; Project management: Christof Breitsameter, Armin Nassehi, Irmhild Saake. Data collection: Niklas Barth, Katharina Mayr, Andreas Walker. Website: https://www.gutessterben.uni-muenchen.de/

questions about the patient. During the course of this research project, it was possible to gather enough data for 20 actor constellations.

The underlying assumption of this study is that different contexts generate different meanings. In sociology, differentiation theory has a longstanding tradition, from Emile Durkheim to Max Weber and Talcott Parsons up to Niklas Luhmann, Luc Boltanski and Laurent Thévenot[12] or even parts of Bruno Latour's œuvre[13]—to just mention a few representatives. This conceptual background leads to the expectation of the emergence of different meanings in each actor constellation. Death and dying of a specific patient do mean something different, for example, for a nurse than for the pastoral care worker. The individuality of each patient is reconstructed differently in each constellation. To go even further: each patient *is* someone different for each actor. This is no fault or defect but rather a characteristic of modern society, as these different perspectives do not occur randomly but are institutionalized in organizations. Returning to the aforementioned dominance of organizations in modern societies, this means that the so-called ›whole person‹ is constantly deconstructed in order to generate endpoints for different ways of addressing a person: as a customer, voter, student, citizen, pensioner, and patient, among others.

Results: Two Cases

It was possible to analyze 20 actor constellations. For this chapter, two constellations were selected for illustrative purposes, since not all constellations can be presented in such detail in one book chapter.

During the analysis of the actor constellations, a very clear pattern could be observed, which was very much in line with the expectation coming from differentiation theory: Professionals from different backgrounds, as well as relatives and volunteers, all achieve different interpretations of the patient's individuality, of the wants and needs of a patient. Sometimes, these differences are more nuanced and, sometimes, they are very obvious or contradict each other directly. Yet, they are visible in every case.

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[12] Boltanski, Luc/Thévenot, Laurent: De la justification. Les économies de la grandeur, Paris 1991.

[13] Latour, Bruno: An Inquiry Into Modes of Existence. An Anthropology of the Moderns, Cambridge 2013.

In the following, two very different cases will be presented: they will be called Martha and Tom.[14] The cases were selected not despite but because of their differences, since they reveal that these differences in perspectives do not depend on a specific case or certain characteristics of a patient, but are commonplace throughout multi-professional palliative care. The actor constellation of Tom consists of five interviews, the one of Martha of six interviews including an interview with the patient herself. The actor constellations are never perfectly symmetrical since each individual case is different. Table 1 gives an overview of the data available.

Table 1. Overview of the interviews used for this book chapter

Patient/Resident	Martha	Tom
Age (years)	61	23
Participants	Hospice Resident	Chief Physician
	Friend	Physician
	Physician	Physician
	Nurse	Nurse
	Nurse	Physiotherapist
	Hospice Manager	

Case #1: Martha – »The illness simply rips you out of your life«

The hospice resident Martha is 61 years old and suffers from lung carcinoma. Just before the interview took place, brain metastases were also diagnosed in her. Before entering inpatient hospice care, she lived alone at home. In the following, the different perspectives on the hospice resident are shown, until Martha's own statement will be discussed. We will start with a friend who visits her from time to time.

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[14] All names are pseudonyms, which are in no way related to the real names of the participants.

What does the friend say?

Her friend Heidrun has accompanied Martha for a long time. Since she lives in the inpatient hospice unit, Heidrun has observed positive changes.

> Well, I have the feeling, I was prepared for the worst. I already visited her in August when she was still at home. During chemo... there, I mean, *now she has physically deteriorated.*[15] But back then, I would say she was a wreck, to put it frankly. Very bad! And now, she has regained more joy of life. For me now. And yes, she is well cared for. Everything she needs is there. And I believe, it's good not having to worry about anything anymore. She has enough to deal with herself. With the situation. Yes. And... she's also happy. She has a very nice, bright room. Nature. She now has a deck chair so that she can lie outside. It is peaceful here. That's good for her, yes.

While at home, Martha's physical decline became increasingly apparent, her condition in hospice seems to be improving. At least she has more »joy of life«, according to her friend. An important factor for this positive development is the relief from the tasks of everyday household chores in the hospice.

> Of course, the fact that *she doesn't have to go shopping, that she doesn't have to cook, that she doesn't have to clean.* Yes, such things, which are increasingly difficult for her. She says, she still makes her bed herself. But even that is a great effort for her. There is always less she can do herself. Therefore, I mean that everything she needs is here.

The hospice staff now takes care of everything. Martha is comprehensively relieved. The only activities worth reporting now are the few that Martha takes on herself: making the bed. Everything else is provided by the hospice. Despite all these conveniences, Heidrun also discusses the topic of dying with her friend.

> She's afraid of suffering. She's afraid of the ›how‹. She isn't afraid of dying per se, but of the ›how‹. I think everyone fears this ›how‹, don't they? You wish to just drift off to sleep... but we had a chat about this too, if it does get too tough, then max out the painkillers. Then it doesn't matter, yes. Then you don't need to remain conscious and all... She just fears that she can't die. Because she's not that old yet. That was her fear. That while all other organs may fail, if the heart continues... If the heart doesn't stop, you can't die.

According to Heidrun, dying is something that Martha evidently thinks about. She knows she has to die. However, she is concerned that the

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[15] Important passages have been typeset in italics.

process of dying will be painful and distressing for her. The sedative effect of strong painkillers is her only hope. The reason why this question regarding the ›how‹ preoccupies both Martha and her friend is not discussed explicitly here.

Martha's friend Heidrun has not been to an inpatient hospice unit often before. Therefore, she carefully observes the peculiarities of this establishment and its residents.

> I saw her in the kitchen this way. We sat together at dinner in the kitchen yesterday. And... yes for *an outsider, who is not sick,* for me...that was my feeling, some patients...how should I say this... are *a bit grumpy.* When...one complained because she was woken up at half past five with a ›Good morning‹. That was likely meant as a joke, but she was very angry about it. Such trivial things...the patients are very sensitive. Or how do you say it? The guests.

Heidrun sees herself as an »outsider«, as »not sick«, surrounded by the sick, now getting to know this new environment up close. She observes the residents and seems to wonder why they are not always in a good mood and are rather »grumpy«. Her position as an outsider is further emphasized by her insecurities regarding the proper terminology (patients or guests).[16]

What does the physician say?

The physician is providing palliative care to Martha. For her, an important aspect when treating Martha is her being aware of the situation. She specifically talks about a decision she made together with her.

> Take Martha as an example, she said: ›Now I do have brain metastases.‹ I had already talked to her about it before. ›Do you really want this? Do you want to have another CT or MRI.‹ I think she had a CT. ›What does this imply for you?‹ Then she was very ambivalent. [...] And then she had it done and then she said: ›*You know what, I feel relieved. I know it now. I don't have the uncertainty. I know, the disease is progressing. And maybe my memory or my cognition will be affected at some point. But honestly: I am glad about it.*‹ And then I talk to her about it. ›What does this mean for you?‹ Then, she has a very strong need to talk, so she says: ›I'm still doing well.‹ Today she is still celebrating, I don't know, she is having a party with her friends. She confronts the topic very actively and then I talk to her about it. What this means for her, whether this takes away some of

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[16] In some German inpatient hospice units, the term patient is uncommon. The staff prefer to talk about guests or residents. In this specific case, it could also be irony.

> her fear of dying. *Actually, I talk to all patients about dying, because I always find that often unspoken fear puts a lot of pressure.*

Martha is described as a patient who is aware and actively wants to be fully aware of her situation, her progressing disease. Even though the CT was bad news for Martha, she still feels »relieved«, according to the physician. The wish to diagnose the brain metastases signifies Martha coming to terms with her illness. The physician talking about dying—which is sometimes referred to as ›breaking bad news‹—does something good for the patients, since it relieves them from »a lot of pressure«.

What does the hospice manager say?

For the hospice manager Martha is an example to discuss whether or not a patient is a good fit for inpatient hospice care.

> With Martha, one might think that she has an illness and an environment *where you might wonder, why didn't she stay at home longer.* And due to her reaction, how she suddenly said: now it has to be very quick and she can't stand it at home. We were also in conversation, where at first it was like: in the next weeks we will probably get in touch, we will keep in touch, but at some point the time will come. She couldn't handle that well. So, you could tell what kind of fears probably arose at home. Insecurities, fears, linked with pain, fear, loneliness. So, there's a lot to it. She is certainly, so to speak, a well-established woman in her surroundings with good social contact and still the fear speaks for something. And that's how I see her. *At the beginning I thought, it's too early and the circumstances are the major issue,* but I believe, she truly is and she is lucky, that everything worked out so well, that she can really benefit from this. And I think, she also requires the time, the accompanied time, I would suspect.

For the hospice manager, it is about fundamental issues, namely whether Martha is actually a hospice guest. The hospice manager expected her to stay at home for longer. In the beginning she was suspicious whether Martha might have entered hospice care too early. But now, she has come to the conclusion that Martha entered hospice just at the right time and that she is able to benefit from it.

What do the nurses say?

The nurse who cares for Martha uses her as an example for how patients retain their autonomy inside the inpatient hospice unit.

> And it is actually intended that way, *that they retain some autonomy.* So, ideally they should not be... and that's not our claim, to tell them how things run. For example, with Martha, we also do this in a way, it's a small story, that *she has her own medicine, manages it herself.* We actually never let other people here manage their own medication; usually, the staff handles it.

Martha managing her own medication is her autonomy's last resort. For nurses, it is about what patients are physically and also cognitively still able to do and what they are unable to do.

Another nurse who was interviewed about Martha approaches a much more difficult topic:

> I believe, about a week ago, she had an MRI to check why she is having certain symptoms. And metastases were detected: three bigger ones. And I think she was already aware of it, but she was very scared. And above all, she's afraid of giving up control. And I think that's simply the case with her—and we often agree on this in the team—that we say: *Ok, if we now tell her that she could vomit blood so severely that we would need darker towels to absorb this blood, she would worry more and I believe it would actually hinder her existence.*

Contrary to the physician, the nurse here emphasizes the advantages of Martha being more or less unaware of her situation. Telling Martha that the dying process might involve vomiting blood and that hospice staff are already preparing for this situation is seen as a hindrance to »her existence«. According to this nurse, they have collectively decided to not approach this topic with Martha.

What does the hospice resident say?

Lastly, for the hospice resident Martha herself everything is first and foremost about her long medical history.

> So, *I've been through the whole package* as well. I couldn't undergo surgery. Although, I also don't know if it's a blessing or a curse [being unable to undergo surgery, A.B.]. I have no idea. But I've been through everything including chemotherapy, immunotherapy, antibodies, and radiation therapy. And I was supposed to undergo chemotherapy again. But I decided against it.

Martha has undergone a long treatment. She has been »through the whole package«. However, she sees herself having agency in her medical history, as it was ultimately her who decided against the final chemotherapy and thus ended the treatment. As she is now in the hospice, the issue for her now is acclimatizing and adjusting to the new environment, as the transition from her own home to the hospice is a turning point for her:

> That I could let myself go, if I could. That's what I'm learning right now. (laughs) So that's very, very difficult for me. Because *I have always been an independent person and the act of giving up your own, well, I always say freedom, giving up control,* realizing that I am becoming more and more dependent. And that's the special thing here. I am cared for. That means, if I want, they'll butter my bread roll and bring it to my bed. *They are really lovely here.*

She observes her own physical decline and loss of autonomy. While she could do everything herself before, now everything is done for her. For Martha, this is an ambivalent situation: on the one hand, it is difficult for her to »give up [...] freedom« and lose self-determination. On the other hand, it is also »really lovely« when she doesn't even have to worry about preparing a sandwich and everything is brought to her bed.

Similarly to the hospice manager, she wrestles a lot with the question of whether it was right to move to the hospice at all. Again and again, she explains why it was ultimately the right decision for her:

> And for me, this current feeling of not knowing anymore how sick I really am or whether I'm just letting myself go over these past few months, where I would say, the strength isn't there anymore. I can't judge it anymore. Of course, if there is more pain, I always think, whoa, the tumor is growing. And that's not necessarily the case. Because it could simply be that my medical tuning is not good. And that the tumor hasn't changed at all. But that is something, I am no longer in control of the situation.

The main reason she could no longer stay at home was the inexorable progression of her disease and the associated physical decline. The tumor is something unpredictable for her, that she cannot gain control over. She notices how she is gradually losing judgment over her own physical condition. Therefore, coping with the disease is a significant topic for her:

> I also have to see about letting go of my job. That was also because of... those are the things. *The illness simply rips you out of your life.* And the body... I always call it ›forcing me to my knees‹. […] And I have to *mentally catch up with that now.* To become aware of *where I am currently.* And that it's not so easy for me to accept. We talk a lot about that at the moment. The disease is where it is. So, I will talk about that with the therapist, who also comes once a week. That's really nice too.

What is quite obvious here is that the biographical disruption and the physical decay must be processed and accepted. »The illness simply rips you out of your life« is a strong statement that is typical for hospice residents. They have gone through very significant changes during the course of their illness and also when arriving at the inpatient hospice unit. Eventually, they will have to come to terms with these changes. Conversations with a therapist help Martha with this.

Getting used to the new environment also involves observing the other residents.

> We mostly get together at mealtimes here. And then we eat together. We try to joke a little. Everyone is somewhat different in their structure, in their illness. *I believe I'm quite the youngster here. And probably still the fittest.* But we do exchange as much as we can. Yes, yes. *And laugh a lot too.*

The other hospice residents primarily appear as carriers of diseases and are individualized through this. Meeting the other residents allows Martha to draw comparisons: unlike others, Martha sees herself as somewhat younger and as a relatively »fit« woman. Contrary to what her friend told us about hospice residents being »grumpy«, Martha talks about herself joking and laughing with them.

As has already been made clear from the other interviews, Martha is very preoccupied with the way she will die.

> At the moment, I also say that I have no fear of death. I'm more afraid of the ›how‹. I have lung carcinoma. That really worries me. So that I simply say, *I don't want to suffocate,* or something like that. I just want to fall asleep peacefully. I want to be able to say, people, now give me something so that I sleep. I don't know yet if I want to see friends from a certain point on. I have no idea! I'll have to decide that along the way.

The diagnosis of lung carcinoma and the fear of suffocation greatly troubles her in this context. All other circumstances of dying seem to be of no great importance against this background. The possibility of bleeding mentioned by the nurse, however, is never explicitly mentioned by Martha. Her wish, to »give me something so that I sleep«, which could be interpreted as requesting assisted suicide, is seemingly not acknowledged by the staff members, since hospice care and assisted suicide are in direct opposition to each other.

At the end of the interview, it becomes clear that Martha, who at 61 years old is indeed one of the relatively ›younger‹ residents, primarily does not want one thing: to die.

> The only thing I would still like to do or would have liked to have done is to learn Italian. And for that, *I simply need more time.* And generally, *I would like five more years of life!* And then I would like to explore Europe. And, and I always traveled a lot in Asia. I didn't get to know Europe... But I would also take much

> more time for myself. For me and my friends. This was always neglected in the past. […] But I simply… *I would like five more years.* But I think somehow you always need more time. *Always a few more years.*

Despite her overall rather positive evaluation of the situation in the hospice, it is becoming quite obvious that she actually does not want to die yet. She wants to have more time to learn languages, to travel, to have time for herself.

Case #2: Tom – »I'm a footballer, he's also a footballer«

The second patient to be discussed is Tom, who is in a hospital palliative care unit. His diagnosis is carcinoma in the throat area. The unique thing about this patient is his age: he is 23 years old. Not only, but also because of this peculiarity, no interview could be conducted with the patient himself and the relatives, his parents. Interview data on Tom is available from the following professional groups: chief physician, physician 1, physician 2, physiotherapist, nurse. In addition, Tom was mentioned in two observation protocols that could be produced during team meetings on the palliative care unit.

What does the chief physician say?

In Tom's case, the medical competency of ›breaking bad news‹ is especially required. For the chief physician interviewed, it is the main professional competence that sets him apart from other professional groups, to clarify the unvarnished truth about the patient's future prospects to the relatives.

> The son [Tom, A.B.], he can hardly speak, he just writes on his phone. Or not ›hardly‹. He can't speak at all. And I then said: ›I dare to be honest here about how it is. And that we're trying, but we can't cure this. And that we can't make you healthy and you will die.‹ And the parents also feel that. But I understand that they can't talk about it, and so on. *Then it's out there.* And the upshot is; of course some are *maybe even shocked:* ›How can he say it so clearly?‹, or: ›How can he say that?‹ But I would say, 98 out of 100 are extremely grateful to you, *that it's out there and that it might also be an occasion to talk about it.*
> That's how it got started, because I, or rather, we, as this team, would say: ›They are so awfully religious and they find this so awfully hard.‹ Then I say: ›Well, hello? Who wouldn't find it hard, that your 23-year-old son is lying there and dying?‹ But to try, *to slowly approach this in a conversation: Where are these parents?* Then you see, the father is completely lost. He can't even have a sensible

> conversation with you because he is always crying. The mother is a bit more composed, but of course also totally lost.

The patient Tom is an example for the chief physician to demonstrate the necessity of an open conversation about the patient's situation. Even though other team members might find excuses for not talking openly about Tom's prospects to his parents—because they are »awfully religious«—the chief physician emphasizes the need to disregard these fears. It is recommended not to use brute force but instead to »slowly approach« the parents. By talking openly, the chief physician tries to help the parents. Even though they might not like to hear what he has to tell them, his assumption is that they are nevertheless »extremely grateful« for him telling the truth.

Initiating these kinds of conversations is still seen as a domain of the physician, since this is the only long-standing member of a classic profession in modern society, which attributes a particular competence to them. The physicians' words still carry more meaning and hold more weight in conversations with patients and relatives than those of other professions. While religion is usually seen as helpful regarding dying and bereavement, in this case, it is perceived by the chief physician as a misleading and false source of hope, as well as a hindrance to acceptance.

What do the other physicians say?

One doctor reported several failed attempts to start a conversation with the young patient's mother. She feels that the mother actively wants to avoid the conversation. This is a problem for the doctor:

> We should not blame ourselves. We do not leave them *with a false picture*, so to speak. Yes, we also need to tell them how it looks, that things are getting worse, so that they can cope with it.

In the same vein as the chief physician, it is about telling the parents the truth, to not »leave them with a false picture«. Another physician corroborates on this point even further:

> It's a burden. It was especially a big burden at the beginning, because it's truly a huge effort in terms of medical, nursing, wound care. It's a complex family surrounding him, they have a very own approach, which is very much carried by faith, *they believe that they can heal the young man through prayers*, and they keep expressing this and also expect that this will succeed sometime, and every little improvement is seen as a step towards healing. *Every success, even the fact of*

> *placing a venous cannula, is immediately seen as a sign from God that he will become healthy,* and you really have to continually involve yourself and naturally, this could be the son of many employees here.

Again, the religiousness of the family is mentioned as the main obstacle for acceptance. Everything the palliative care staff does is interpreted in a hopeful way by the parents. They still strongly believe that the patient will not die and will become healthy again. Telling the truth and accepting death is clearly a major theme for all three physicians interviewed.

What does the nurse say?

Interestingly, the nurse has something entirely different to say about Tom:

> Yes, everything comes together there. Youth comes together, exulcerating comes together, and ENT[17]. So, it's quite intense right now, having thirty[18]. That's why it's also important for me to always know how the patients are, *because I say that the person who takes care of the patient at thirty, absolutely cannot do four.* So, you always have to look and differentiate. These are patient groups where care sometimes becomes difficult. But they also come, for whatever reason, in phases, the ENT tumors for example. And when they exulcerate, *the acute risk is higher, I'd say, that they'll bleed.* It's also there when you just do it, but it's always in the back of your mind, it could bleed.

The nurse's focus is immediately on the strain and workload of the nursing staff and the division of labor within the nursing team. It's all about the diagnoses and the risks coming with it. The issue with Tom's tumor is that it is exulcerating and could easily bleed. The difference to the physician's perspective is pretty striking here: the parents, religion or acceptance play no role at all for the nurse, while this was the main issue the doctors talked about. However, the doctors only talked very little about the disease and the risks which it entails.

What does the physiotherapist say?

Lastly, the physiotherapist was interviewed.

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[17] Abbreviation for ear, nose and throat

[18] The patients room number.

> Well, yeah, right now, in room 37, there is a young man, he is 23 years old. *And I'm a footballer, he is also a footballer, a goalkeeper.* Well, we talked about stuff and that is a pleasant encounter, he is happy, he always wants me to come. And yes, and he has lost interest in many things and doesn't want to carry on and you say, are you coming back tomorrow. That's a question then. *And yes, his family is there, we talk, he enjoys the conversation.* And it does him good, then, I also enjoy it, it's, yes, something like that, exactly.

For the physiotherapist, Tom is first and foremost not a patient but a footballer. Interestingly, the physiotherapist does not talk about performing any physiotherapeutic tasks with Tom. Instead, he talks about the conversations he has had with him while Tom was still able to speak. Tom and the physiotherapist share a common interest in football. He depicts Tom as »happy«. The family is also mentioned, but they don't seem to bother the therapist in any way.

Discussion – Multi-Professional ›Death Brokering‹

Before entering the sociological discussion of the results, a brief summary of the two cases and the different perspectives should be given. The two cases of Martha and Tom are vastly different from each other, yet there are similarities, and they are suitable to demonstrate the main argument of this book chapter, as it was already outlined in the introduction.

Summary of the two cases

It became very apparent, that *physicians*—in both cases—typically focus on telling patients the truth, in order for them to be able to accept the situation. Physicians are the ones who are experts in breaking bad news. They are the only ones, who are forced to talk about death and dying with patients and relatives. They try to walk the fine line between confronting them with the hard truth while also avoiding brute force by being compassionate and empathetic. On the other hand, *nurses* tend to talk about the body, about bodily fluids and about the workload a certain patient puts on their team—but, of course, not necessarily with the patients. With them, they seem to talk about matters of everyday life and not so much about dying. The example of Martha shows that *hospice residents* typically talk about their medical history and the biographical disruption they have gone through and with which they have to come to terms now. *Friends* *and relatives*, in this case Martha's friend Heidrun, talk about themselves getting used to hospice care and about feeling relieved that they or the patients themselves are in a safe environment and not in charge anymore. The *hospice manager* talks about whether or not someone is a proper fit for hospice care. Interestingly, the *physiotherapist* is able to talk freely about more or less everything he wants to, giving the patient the opportunity to take on a different role—the one of a football player.

These results are not surprising at all. The fact that physicians talk differently about patients than nurses or physiotherapists is hardly news for anyone working in hospice or palliative care or any kind of multi-professional environment. Everyone talks to patients, but in a different way and with different goals in mind. The so-called ›whole person‹ of the patient is reconstructed through different lenses and different perspectives. However, the result from that is not a single, unified view of the patient, but in fact a fractured picture. The patient is decomposed into many parts and there seems to be no way of putting these parts together again. The two cases presented above are given multiple different meanings, which do not necessary overlap or complement each other.

For example: Physicians clearly stress the importance of Martha knowing everything about her disease and that it might be beneficial for her to know about her brain metastases. However, Martha herself seems to be very worried about this and it seems questionable whether she is really relieved. In a similar vein, physicians see Martha as a hospice resident who has accepted dying, while Martha herself gives mixed signals: on the one hand, she talks about having accepted her fate, on the other hand, she talks about not wanting to die and needing more time. For the hospice manager, the dying process itself seems to be nothing to worry about. The physicians in Tom's case are very much preoccupied with the acceptance of his parents, since they need to be put in a position where they can anticipate their son's death. This is important for the physicians, as the parents are the ones who will survive Tom's death and are likely to accuse the physicians of not having done enough. The physiotherapist, however, does not seem to care about this at all. All of this is only possible through differentiation, specialization, and the division of labor in modern hospice and palliative care.

Distributed ›death brokering‹

Within sociology, a quite critical discourse around these practices of multi-professional palliative and hospice care has been established, usually employing Michel Foucault's concepts of »biopolitics« or »governmentality«.[19] More than twenty years ago, David Clark already diagnosed a »creeping medicalization« in palliative care.[20] Medical sociologist Stefan Timmermans stated that in so-called »late modern societies« it »is virtually impossible to die or be dead without encountering some medical involvement.«[21] He argues that medical practitioners and health care workers perform what he calls »death brokering«. The term refers to all kinds of practices and activities that »render individual deaths culturally appropriate.«[22] This means that medicine steers the dying process in such a way that it takes on an acceptable form (such as good death, natural death, dignified death), to deflect attention away from the question of medical involvement in death and dying. According to Timmermans, »death brokering« thus undermines the activities of the hospice movement, which »aimed to de-medicalize the dying process, change the practices of health care professionals, institute alternative forms of dying, and, most importantly, give more autonomy to the dying and their relatives.«[23]

The analysis of the different actor constellations allows for a more nuanced perspective on this assumed medicalization of death and dying. While Timmermans is certainly right about the fact that medicine has a »sustained stronghold over death and dying«[24] with physicians and nurses playing a major role in multi-professional hospice and palliative care, it seems obvious that other professional perspectives still remain relevant, such as the hospice manager or even the physiotherapist, in Tom's case. For example, a recent study was able to demonstrate the significant contributions pastoral care workers make to multi-professional hospice care.[25] One of their core competences which cannot be fulfilled by medical

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[19] Clark, David: ›Total pain‹, disciplinary power and the body in the work of Cicely Saunders, 1958-1967, in: Social Science & Medicine 49 (1999), No. 6.

[20] Clark, David: Between hope and acceptance: the medicalisation of dying, in: Bmj 324 (2002), No. 7342.

[21] Timmermans: Death brokering, p. 1005.

[22] ibid., p. 993.

[23] ibid., p. 995.

[24] ibid., p. 1006.

[25] Nassehi, Armin et al.: »Do you Really Believe that There is Something More?«–The Offer of Transcendental Communication by Pastoral Care Workers in German Hospices

staff lies in giving transcendent meaning to death as well as performing rituals.[26] In addition to that, social workers also contribute to palliative care, while not necessarily following a medical script.[27] Moreover, hospice volunteers have no medical education at all and are just there to add spontaneity to the organization,[28] to be the other, more accessible »face« of nursing.[29]

Timmermans is right in his assumption that dying is certainly medicalized, but this is amongst many other things, which not necessarily have anything to do with medicine. Medical practice was not entirely replaced by »total care« of the dying process, as it was mentioned in the beginning, but it has undergone a shift towards a more polycontextural[30] phenomenon. »Death brokering« thus cannot be described just as a medical task but as a distributed and differentiated practice that is carried out through a multi-professional organization and division of labor.

Conclusion – Liminality and the Transfiguration of Agony

To conclude: This chapter presented two cases out of a research project, which was focused on the actor constellations in inpatient hospice and palliative care units: Martha and Tom. Even though these cases appeared very different, they tell a similar story when it comes to multi-professional division of labor. Doctors' »death brokering« activities are focused around managing expectations of patients and relatives. They wanted them to know everything in order to be prepared for things to come. On the other hand, nurses' »death brokering« activities centered around the more

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and Palliative Care Units: A Qualitative Study, in: American Journal of Hospice and Palliative Medicine 41 (2024), No. 7.

[26] Mayr, Katharina et al.: Organized rituals – ritualized reflection on mourning culture in palliative care units and hospices, in: Mortality 29 (2022), No. 1.

[27] Bitschnau, Karl W./Firth, Pam/Wasner, Maria: Social work in hospice and palliative care in Europe: Findings from an EAPC survey, in: Palliative and Supportive Care 18 (2020), No. 6.

[28] Nassehi, Armin et al.: Adding spontaneity to organizations – what hospice volunteers contribute to everyday life in German inpatient hospice and palliative care units: a qualitative study, in: BMC Palliative Care 23 (2024), No. 81.

[29] Vanderstichelen, Steven et al.: The liminal space palliative care volunteers occupy and their roles within it: a qualitative study, in: BMJ supportive & palliative care 10 (2020), No. 3, pp. 3f.

[30] Günther, Gotthard: Life as poly-contexturality, in: Günther, Gotthard (ed): Beiträge zur Grundlegung einer operationsfähigen Dialektik, Hamburg 1979.

physical aspects of dying: bodily autonomy and physical reactions to different kinds of dying (vomiting, blood, etc.) as well as the strain and workload this puts on their team. Martha's friend Heidrun is also part of »death brokering«, since she seems to be prepared for her demise and also talks with her about it. The physiotherapist's contribution to »death brokering« seems to be simply talking to Tom about football, which the patient seemed to appreciate.

What we observe are the ambivalent results of differentiation and specialization. That the physiotherapist in Tom's case is able to talk to the patient about football and doesn't have to worry about the parents, who refuse to accept the dire situation of their son, is the result of the division of labor. Only because the physicians are focused on the medical side, the physiotherapist is able to freely talk to the patient. In Martha's case, the nurses don't talk to her about her dying process, which will very likely lead to her vomiting blood, which is only possible, because the physicians will take care of that. On the other hand, this division of labor makes it impossible to achieve a unified holistic picture of the patient.

Literature about dying processes often describe dying as a transformation from one ontological status to another, the dying process thus becoming a liminal space between life and death. For example, the aforementioned Elisabeth Kübler-Ross suggests that there is a transition taking place, starting from the denial of death, proceeding through various stages, and ultimately achieving the acceptance stage. This transition doesn't occur spontaneously, but it requires the patient's work.[31] Only if the patient has done their ›homework‹, they will reach the final stage of acceptance and be finally delivered from suffering and agony. Similarly, the sociologist Debra Parker-Oliver employs the metaphor of a »hospice drama«. This drama narrates the transformation from the patient role to the dying role, wherein, in the very end, when »the final deathbed scene begins«[32], all conflicts are resolved, and everything comes to a close. The »drama is over«[33] and a peaceful state is achieved. According to Parker-Oliver, the acceptance of the dying role imparts »authenticity to the moment.«[34] It appears that, to be ›culturally acceptable‹, the narratives

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[31] Kübler-Ross, On Death, p. 99.

[32] Parker Oliver, Debra: The Social Construction of the ›Dying Role‹ and the Hospice Drama, in: OMEGA – Journal of Death and Dying 40 (2000), No. 4, p. 509.

[33] ibid., p. 510.

[34] ibid., p. 511.

being told about the dying process invariably must include a transfiguration moment of the patient's agony—a *periptery*, to extend the drama metaphor—to arrive at the final deliverance and to resolve the precarious liminal situation.

Through the multiple lenses of the multiple perspectives on patients and relatives detailed in this book chapter, it seems like that this transfiguration does not only pertain to the dying process, but also applies to the person of the patient. The person is undergoing multiple transfigurations through multiple perspectives, each one of them transforming the patient's agony in a slightly shifted, unique and different way. However, the differences created by these transformations can never consolidate into a singular, harmonious and homogenous perspective, because they are the result of the very structure of the multi-professional organization. Dying here is not a »hospice drama« where everything comes to a close, reintegrates and becomes whole again, but rather a complex, messy and distributed occurrence where very different perspectives emerge. Organizations ultimately only offer difference rather than deliverance.

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