FIGHTING HYDRA

The Uncertainties of Waiting for a Liver Transplant

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Abstract

This article sheds light on the experiences of people waiting for a liver transplant. I argue that waiting lists serve as a technological tool to deal with the uncertainties inherent in medicine, but like Hercules fighting Hydra, one tamed uncertainty is merely replaced by two new ones. Drawing on ethnographic material from Germany, I argue that these lists retain those waiting in a temporal limbo of uncertain duration and outcome, making them spatially, temporally and existentially immobile.

Keywords: *uncertainty, im/mobility, waiting, organ transplantation, liver disease, Germany*

Introduction

Whilst researching liver transplantation for my doctoral thesis, one question began to overshadow all the others: How do people, who are somewhere between life and death, wait? Initially looking for transnational movements in the field of organ transfer, the seemingly mundane issue of waiting increasingly came to bother me. What happens during waiting? More precisely, what happens whilst we wait for a life-saving medical procedure that may help us to defy death for a couple more years, or that, when no organ can be procured, may not occur at all?

The issue of human organ procurement and transplantation is not a new one, in fact it has been of interest to anthropologists since the 1990s. It continues to be a highly debated issue that touches upon topics such as personhood, self and other, body and technology, conceptions of life and death, gift and commodification (cf. Lock 2002, Crowley-Matoka & Lock 2006, Ikels 2013, Sharp 2014). Anthropological perspectives are particularly useful for shedding light on the way technologies affect social and individual experiences and imaginations, for example how transplant recipients and their families make sense of a new organ inside the recipients' bodies (Sharp 2006); how discourses about organ transplantation are infused with ethical considerations and related to broader socio-economic factors like the privatization of health care (Hamdy 2012); or how the uses of human tissue and organs are related to the politics of nationalism (Hogle 1999). As people, ideas and knowledge become ever more mobile and national borders more easily transgressed (Strasser 2009), an unprecedented border-crossing demand for potential organ donors and transplant professionals has emerged. Increasing «bioavailability» (Cohen 2005) has resulted in giving rise to legal transnational exchange and illegal organ trafficking on a global scale, actualities that Nancy Scheper-Hughes (2003) has been at the forefront of revealing. While the biotechnologies may circulate on a global level, they have to be made sense of on a local and individual scale (Sanal 2011). In this diverse work,

on transplant technology and its effects and imaginations, little attention has been paid to the time before a patient receives a transplant; the unnerving, uncertain time of waiting for a new organ. The phenomenon of waiting has not been of major interest for anthropologists in general, as the limited scientific literature implies (cf., for an overview and exemplary ethnographic account, Auyero 2011) – even though it is such a pervasive phenomenon in social life that Ghassan Hage (2009a: 1) describes it as «almost synonymous to social being. »

This article focuses on waiting within a medical setting, the field of liver transplantation[1], a non-reversible life-changing procedure. Drawing on 12 months of ethnographic fieldwork in Germany, I aim to illuminate how those with a life-threatening disease deal with the temporal and existential uncertainties they face. I approach waiting with three questions in mind. The first question I engage with is how people wait for a transplant. Following Zygmunt Bauman (1992) and Lesley Sharp (2014), I argue that transplantation medicine serves as an example of the techno-medical pursuit to extend life, a technological longing to overcome mortality and defy death. Renée Fox's (2000) analysis shows that with every medical progress new questions and problems arise, many of which cannot be anticipated. I argue that waiting lists serve as central technological tools to tame the numerous uncertainties inherent in transplant medicine and make waiting as objective as possible. But like Hercules fighting Hydra by cutting of her head(s), one solved, or rather tamed, uncertainty is merely replaced by two new ones. Serving as a necessary step on the way to an awaited transplant, these lists create hope for a future but simultaneously retain people in a temporal limbo of uncertain duration and outcome. Drawing on Ghassan Hage's (2009b) notion of «existential im/mobility», I claim that these waiting lists make the people spatially, temporally, and existentially immobile. Secondly I ask, where people wait for a transplant. By doing so, I not only explore the spatial side of waiting but also different qualities of waiting related to the respective sites. Whereas waiting in the medical waiting room is more focused, situated and public, the waiting taking place in patients' homes is more diffuse and intimate. Finally, I engage in the issue of temporality by asking when people wait for a liver. By addressing temporal horizons and cyclical movements in patients' lives, I examine different aspects of temporality regarding transplantation and additionally give a glimpse into the «beginnings and ends» of transplant trajectories.

A Note on Methods

The ethnographic material I present results from fieldwork conducted between October 2014 and September 2015 in Germany, where I got access to two university clinics with transplant centers. Most other anthropologists conducting hospital ethnographies position themselves by either joining the hospital's staff (by putting on a white coat), the patients or the visitors (van der Geest & Finkler 2004). I, however, did not take a clear side in the arena of the transplant center where I conducted most of my fieldwork. I dwelled in the waiting room with patients and relatives, spent time at hospital beds, as well as in the nurses' office, where I had access to medical records and was able to witness the interaction and communication between nurses, patients and doctors. I did not attend medical appointments in physicians' offices, but had the opportunity to talk to doctors about patients, their medical conditions and the chances of a transplant, as well as to ask medical questions to understand the physical processes that patients had to deal with, essential knowledge to grasp the experiences of those affected. As patients before and after transplantation undergo medical tests repeatedly and thus visit the clinic repetitively, I met some of them several times, witnessing how physical and mental conditions fluctuated over time. Additionally to the clinic I visited people at home, spending time apart from the medical setting. Nevertheless, most encounters were limited to the hospital, where the conference room was at my disposal for conducting interviews in privacy. Many patients and medical staff alike welcomed this, as psychological support was underfunded and scarce in both clinics, and the role I performed took on therapeutic aspects. I was filling in a vitally needed role in a context of diverging temporalities: limited and compressed time of physicians and surgeons meeting the de- and accelerated time experiences of patients, depending on the waiting time, urgency, and severity of their medical conditions. In this setting of different and conversing temporalities and experiences I was offering my time and attentiveness whilst they shared their stories.

Of Un/certainties and Im/mobilities

Mortality is a certainty we face in our lives. Despite or because of this certainty most of us are not at ease with it, or as Zygmunt Bauman put it, «it is really curious why our own death fills us with horror» (1992: 3). The certainty of death brings

[1] The liver possesses special qualities compared to other organs: first and foremost no long-term technology available today can substitute its complex vital functions. Furthermore has the second biggest human organ the capacity to regenerate itself, to regrow liver tissue. After the first liver transplantation in Germany was performed in 1972 (five years after the U.S.), it became the second most performed organ transplantation in the country.

along the uncertainty of the when and how, which leads Richard Jenkins et al. to argue that uncertainty is a «generic feature [...] of the human condition» (Jenkins et al. 2005: 12). Facing this existential uncertainty, people try to influence it, a struggle for control that becomes especially obvious in a medical setting. According to Bauman (1992) the overcoming of mortality is humankind's central driving force, a motivation that I argue becomes explicit in biomedical practice, research and 'transplant imaginaries' (Sharp 2014). People turn to medical treatments to influence the un/certainty of death even though «uncertainty is inherent in medicine» (Fox 2000: 409). Renée Fox discusses different aspects of medical uncertainty, showing that most of the time the gains of medical knowledge bring along new questions and uncertainties.

For most people suffering from life-threatening liver diseases, getting a transplant is their hope for a future. But as there are more people in need of a liver than organs available, people first have to become eligible for a transplant. They have to undergo numerous tests to make sure they are sick enough, but not too sick, and not every patient in need of a liver gets on the waiting list. These lists that are so decisive about patients' fate are in constant flux, people with high urgency who might be on the list just a few hours, get treated prior to other – less urgent – patients who may be on it for years. Others can be kicked of the list if they fail the requirement to stay abstinent or because their cancer has progressed in a way that is outside accepted criteria. Based on an algorithm, they are technologies of waiting, tools that organize queuing to make the process as «impersonal and independent of any human factors such as liking or disliking someone» (Hage 2009a: 3), as possible. At the end of 2015, 1'280 people were waiting for a new liver in Germany, most of them for 24 months or longer (Branger & Undine 2016). Ranked according to the MELD score (Model of End Stage Liver Disease), these lists are based on laboratory values intended to reflect a patient's chance of survival without a transplant. The problem with laboratory values is that they do not cover all relevant aspects of liver disease. A surgeon told me that he did not think of the score as being objective, «because the results are not objective; it depends on the laboratory, on the muscle mass of a person, and many patients with good chances will not get an organ» (Peter 07.12.2015). Most doctors I talked to were quite critical of the currently used MELD score, as it often fails to give account to patients' individual cases, but were lacking suggestions for an alternative. Being aware of the necessity of a tool as objective as possible, they had to face the shortcomings of its applicability on a daily basis. What became intriguing for me was the fact that – although important – hard numbers, in the form of the actual waiting time or the MELD score, were not as significant in people's experiences as expected. Although an important source of information, these lists and scores were not representative of patients' medical condition and its severity, and people's waiting had often started long before their actual listing, accompanied by uncertain diagnoses and suffering.

Getting listed for a transplant entails that patients need to stay close to their transplant center, being able to get there in about four hours. This temporal radius is caused by the organ's own «time», its ischemia: after removal the liver's blood circulation gets interrupted and to maintain its vital function it is crucial to keep this bloodless time to a minimum. The allocation of organs therefore depends not only on blood type and medical values (resulting in the MELD score), but on geographical and temporal distance as well. Not only do these conditions limit people in their movement, it sometimes contradicts peoples' ambition to enjoy their remaining time as much as possible. Tim Cresswell (2010), discussing mobility, argues that we should also draw our attention to situations where movement is obstructed and causes frictions, like immobilities. Things stop. People stop. Be it by choice or not. Whilst waiting they exist in a spatial and/or temporal limbo, a liminal space (Turner 1995 [1969]), or as John Rundell poignantly put it, «on a boundary between a present (or even a past) world that they cannot leave and a future one that they cannot automatically or immediately enter» (2009: 45).

Becoming immobile in a world that is defined by an ever increasing mobility entails a drastic experience, a kind of crisis for the people affected by it. Travelling abroad, going hiking in the mountains or sailing at sea become impossible undertakings, and the mobile phone (itself a symbol of mobility) becomes both one's hopeful (and torturous) constant companion and frequent reminder of one's immobility. Arthur, one of my interview partners waiting for a liver, felt like a «yard dog lying in his shack, a chain around the neck» (Arthur 21.09.2015). Being trapped on this boundary between a present he could not leave and a future he could not yet enter (Rundell 2009), the 70-year-old started weighing his options, asking himself whether staking everything on one chance (transplantation) was the only way to go. Longing for some self-determination he pondered whether to quit waiting by getting himself off the list, but was too afraid that he would miss the opportunity for a transplant, and miss out on his preferred version of possible futures. The unpredictability of the future is tantalizing for most people involved, which becomes evident in another one of Arthur's statements:

> *What bothers me the most during waiting, what wears me out, is the uncertainty. I can cope with anything else, I «know» what lies ahead of me. They will cut me open, out with the old liver, in with the new one [...]. Of course I am afraid. But what wears me out is the uncertainty.* (Arthur 21.09.2015)

The uncertainty he mainly referred to was whether he would get «the call» and thus a liver in time, but also included worries whether he was still eligible for a transplant due to his age and progressing cancer, and what life might be like *after* transplantation. He tried to cope with the uncertainties he faced by gaining information about the surgical performance, only leading to more uncertainties about whether he would survive the six to eight hours long procedure. This also serves as an example for the complex relationship between information and un/certainty, an issue I shall return to further below.

To grasp the complexities, tensions and ambiguities of waiting for a new liver, a liminal space where one's death seems as close as the chance to prolong one's life, I draw on Hage's (2009b) notion of existential mobility. Discussing existential mobility and the fear of its opposite in the context of transnational migration and racism, I argue that his ideas of waiting or sticking out a crisis as well as the importance of endurance during that time, offer an exciting approach to discuss the uncertainties of waiting. Because despite the fact that we are driven by an innermost urge to keep «going somewhere», people get stuck in life, temporally, spatially and existentially. Hage focuses on existential *im*mobility as the source of much of contemporary discontent, because getting stuck significantly stresses those who have to slow down and dwell in this limbo. As such, a tension emerges between the innermost urge to keep going, to be existentially mobile and patiently waiting for one's turn. This tension becomes especially critical when others seem to not wait their turn, or to jump the queue. In the transplant sphere this tension is embedded in discourses about scarcity, chances of success and urgency, and layered by moral judgment about who «deserves» another chance. Should those suffering from a genetic disease have the same chance for an organ as those whose medical condition was mainly caused by alcohol abuse? How to decide whether patients are too sick to receive a transplant, depriving them of a chance for treatment? As mentioned above, medicine's quest to prolong life brings along new uncertainties. As a consequence, tools and means to tame these uncertainties become central in medical practice. One of those tools in the context of transplant medicine is regulating access to treatment through waiting lists. These lists create hope for a future, but simultaneously retain patients in a temporal limbo that makes them spatially, temporally and existentially immobile. And as people wait for a vital, but scare good, the uncertainties of waiting become a matter of life and death.

Immobilized Bodies

Following the discussion of *how* people come to wait for a transplant in the first place – by problematizing the techno-medical pursuit to extend life, the creation of new possibilities and uncertainties, as well as the consequential tools to tame those uncertainties – I turn to the spatial side of the waiting process. By exploring *where* people wait, I not only examine the two different sites of waiting in the hospital and at home, but also distinct qualities of waiting related to the respective sites.

During my fieldwork, I spent a lot of time in the transplant center's waiting area, where people waited for appointments, for the nurses to take their blood samples, or to get the results of their medical tests. Most of the time it was so quiet in the waiting area you could hear a pin drop. People sat and waited silently except for some whispering from time to time. The only thing disrupting the quietness were the nurses' or doctors' voices calling a patient's name, and the automatic doors opening and closing when medical staff (rarely patients) passed through. Most people were looking at the TV which was high up on one wall and whose channel never switched. All the rows of seats pointed at it, almost none were facing each other. As one nurse told me, this positioning was the result of numerous patients' requests; it was not long ago that most seats used to face each other.

David H. Maister, who discusses «techniques for facilitating waiting» (Ehn & Löfgren 2010: 23), argues that during waiting a temporary community is created, for example, at train stations when a delay is announced. The exception is when people feel those waiting with them are competitors rather than fellows in waiting: like waiting for a liver transplant. As a psychologist told me, community building for people waiting for a liver seems to be more complicated than for other transplant patients. The crucial issue seems to be that liver diseases are often associated with self-affliction and «immoral life choices», like alcohol or drug abuse, as well as sexual promiscuity. The question of responsibility, and the discursive power of it, becomes critical here in relation to the question of guilt, how liver diseases are framed and perceived in the general public but also among affected patients. Anna, for example, who suffered from a genetic disease thought it was unfair that people with a history of alcohol abuse have the same right for a transplant as those suffering from a hereditary disease. Katrin, whose liver cirrhosis was mainly caused by alcohol abuse, revealed the main cause of her illness only to a very limited circle of people, not even telling close friends. Arthur, suffering from cancer due to a hepatitis B infection, did not want to participate in meetings of patient support groups. He did not want to sit next to people who had already received the one thing he was tensely waiting for. Embedded in a moral discourse, being fellows in waiting but also competitors for a scarce good might create a setting in which waiting *together* becomes almost impossible, and an exchange about the experience only possible after receiving a transplant, after enduring this time. This also became apparent at meetings of patient support groups, where the majority

of people participating were people who already had received a liver and only a few participants were still on the waiting list for a transplant. Was the quietness in the waiting room a sign of this lack of exchange and community building? Although one might argue that way, I think quietness in medical waiting rooms is not the exception but common due to the discomfort this space causes to most of us. In her critical analysis of medical waiting rooms Laura Tanner (2002) argues that the waiting room provides a space where seemingly separated categories concerning the body become blurred and contested. It is a liminal space, a temporary stop, a place we have to pass through to get somewhere else, one we rather avoid. The privacy of illness or impending death becomes public in this liminal space, and it seems to be this inversion which makes lingering in it so uncomfortable. It threatens mobility and ideals of healthy, productive individuals; it «serves as a place in which we are immobilized *in* and *as* our bodies» (Tanner 2002: 116).

The diagnosis of a life-threatening disease marks a breaking point in a person's life, and even if everything goes on as usual those lives are irreversibly changed. Being confronted with the possibility of one's death, the means of a life-saving procedure, but the uncertainty of the actual feasibility of this procedure, is a living situation I call extraordinary. But as this situation prevails, for months and sometimes for years, it becomes a new ordinary. Being put somewhere between life and death for an indefinite period of time creates an extraordinary everydayness, a new extra/ordinariness. Hage discusses the idea of «waiting out a crisis» (2009b) by addressing the importance of endurance in critical situations, and points to the way that it has taken on a central role in contemporary life. Moral judgments are made about the way people wait/endure, and I argue that the extra/ordinariness of waiting for a liver transplant is also discursively framed as a time which has to be endured. Good patients have to wait patiently for their turn while not complaining, otherwise they get perceived as ungrateful and not deserving. In hospital settings a tangible normative discourse exists about patients who behave well and those who are «difficult», depending on the situational amount of un/gratefulness and im/patience they demonstrate. But waiting patiently for one's turn is not the easiest thing to do when your future and life seem highly uncertain. Due to the everyday unpredictability of hospitals with emergency cases and unforeseeable delays, I encountered many patients who did not know whether their appointments or medical tests were going to take place as planned. This was especially the case during the extensive period of testing before patients were put on the waiting list, which requires repeated hospital stays for several days. These stays are often accompanied by delayed appointments, uncertain timeframes and confusion over when one can go home. Today? Maybe tomorrow? Furthermore, the uncertainties of waiting transcend the clinical setting, they follow people from hospital corridors and waiting rooms into their homes and everyday lives. Waiting becomes a person's chronic state of being, part of a daily routine, a new normal although somehow extraordinary, taking place besides the repetitive tasks of everyday life. I want to examine the way this extra/ordinariness of waiting unfolds in people's everyday lives, by discussing an encounter with Arthur, a 70-year-old cancer patient.

When Arthur invited me to his home, I was curious to get to know him in «his» environment, the private sphere of his waiting. Although we covered a whole range of topics exceeding his illness during our repeated meetings at the clinic, we always kept the use of the formal form of address, the German «Sie». We sat down in the living room and after he had made sure that his phone was right next to him, we started talking. The 70-year-old told me that he could not travel at the moment, which bothered him, as he has lived a highly mobile life and was not done exploring the world. But as two more little tumors had grown in his liver, he had to stay put, had to get treatment for the tumors, requiring repeated visits at the hospital. What occupied his thoughts more than the bad news about his cancer was the fact that, after a forced break of a couple of months due to suspected alcohol consumption, he was back on the list for a transplant. Since being back on the list he has kept his phone always within reach, waiting for a call, hearing it ring although it was not. The phone's ringing followed him into his dreams, he even had a nightmare about getting «the call» on top of a mountain, unable to make it back to the clinic in time. Dreams about the ringing phone replaced his more violent nightmares, in which he repeatedly had been lying on a cold operating table, cut open. In these dreams the surgery was never completed, and sometimes the operating team removed various items from his abdomen – once even a children's bicycle. Over a couple of months his nightmares became so frightening that his bed became a threatening place, not one of safety and relaxation. Arthur's concern that he might no longer be eligible for a transplant due to his age and progressing cancer was replaced by a new one: whether the phone was going to ring or not. The *mobile* phone, which he had to carry everywhere he went, ironically made him *im*mobile, as he had to stay in a certain temporal and geographical radius to his transplant clinic. Not being able to move freely, made him feel like a chained yard dog. I ascribe his exceptional unease with the situation to the fact that he was a person who especially cherished his former mobility. Shortly before leaving, I went to the bathroom and instantly got a «holiday feeling»: besides the many plants decorating the room, it was the wooden bathroom cabinet that caught my eye, painted blue with yellow seahorses. Next to the toilet I found the bestselling book «1000 places to see before you die» and on the wall a huge panorama of Salzburg's Alps. When I returned

to the living room and asked him if there were still some things that he wanted to do in his life, without hesitation, quick like a shot, he answered: «More travelling». I was not surprised at all.

Temporal Horizons and Cyclical Movements

As people wait and become spatially immobile, whether in hospital waiting rooms or at home, the issue of time plays a crucial role. People on the waiting list do not know the duration of their wait. By discussing the role of temporal horizons, I show how differently people deal with the uncertainties they face. Furthermore, I examine the issue of cyclicality in transplant endeavors, ranging from cyclical movements inside bodies, to patients' repeated visits to clinics before and after transplantation. I scrutinize the idea of transplantation as a unilinear endeavor, a medical treatment with a beginning and an end. Rather, it is accompanied by life-long medication, repeated medical tests and repetitive hospital visits, emphasizing the role of temporality and cyclicality in medical practice and illness trajectories.

Temporal Horizons

Liver cancer patients' temporal horizon, their life expectancy, is always hard to tell. They can seem relatively healthy, usually do not suffer from any pain and do not «feel» their cancer. But liver cancer is like a ticking bomb and patients often die suddenly and unexpectedly. Discussing temporality in the context of kidney disease, Ciara Kierans states that it is «[t]he unpredictability of illness, the uncertainties attached to the future, and the unexpected implications of medical interventions [which] contribute to discontinuities in experience and the very construction of time itself» (2005: 349-350). The unpredictability of his illness and the temporal uncertainties turned out to be a great worry for Arthur as well: «If he [the hepatologist] could only tell me how long I am going to lengthen my life with a transplantation. [...] Because if it was only for a short period of time, I would reconsider it, due to my age» (Arthur 04.08.2016). Leaving aside the fact that no one could have given him an answer to those questions, a certain time frame or expected outcome, his need for more information, for numbers, for hard facts appear pressing. A need that – on a first glance – seems reasonable and relatable. But things are not that straightforward, especially in the context of life-threatening diseases and uncertain futures. I aim to complicate the relation between information and un/certainty, by discussing how that same conversation continued. So after voicing his wish to know how long he would be prolonging his life with a transplant, I got curious whether Arthur had a number in mind, of how much time he probably had left *without* one:

Julia Rehsmann: So you don't know how much time you have got, with your HCC [hepatocellular carcinoma]?
Arthur: No.
JR: Have you ever asked?
A: No.
JR: Do you even want to know about it?
A: No. … I check on the Internet. (Arthur 04.08.2015)

These statements, expressed in the same conversation shortly after each other, show how conflicted Arthur was about knowing about his temporal horizon. He obviously preferred more general, impersonal information available on the Internet to more personal data. The complex interrelatedness of medical information and un/certainty was also something physicians told me about, stating that too much diagnosing and testing was often disadvantageous to patients' health. These critical statements about biomedicine's potentialities and perils are also supported by findings in Communication Studies, pointing out that in some cases patients want to *increase* uncertainty by avoiding specific information (Stone et al. 2013). I follow these arguments, claiming that Arthur wanted to gain more general information to *de*crease uncertainty (only leading to more uncertainties), and simultaneously avoided more personal data to *in*crease uncertainty. When getting diagnosed with a life-threatening disease, «the openness of uncertainty may be preferred to certainty and control, not least when your prospects seem grim» (Jenkins et al. 2005: 9). On the one hand, Arthur preferred the openness of uncertainty by avoiding specific information, whilst on the other hand, he was well aware of the severity of his medical condition and that his prospects were grim. So the wish to prolong his life and to push his death further away, was his driving force: «The horizon would adjourn again, that is the only reason I want to do this. [...] Without the current possibilities my death sentence would be passed» (Arthur 04.08.2015). He was not at ease with the fact that he might not be around in five years, not like Martin, a 62-year-old suffering like Arthur from liver cancer and cirrhosis. Unlike Arthur, Martin seemed reconciled with the probability of dying:

> *This is life, it starts with birth and ends with death. Death is also part of it. Most people tend to uncouple those two, but not me. […] I am 62 and had a good life, okay, not* all *the time but those bad times belong to it as well. […] I am aware that this view may seem odd.* (Martin 21.04.2015)

Arthur's life has been an exciting and challenging one, but there was so much more he wanted to do: to see his grandchildren grow up, spend more time with his wife and travel. Martin's aspirations for the future on the other hand were much more modest: «To live normally. Nothing extraordinary» (25.06.2015). He considered himself content and happy

because he was free of pain and still had «hope for a future». As it would turn out later, Martin's hopes for a future, for a transplant, were dashed as his cancer progressed and he was kicked off the list. But although facing death, his calm and serene attitude was not affected by the drastic change of circumstances. I trace his serenity back to the fact that in his family he was the person reaching the oldest age, «Methuselah», he even called himself. As most of his family died at a far younger age, mostly because of cancer, Martin's imagined life span seemed to have reached his aspired limits. Arthur and Martin both suffered from cancer, their life expectancy was similarly uncertain, but the way they dealt with these issues seemed almost diametrical. Their imagined futures and hopes had similarities, but they mostly differed. The way we imagine our lives to be is a highly complex matter. It is an assemblage of things we came to perceive as realistic expectations, things worth striving for, intimate hopes and aspirations in relations to the structural and socioeconomic limitations we face. Due to the fact that their imagined futures and expectations from life differed from each other, Arthur and Martin dealt very differently with the uncertainties they faced. Whereas one was tensed and worried, hoping for many more years to come, the other – younger one – seemed calm and accepting of the limitations of life and his approaching death. As mentioned above, Arthur's life had been a very mobile one, and so the immobility he had to face whilst waiting for a transplant was much harder for him to deal with. Compared to Arthur, Martin had a much more stable life, being born and living in the same region, having a steady job as a mechanic, surviving all relatives on his fathers side by the age of 62. His life and expectations of it were far less mobile than Arthur's, and I ascribe their almost diametrical approach to the uncertainties of waiting to this difference of actual and imagined im/mobility in their lives.

I nevertheless want to stress how important the time of waiting can be, despite its uncertainties, by including a transplant trajectory in the discussion that is defined by a *lack* of it. Although frustrating, the waiting time is an important period giving the chance to prepare oneself for the life-changing event to come, to accept oneself as being sick, to synchronize the imagined to the actual temporal horizon one faces. To some extent, waiting and time to reflect is relevant to patients' long-term wellbeing, and the lack of it might have enduring consequences even decades after a successful transplantation.

Most people suffer for years before getting a transplant and the first months after transplantation are often marked by tremendous euphoria and gratefulness for a «second chance». People without time to prepare tend to lack these positive emotions. 40-year-old Anna suffered from depression after her transplantation, which she suddenly needed at the beginning of her twenties, shortly after she had given birth to her first child. Her future aspiration and dreams were shattered and she was not able to live the life she had envisioned for herself. The medication she had to take made another pregnancy impossible and her planned move to Mozambique became an unattainable endeavor. Facing transplantation 20 years ago, Anna did not consider herself lucky: «What kind of luck should that be? That is all bullshit. I did not want to get a transplant» (Anna 23.08.2015). If it was not for her child, she would not have made it, her driving force, goal and self-imposed duty, was to survive until her daughter turned 18, which occurred three days after our meeting. «Now I am 40, I am ready to go!», she laughed. But even now, almost 20 years after her transplantation, it was hard for her to swallow the pills, her daily medication, on «bad» days and she needed to force herself to keep them in. The mobile life she had envisioned for herself was no longer possible after transplantation, and the tension that arose between the life she imagined for herself and the life she had to live, had profound ramifications. Waiting, or the lack thereof, can have lasting consequences, even decades later. As such it transgresses the temporal space beyond its actuality, affecting people's present and future.

Cyclicality in Transplant Medicine

Waiting for a liver has consequences for the body and mind. As the organ is the body's tool for detoxification, its reduced function entails the intoxication of the body, especially the brain, which might cause memory loss, dizziness, personality changes, speech impediments and at worst coma. But of all the physical ramifications, ascites is where the passing of time is experienced in a most distinctive way. Recurring abdominal fluid puts pressure on lungs and other organs, making it hard to breath and limiting every move. This forces patients to the hospital to have their bodies punctured and this liquid drained, in some cases every two weeks, like Katrin. While she told me about her illness, the 63-year old women repeatedly pointed at her belly, which looked heavily pregnant:

> *I am not fit anymore, physically but also mentally, which bothers me the most. […] I forget so many things, […] things I have done a thousand times. […] And the worst thing is this: ascites. By now I have to get punctured every 14 days. At the end it is almost unbearable. […] I had up to 14.6 liters in here: [*she points at her belly*] that is a lot! Try to carry that around once and…live with that.* (Katrin 21.04.2015)

Bernhard Stiegler (2009) discusses the symbolic meaning of Prometheus' liver, which gets partially eaten by an eagle during the day but grows back over night. Prometheus was

punished by the Gods and his daily repetitive, infinite torture is a symbol for his and humanity's recurrent everyday worries. His ever re-growing liver becoming his personal clock. Unlike Prometheus' liver, Katrin's was unfit to regenerate itself as her alcohol abuse had turned healthy liver tissue into scarred one, reducing its vital function and causing her body to fill up with fluid. Similar to Prometheus' re-growing liver, Katrin's recurring ascites became her personal rhythm. Every 14 days she had to go to the clinic to get some temporary relief, ascites becoming her agonizing bodily clock.

Cyclical treatments, repeated tests before and after transplantation, coming back to the clinic every couple of weeks or months to give blood samples: that is most transplant patients' routine. One of Maister's principles emphasizes the importance of mobility in waiting. «*[P]eople want to get going*» (Ehn & Löfgren 2010: 23), they want to get the sense that they have not been forgotten, that *something* is happening, which is one of the reasons why patients' recurring appointments are important for them (and nevertheless tedious for most). Before receiving a transplant medical staff have to ascertain whether patients' are still eligible according to their blood samples and tumor sizes, making sure they are sick enough, but not too sick. And the tests are not finished with the transplantation: people repeatedly have to undergo tests to check whether the body is rejecting the new organ or to adjust the immunosuppressive medication. Getting a transplant is not a cure, it is a risky process to prolong one's life, a non-reversible life altering procedure, accompanied by life-long medication to suppress the immune system and fight organ rejection. Many uncertainties, predominant during waiting, are not resolved with transplantation, but are merely replaced by new ones. How long am I going to live with the «new» liver? Are the immunosuppressant's working? How to cope with the side-effects? How to make sense of another person's body part in my body? These uncertainties are accompanied by repeated medical tests and hospital visits, very frequently right after transplantation, later on only twice a year. These uncertainties indicate that transplantation is not a unilinear treatment, with a clear cut beginning and ending. It is a non-reversible, life-altering medical procedure, the only available treatment for many cases of liver diseases, but with its performance, new uncertainties come along.

Conclusions

In this article, I shed light on waiting and its technological, spatial and temporal dimensions, where at first glance it may appear that nothing is happening. Whilst people wait for a life-saving medical procedure, hoping that an organ gets donated in time, they get stuck in a temporal limbo between life and death. Waiting lists are the central tool to regulate the access to this high-end, high-tech medical procedure, based on medical as well as legal terms and requirements. But while they aim to order and put people's lives on hold, people inevitably keep on living. I argue that these lists make people spatially, temporally and existentially immobile. Waiting always encompasses questions of where, when and how, and thus engaging in elements of place, temporality as well as technology and discourse is essential in an exploration of waiting. By giving account to the experiences of people with a life-threatening disease, as well as to medical staff, I show how waiting is always dynamic, intersubjective and transgressing spatial and temporal actualities. The engagement with waiting in an ever emerging world characterized by mobility is a crucial endeavor to grasp the complexities of experiences and imaginations when mobility gets disrupted and people become *im*mobile. I compare the uncertainties in medicine and its pursuit to tame these uncertainties with Hercules fighting Hydra by repeatedly cutting of her re-growing heads. By examining the experiences of those affected by these appearing and re-appearing uncertainties, I contribute to an ongoing exploration of medical, moral, and intimate uncertainties in the world of today.

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