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Swan Song

An Account of Organ Donation after Circulatory Death

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Abstract

This is an account of a procedure of organ donation after circulatory death (DCD) that took place in July 2019 in a French hospital. Based on an ethnography in the neuro intensive care unit (neuro-ICU) of this hospital, I describe the impressions that DCD leaves on those taking part in it, the surprise effects it may produce, and the questions that it poses about what remains alive in a person on the brink of imminent death. This account is also that of a medical and technical complication, the advent of which makes it possible to document how organ donation protocols force doctors to clarify the dividing line between life and death.

Keywords

ICU, Ethnography, Brain death, Organ donation, Symbolic.

The Incurable

Elli enters the neuro-ICU hastily; we've been waiting for her for an hour. Eyes down, she walks straight past us without a word, not even a hello. Wearing green scrubs and carrying a huge black backpack, she heads for one of the empty bays. Sitting by the computers at the central monitoring station, we watch her removing her enormous bag, tying up her long curly hair, deftly shoving it under a surgical cap, putting a mask on. 'I didn't think she'd be so young', mumbles a nurse behind me. Elli is not happy to be here. She tried not to come, but all she managed to do

was to waste everyone's time and to piss off Charlotte, the organ donation coordinator. Now she no longer wastes a second: opening her backpack she takes out a large machine, tears open the plastic, unwraps the packaging, quickly unpacks sterile instruments. Charlotte heads over to the empty bay and stands there, in front of the young woman. Elli softly asks her where is the patient. 'He is there', answers Charlotte curtly, pointing to a man asleep two bays away. The man is naked, his body covered by a sheet, a ventilator tube coming out of his mouth, his grey hair billowing around his face onto the pillow.

Two days earlier, the team had met to decide his fate. It was the morning, the resident had been on the night shift and presented patients' cases in a tired, monotonous voice. The man is fifty-seven years old, he has been living in a nursing home for six months; a few nights ago he was found unconscious in his room, assessed to be a 4 on the Glasgow Coma Scale.[1] He had had a brain trauma in his youth that had caused hydrocephaly (the accumulation of liquid in the brain) numerous times throughout his life, which had been treated by multiple ventriculoperitoneal shunts (a device in the brain to drain the liquid). That night, there was another hydrocephaly, which this time plunged him into a coma. When the man arrived in the ICU, the team called his neurosurgeon on the phone. The neurosurgeon told them not to do anything. 'There is no point, he's a goner', he told them. Chewing on the plastic lid of his pen, the chief of the neuro-ICU listened to the resident with a blank look on his face. The senior intensivist intervened to summarise the situation for him:

The senior intensivist (*to the chief*): We decided not to treat his acute hydrocephaly and to let him go. The family was pretty OK with that and told us that he was an organ donor. So we're doing a DCD [donation after circulatory death] tomorrow.

A silence.

The resident *(to the chief)*: Because they [the family] said he owed medicine a lot!

Someone (*laughing*): Wow!

The chief, looking aghast, examines the brain scan, scrolling quickly on his mouse to zoom in.

The chief (*to himself*): What …! This is atrophy, this is complete [cerebral] atrophy! His brain is a puddle of water! (*To the senior intensivist, in a dismayed tone.*) But, did he have children? Did he live? What did he have [as a life]?

1 The Glasgow Coma Scale measures the level of consciousness ranging from 3 (deep coma) to 15 (conscious).

The senior intensivist (*patiently, to the chief*): He has a wife, who is blind like him. She asks very specific questions [about the donation]: “How will his heart stop?” etc. And, he has no children. He has an aunt who took care of him because she lives nearby and he has other family, a brother, who will come tomorrow for the extubation.[2]

The chief (*glancing rapidly at the senior intensivist*): Check that everything is ready for the procurement.

The senior intensivist (*reassuringly to the chief*): It’s all sorted, the family is perfect. No problem.

Donation after circulatory death

The decision was simple. Everything is in place, the senior intensivist is happy. All the happier perhaps, as the DCD procedure—referring to donation after circulatory death, previously referred to as ‘donation after cardiac death’ (and, before that, as ‘non-beating heart donation’)—is usually considered complex; ‘heretical’, a nurse once told me. Authorised in France since 2014, ‘controlled DCD’ is a protocol that allows the recovery of organs after a cardiac arrest following a decision to withdraw a patient’s treatment.[3] Compared to organ procurements from a person declared ‘brain dead’ (known as ‘heart beating donors’),[4] controlled DCD presents two possible complexities.

Firstly, the decision to withdraw treatment. In consultation with the family, the doctor decides to withdraw what is actually keeping the patient alive.[5] This kind of decision is an ordinary part of an intensivist’s work and, while never taken lightly, it is not the decision per se that poses a problem but rather the fact that it will be followed by organ procurement. To recover organs, the patient’s death must first be agreed upon, raising the question of the instrumentality of DCD: ‘It’s a bit vulture-like’, in one nurse’s words. By contrast, in the case of donation after brain death, in which the patient is considered already ‘dead’, the ICU team is not faced with such a decision. Secondly, determining the moment of death following cardiac arrest is a difficult task. When exactly does death occur? Is it two, five, 10 minutes, or more, after cardiocirculatory arrest? People die of cardiac arrest every day

2 The senior intensivist is here talking of ‘terminal’ extubation, the act of taking off the breathing support tube in order to provoke death.

3 In France this procedure’s name is ‘Maastricht 3’ (abbreviated as M3); the term ‘controlled DCD’ is used in Anglophone countries. To simplify I will use DCD in the rest of the text. During DCDs in France, the kidneys, lungs, liver, and pancreas may be recovered, but not the heart. It is possible nonetheless to recover the heart during a DCD and this is permitted in the UK, Australia, and the US.

4 Brain death is defined as a state of total and definitive absence of brain activity in a person, and the absence of breathing and heartbeat. When organs are recovered in a state of brain death, this is done while the heart is beating thanks to respiratory assistance and other kinds of reanimation measures.

5 Doctors take the decision to terminally extubate a patient in agreement with the family, but in the event of a disagreement in the family, or between the doctor and the family, French law stipulates that the decision is ultimately that of the doctor.

without this question being raised, but in the event of an organ donation the dead donor rule prevails: the question has to be asked before beginning the procurement; it must be ascertained that the person is ‘truly dead’ (Harrington, 2009). What does that mean? The heart is no longer beating. What other sign should we be looking for so as to say that we are faced with true death? Rather than a sign, it is the absence of a sign: the impossibility of resuscitating, the irreversibility of the situation, the point of no return. This point of no return is established by cerebral death, caused here by the brain being starved of blood for a certain duration.[6]

The question that remains then is to know at what point brain death occurs after cardiocirculatory arrest. This moment is determined *a priori*—indeed, DCD protocols do not require objectifying brain death by means of tests (as is usually the case for any brain death evaluation) during the DCD procedure itself—and it varies depending on the regions of the world: in the US, France, Spain, the UK, and in most of the European countries allowing DCD,[7] the moment of death is set at five minutes post-cardiac arrest; in Ireland, Portugal, and Austria it is 10 minutes; in Italy, 20 minutes; in Russia, 30 minutes. The choice of the duration is determined on the basis of results from scientific studies—data from animal experiments and from known clinical cases of self-resuscitation—and on the basis of a temporal constraint: it is not possible to prolong this moment too much since the organs to be recovered suffer by the minute from lack of blood circulation (as a result, the duration required in Russia and Italy makes organ donation after cardiac arrest inoperable in these countries). This length of time is known as the ‘no-touch’ period. It is a moment when everyone waits, touches nothing, does nothing apart from attentively observe the patient and verify the cessation of his or her pulse. During this period of time the difference between a living and a dead person is looked for, but, in reality, the difference is very slight.

In France, the no-touch period begins at the time of cardiac arrest and, if all goes to plan, ends five minutes later with the pronouncement of death. The DCD procedure may then go ahead, which is the point at which Elli will actually enter the scene. Elli is a perfusionist. Her job consists of operating a machine that pumps the blood out of the body, oxygenates it, then reinjects it, thereby oxygenating the tissues in lieu of the heart and lungs. The machine is more frequently used for open-heart surgery than to preserve the organs of donors after circulatory death.

6 In the context of organ donation, the ultimate reference is always established by brain death. Pierre Mollaret and Maurice Goulon’s concept of *coma dépassé* (1959), renamed ‘brain death’ in 1968 by the Harvard Ad Hoc Committee, subsequently allowed for the development of organ procurement procedures (Lock 2002). Therefore, even if cardiorespiratory arrest is commonly recognised as the criterion for determining that a person has ceased to live, the historical link between organ procurement and cerebral death explains its decisive role in settling the distinction between life and death in the specific context of organ donation.

7 DCD is not authorised in Germany, Finland, Estonia, or Greece, for instance.

Therefore, as Janet Carsten recounts in her introduction to *Blood Work* (2019), the perfusionist usually has patients' lives in her hands, rather than their cadavers.

This role change might account for Elli's lack of goodwill to operate her machine for the DCD this morning. Also, this is Elli's first DCD. It is my first as well. I began fieldwork in this neuro-ICU in January 2019 and had spent almost three months there since then, but I had not yet had an opportunity to observe this procedure. It is not that frequent—in this unit there are seven to ten DCDs a year (for the whole of France for the year of 2019 there were 393 donor patients through DCD). Furthermore, my anthropological research does not bear on organ donation as my aim is to document the ways in which, beforehand, the medical team and families decide to withdraw treatment from coma patients. That morning in July 2019, I know almost nothing about DCDs—I've never heard of the no-touch period, I don't quite understand its purpose, I don't know that there is a controversy about its duration, nor that, in some people's opinion, DCD violates the dead-donor rule (Menikoff 1998; Truog and Miller 2008; Gardiner and Sparrow 2010). I had grasped, however, that this protocol is a source of tension which, for those working in the unit, appears to be mainly related to the role it gives to the intensivist with respect to the patient's death.

'What's most complicated', a nurse taking part in the DCD that morning whispers to me, 'is the need to intervene'. In order to recover organs, the intensivist must extubate the patient—that is, to carry out the act of withdrawing breathing tubes. Two acts, in fact, need to be performed. For the heart to stop rapidly, the patient needs also to be 'deeply' sedated, 'otherwise, it [DCD] won't work', explains the senior intensivist. The so called 'deep and continuous sedation', which has been permitted in France since 2016 by the passing of the Claeys-Leonetti law, is an injection of a mixture of benzodiazepines, neuroleptics, and sometimes propofol (an anaesthetic) that accelerates cardiac arrest by acting as a respiratory depressant and by suppressing reflexes fighting against the lack of oxygen. DCD protocol hence gives the intensivists—and only them—the responsibility for these acts. 'It's you who finishes the guy off … and I'm not all that comfortable with that', comments one junior intensivist. For that matter, like some of her colleagues in the unit, she refuses to practise DCD. Such unease and refusal surprises me, since intensivists do frequently take decisions to withdraw treatment and extubate patients in order to provoke their death intentionally, an act that they willingly take responsibility for. What is it, then, that is particularly disturbing about therapy withdrawal in the context of a DCD procedure? One of my discussions with the senior intensivist that I recount in the following paragraph gives some answers: it underlines that there can be something forceful in the making of death, now, because the organ is a gift, it cannot be taken forcefully, otherwise it would raise the possibility of a violation that would turn a gift into theft.

I was talking one morning with the senior intensivist in the hospital cafeteria. We were discussing a fifty-something man who was in a coma. His family had just decided to withdraw treatment due to the likelihood that he risked being pretty severely disabled on waking up (it should be noted that the medical team did not doubt that he would have woken up). Organ donation was suggested by the team but ruled out by the senior intensivist, because 'we recommend DCD for patients we know will not regain consciousness [i.e. will not wake up]'. I said I didn't understand—given that they had decided on therapy withdrawal, what difference did it make what would happen after death (whether his organs were recovered or not)? The senior intensivist answered hesitatingly: 'Maybe it's me who isn't very comfortable with that but, for the time being in this hospital, we have given ourselves an ethical boundary: we suggest DCD for those in the "won't wake up" category and I don't see myself physically carrying out DCD on someone with a favourable neurological prognosis'. I grimaced sceptically: 'But you would withdraw therapy from that someone, right?' 'Of course!', he replied. 'Why?' I insisted. 'Technically, it's not the same thing', he explained. 'When you withdraw therapy, you take your time, but when you extubate for DCD the heart has to stop in a very short lapse of time'. 'In truth', he continued, speaking faster, 'we know that we can end up facing a nightmare scenario: we have a patient whose treatment we decide to withdraw, the family says "No problem", and the next day we begin talking of organ donation and the family says "Are you crazy or what? You want to withdraw therapy so you can harvest organs?! No way! We've changed our minds!" And there, they change their minds on TWO things: we don't carry out DCD and we don't withdraw therapy either. And the patient ends up waking up, regains consciousness, and goes on TV saying, "They wanted to remove my organs!" It's the nightmare scenario that could never happen with DBD [donation after brain death]'. I probed him a little further: 'Whereas if you just say "withdrawal," people are fine with it and end of the story?' 'Yes', he replied, 'but if you ask me again in two years' time maybe I'll have changed my mind. But for the time being we've decided to select a group [the 'won't wake up' group] for whom it's straightforward to suggest an organ donation. And at the end of the day, unconsciousness plus therapy withdrawal it's a bit like brain death … So, it's better to do less [DCDs] and only good ones, than to do lots and to find ourselves with terrible moral dilemmas that keep you awake all night and which you can no longer get your head around', he concluded.

Our discussion emphasises that the active making of death can pose a problem depending on what one plans to do with the body afterwards: in itself it is not a problem—'of course!' the senior intensivist is fine withdrawing treatments when he and families have agreed to do so—but he might get uncomfortable when DCD is at stake. Is the unease that intensivists experience, and their refusal, at times, to carry out DCD, the result of ethical and/or technical concerns? The senior

intensivist first referred to an ‘ethical barrier’ but then mentioned having selected a group for whom it’s ‘technically’ simpler to suggest DCD. As a result, this group doesn’t confront him with unbearable moral dilemmas. Simpler because these patients are in a state ‘a bit like brain death’. They are more or less dead. It is their resemblance to brain-dead patients which makes the act simpler because their death is believed to occur quicker (their heart would stop ‘in a very short lapse of time’). The making of death would not run the risk of becoming forceful for these patients. It is therefore a technical reason that helps the senior intensivist decide which patients are and which patients are not suitable for a DCD, rather than the more general ethical problem posed by therapy withdrawal and the act of ‘finishing the guy off’. As death approaches, proposing DCD for people who are already a ‘bit dead’ might spare the senior intensivist terrible nights, haunted by moral dilemmas and images that you can no longer get your head around. Moreover, the smoothness with which these patients seem to transition to death would make the ‘nightmare scenario’ less likely (if a family were to go back on their decision, these patients would probably never wake up). For the senior intensivist there is a risk of being haunted by these deaths, a risk that appears to be related to problems posed by the actual making of death, the determination of death, and the question of ‘when exactly is a person dead?’. The problem posed by DCD to doctors would be the old difficulty of drawing a line between the living and the dead, which remains a challenge today as it has been in antiquity, as Daniel Heller-Roazen (2021) recounts in *Absentees*.

In the remainder of this article, I describe the DCD that began that July morning with Elli’s bad-tempered arrival in the neuro-ICU and I give an account of the impressions DCD leaves on those taking part in it, the surprise effects it may produce, and the questions it poses about the difference between the living and the dead. This account is also that of a medical and technical complication, the advent of which makes it possible to document how organ donation protocols force doctors to clarify the criteria of life and death. Before describing the situation and the protagonists’ actions that morning, I first present the setting in which this procedure took place and the way in which things are *normally* meant to happen so that the reader does not get lost in the technical details that are unfamiliar to most people (and of which I, too, was unaware that morning).

July 2019, a.m.

This DCD takes place in the neuro-ICU unit situated in the basement of one of the buildings of a major French hospital. It is overseen by a nurse, Charlotte, the organ donation coordinator. In this unit the rooms are open, that is, they are separated from one another by thin partitions and have no shutting doors (bays). This layout allows nurses to keep an eye on all the patients while they are busy at the central

station logging patients' data on computers. Elli is in one room, two bays down from that of the man. For the time being, the room in the middle is occupied by a young patient, who is due to leave the unit the very same morning; the intermediary bay will thus be empty at the time of the DCD. Eric, a young heart surgeon, soon joins Elli in the bay. Charlotte is very happy that it is him on duty this morning because 'Eric is really easygoing, he's great'. At this point, Elli and Eric are getting ready—Elli, her machine; Eric, all the equipment to connect Elli's machine to the patient—out of sight: a sterile drape has been hung on a screen unfolded at the entrance to their bay because Charlotte did not want 'the family to see everything, the surgeons getting ready and all that'.

At the same time, Raphael, the neuro-intensivist, is in the patient's room. He is looking at the man lying on the bed. As usual with him, Raphael's face is impassive and he is standing up very straight. That morning before the start of the DCD, he asked me in an unusually enthusiastic tone if I wanted to go get a coffee with him. Perhaps to pluck up courage (it is his first DCD too). We went to the cafeteria. When we came back, the nurse had prepared the patient's room, freeing up lots of plug sockets and arranging several yellow dustbins around the bed 'because they fill up really fast'. Later, Raphael will extubate the man. After the extubation, his family will come into the room to say goodbye. During that time, standing back a little, Raphael and Charlotte will attentively surveil the man's systolic pressure. Once the blood pressure falls to 45 mm mercury [or mm Hg], Charlotte will give Raphael a sign: the signal for him to tell the family that the time has come to leave. 'We usher them out', Charlotte explains to me, 'because after 45 [mm Hg] things can go very fast and the heart surgery team [Eric and Elli] have to be able to set up, swab down [with Betadine], etc.' After reaching 45 mm Hg, the man's blood pressure will keep falling and Raphael will have to determine a value of the systolic pressure at which the no-touch period will start. It's up to Raphael to choose this number: 'You're the one to decide', Charlotte tells him, 'it's you who is in charge of that. There are doctors who tell me 15, others who tell me five … It's you who decides'.

The number Raphael is going to choose will mark the start of circulatory death and the beginning of the no-touch period. Charlotte will set her stopwatch to five minutes and if nothing budges after that time is up, Raphael will declare the death. Eric will then rapidly insert the cannulas [little tubes] through the man's skin into his femoral vein and artery. 'It's after death and only at that moment that we insert the cannulas, but we don't put them in before: very important!', Charlotte warns me with a smile. Eric will then connect the cannulas to Elli's extracorporeal oxygenation membrane (ECMO) machine and the perfusionist will start the ECMO. While inserting his cannulas, Eric will also make sure to stop the blood circulation in the upper part of the body (in the man's heart and brain) by placing a small

occlusion balloon in the thoracic aorta, above the diaphragm. The goal is to prevent brain and cardiac recirculation by the ECMO (otherwise the heart and brain 'start again'), while allowing revascularisation of only those organs being recovered: the liver, pancreas, kidneys, and lungs.

Eric and Elli need to act fast so that the ischemia period (the cessation of blood circulation) of the future transplanted organs is as short as possible. The time between the moment when the blood pressure reaches 45 mm Hg and the moment when Elli connects the ECMO must be under 30 minutes when recovering the pancreas; 45 minutes for the liver; 90 minutes for the lungs; and 120 minutes for the kidneys. Once the ECMO is working, the time permitted before retrieving the organs is a maximum of 240 minutes. When the man is connected to the ECMO, he will remain a while in the room where his family will be allowed to see him one more time for 'a last goodbye'—Charlotte has planned to drape a sheet over the ECMO pump so that the family doesn't see the blood pumping into the machine to be oxygenated and heated—and he will then be transported to the operating room for the procurement of his organs.

But for now, Elli has just arrived in the neuro-ICU unit.

Vincent Lambert

In the bay, the perfusionist unwraps plastic tubes and pipes, connecting them to the machine. Charlotte stands, watching her in silence. The tension is palpable. Elli raises her brown eyes to look at the nurse coordinator and with her chin gestures to the man lying on the bed.

Elli (*to Charlotte*): He's a bit of a Vincent Lambert, isn't he?

Charlotte (*resolutely*): No!

A silence.

Charlotte (*severely, to Elli*): Not at all! Because he [the man] is brain-damaged. Vincent Lambert is not brain-damaged, he is … well, he is a trauma … (*Firmly.*) We don't do that kind of, of …

Elli (*cutting in, reassured*): OK, I agree!

Charlotte tells her how to prepare the machine, how to place the bags, filters, membranes, tubes: 'Go ahead!' 'OK', says Elli. 'Plug that into the supply!' 'Yep!' 'Put a blood filter on the vein and a Y line on the artery!' Elli hooks everything up really fast, the nurse coordinator watches her doing it. 'Perfect!' she says.

They are working together. The tension dissipates.

On 29 September 2008, Vincent Lambert had a car accident on his way to work at the Châlons-en-Champagne Hospital, in the northeast of France. Aged 32, he was plunged into a coma, and woke up in what is known as a 'minimally conscious state'—that is to say, a response to commands is observed, there is a presence of reflexive movements, there is eye opening, but there is no communication (Laureys 2015). He died on 11 July 2019 (a few days after the conversation between Elli and Charlotte took place) following a decision to withdraw therapy. For nearly eleven years, Vincent Lambert became a familial, judicial, medical, and political affair in France, as well as the subject of a debate on what it means to be alive. On the eve of the day he died, philosopher Frederic Worms summed it up, speaking on French radio: 'We can say that Vincent Lambert is alive but that it is no longer his life'.[8] From the point of view of their brain condition, Vincent Lambert and the man lying in one of the bays in the neuro-ICU unit are not dissimilar and, contrary to what Charlotte claimed, both are actually brain damaged. The difference, rather, pertains to their relatives, the ones at their bedsides. The Lambert family were torn apart for at least eleven years. Journalist Ixchel Delaporte (2020) recounts how the familial conflicts and the 'trauma' (as Charlotte put it) stretched back well before the date of the accident. By contrast, with respect to the situation Elli and Charlotte are in, the man's family rapidly agreed with the doctors that a life with a brain that resembles a 'puddle of water' is not worth living and also gave their authorisation for organ donation. This family is 'perfect'.

No-touch (I)

Eric, the cardiac surgeon—tall, thin, and softly spoken—joins Elli in the bay. He asks her when she'll be ready. 'I'd say five minutes but that's because I'm extremely confident', she replies as she squeezes a big and inflated perfusion bag. Eric unwraps the surgical drapes, covers the table, drops the instruments, making a loud racket, and shouts to Raphael: 'We'll be ready in five minutes! The neuro-intensivist has just given the man an injection of propofol [an anesthetic]'. In the bay, standing cross-armed in a ray of sunlight that is shining through the slightly open window, Raphael is listening to Charlotte. She explains to him what will happen after the extubation: the family will be asked to leave when the blood pressure drops to 45 mm Hg, then Raphael will have to choose a number at which to start the no-touch period. She reminds him that he is the one to give the go-ahead. In the next room, the young patient is being wheeled out towards the door. The nurses wish her goodbye in unison. One of them calls out to her as she heads off, terribly thin in her bed: 'You eat now, right. Promise?' The patient smiles in return, nods, waves her emaciated hand to say goodbye, her long fingers fluttering.

8 Radio programme available here: https://www.franceculture.fr/emissions/linvite-des-matins-dete/invite-des-matins-dete-du-mercredi-10-juillet-2019.

The man's family is shown in, they slowly enter the bay, spread around his bed, a little squashed. His wife, who is blind, sits on a chair and holds his hand. Raphael slowly removes the tube from the man's throat, the machines beep, he switches off the sound. A blonde woman approaches the man and kisses him slowly on his forehead. A dark-haired woman gives him a long hug, pulls back and sobs. His wife is holding his hand, she doesn't cry. Standing at the foot of the bed, Charlotte surveils the blood pressure. At the central station, very much at a distance, Raphael watches them, his arms crossed. I go up to him. I ask him what [blood pressure] number he's going to choose? How does he decide? He chuckles: 'No idea. I'll trust my inspiration at the time!', adding, more seriously, 'I'll choose something low'. Charlotte turns towards us, the pressure is 42, she gives Raphael a sign to come. The intensivist enters the bay and tells the family it is time to leave. Without a sound they leave the unit and go to sit on the couches in the waiting room to bide their time until they are allowed to return for one last goodbye.

The nurse rapidly removes the sheet covering the man and washes his body with Betadine. Eric enters the bay, finishes putting on his blue sterile gown, with the help of the resident who ties it up for him at the back. The nurse plugs in the scalpel base, Raphael turns the sound back up on the machines and he announces the beginning of the no-touch (he has chosen 29 as the number): 'OK, we're good to go, let's start the five-minute countdown!' Charlotte responds: 'OK, counting! No-touch is starting, no one touch anything anymore, please!'

We wait in silence. We observe the man lying there immobile and the blood pressure rates changing on the screen. About two minutes after Charlotte declared the no-touch, I see that they are rising: 36/29, then 58/41, then 75/48. I point out the screen to Raphael, who is right next to me.

Me (*to Raphael*): Why is the pressure rising?

Raphael (*looking at me with a sigh*): We can't explain everything …

After a brief silence, he does in fact explain to me.

Raphael (*to me, with an enigmatic smile*): The swan song …

I smile back and we both fall silent. The blood pressure continues to rise.

Raphael (*turning back to me, didactically*): We are obligatorily heading towards death here, it's irreversible. There's not much reason to wait for circulatory arrest.

Me (*to Raphael*): But the number, it does mean something, doesn't it? Or does it make no difference if it's 45 or 0?

Raphael (*to me*): It doesn't mean much, it says that after a certain point he's irrecoverable. That [blood pressure rate] is insufficient to supply his brain.

Eric joins us.

Eric (*giving Raphael a complicit look, whispers to me*): It's hypocritical.

The man is irrecoverable, explained Raphael, his brain is no longer supplied. Ultimately, he is not far from being brain dead. For the intensivist and the cardiac surgeon, there is no reason really to wait for circulatory arrest. If the man is nearly dead, it does not change much that his blood pressure is 45 or 0. At this stage, it's hypocritical: it amounts to pretending that the man is alive whereas he is in fact nearly dead. A few moments after this conversation, however, Eric determined that the man's blood pressure was too high to commence the DCD process. This first no-touch was abandoned. It was the oxygen saturation that particularly concerned Eric, it was at 100 (the maximum level): 'That's not OK', he explained to Raphael, 'we normally do it at 15 per cent'. Charlotte had to click off her stopwatch. It was necessary to start over again.

No-touch (II)

About twenty minutes later. The man's blood pressure has now dropped to 11. Charlotte has just begun a new countdown: the second no-touch. People are talking this time. Eric is recounting how it rained all the time when he went on holiday to Tahiti; everyone laughs. A few minutes later, Charlotte exclaims: 'That's it! Confirmation of death at 12:26. You can go ahead now, Eric!'

Eric places the catheters, Elli passes him the cannulas, he inserts them in the veins, there's a lot of blood. I move back. Machines are beeping loudly and dissonantly. The perfusionist is scratching something stuck on the ECMO. She then plugs it in. It's working, the blood circulates. Charlotte announces: 'One litre of blood, it's 12:31!' She makes a calculation on a piece of paper: 'It's perfect for the liver and kidneys!' Eric finishes inserting the occlusion balloon in the aorta. The atmosphere relaxes. Elli unties her hair and begins to pack up. She and I chat. Crouching in front of her huge bag, she tells me that DCD are 'extreme cases for which there can always be abuses and excesses'. I ask her if it was that [excesses] she was thinking of when she asked whether the man wasn't a sort of Vincent Lambert. 'Yes', she says, 'and for that matter Charlotte was right to explain the difference to me. That's what I wanted to hear … because those are what the real questions are', she finishes, flicking her head back, seemingly a little on her guard.

Revival

I look at the man. His body rests in strict inertia, his hands look puffy, swollen with blood; I notice that Raphael is looking at him too. He gets closer, touches the skin on the man's face. 'He's warm', he says. Charlotte approaches the bed, she pushes Raphael gently aside to be able to look closely at the face. I approach too: the skin is pink. The first sign of death consisting in the alteration of the colour of the skin (due to circulatory arrest) is lacking. I ask Eric, standing nearby, to explain to me what is going on. 'Oh, nothing serious!' he says, completely cool. I insist, laughing: 'I know! [The patient is meant to be dead, how much more serious could it be?] It's to understand'. 'We inserted a balloon to block the circulation in the upper body', Eric explains, 'but the brain is still being supplied so there is a doubt concerning the blockage'. Raphael joins us. 'And above all, the heart is restarting again, there is a heartbeat!' 'Look', he points out to me, 'it's the beep you can hear'. A little regular beep that I hadn't noticed yet. Charlotte makes a telephone call to the radiologist to ask for help localising the balloon. On the screen, the heart rate is at 52 [beats per minute, or BPM]. Elli has gone to sit with her phone behind the central monitoring station. From time to time, she looks up at the man and us around his bed, looking gloomy. I think about what Raphael and Eric just told me: the neuro-intensivist insisted on the fact that it was the heart that had started up again, whereas the heart surgeon spoke about the brain still being supplied.

The radiologist is taking a long time coming, so Raphael decides to look for the balloon himself. He inserts a large tube with a camera into the man's throat and with the other hand he turns the buttons of the ultrasound rapidly, until the image comes into focus on the screen. Elli watches him doing from afar and winks at me. The heartbeat is 61, the blood pressure has gone back up to 50. Charlotte explains to the nurse that we are going to calmly wait to see if the body changes appearance. I ask her what the body ought to look like. Charlotte answers me simply: 'white'. Then, addressing Raphael with a note of concern in her voice: 'Physio-pathologically, there's nothing coming from him [the man], right?' Charlotte wants reassurance, she wants Raphael to tell her that only the ECMO is responsible for the heartbeat restarting and that the man's organism has nothing to do with it. The neuro-intensivist sets her straight: 'Oh, but it does! The heart is reinfusing and has its own flow rate [it is hence coming from him]'. Charlotte purses her lips. Eric approaches the man to look at the skin of his face. 'He's pink. It's weird', he says, still cool.

Me (*to Eric*): Is what's troubling you that blood is irrigating the brain?

Eric (*without looking at me*): Yeah.

A silence.

Me (*treading gently, to Eric*): Why does that bother you?

Eric (*very quietly, almost inaudibly, to me*): Because it's not the procedure. (*Brief silence*.) In itself it doesn't mean anything, but it's always a little disturbing.

Me (*unsure, to Eric*): It's always a bit disturbing?

Eric (*to me*): Yes. You don't know if blood recirculates in his brain. (*Thinks*.) And in the case of a donor …

Short silence.

Me (*to Eric*): So, there is a doubt then?

Eric (*to me*): A doubt … (*Sighs*.) We know that this patient won't live. (*A little aggrieved*.) But the brain arrest isn't clear cut. (*More firmly*.) At any rate, we know he won't survive and we are going to stop the machine.

Me (*interrupting*): That he won't survive, OK, but the question I imagine, is: is he alive right now?

Eric (*to me*): The question is a legal matter.

Me (*to Eric*): Only?

Eric (*to me*): Yes, only. It's that we aren't allowed, aren't allowed to …

The nurse interrupts him as she comes over, her hands full of small bottles of chilled water: 'Supplies for the troops!' Eric heads over to the central monitoring station with a bottle in his hand. I am thirsty; I open a little bottle of cold water too.

Half an hour later, the man's heart stops. Before that, Eric had put the balloon back in place (it was badly positioned) but this was not sufficient: the heart was now self-infusing. The solution was first to reduce the oxygen flow produced by the ECMO. Then Raphael asked Elli to turn it off completely. The heartbeat gradually slowed. After 20 minutes, the man's heart stopped and his face became livid, taking on the reassuring colour of the dead. The man was then quickly taken by ambulance for the organ procurement surgery in another building of the hospital; his family could see him for a very short moment only. Elli did not follow the ambulance. 'You're not going with them?' I asked her. 'No', she answered in a tired voice, 'they can manage'. We looked at each other briefly, in silence, then I finally said: 'For a first [DCD], it was …' 'Yes', she continued, completing my sentence, 'dreadful'.

Symbolic lines

Later that day, I run into Raphael in the corridor. Smiling, he calls out to me: ‘Laurence, I need to re-explain it to you with a diagram!’ I meet him in his office and under the white neon lights, Raphael draws me a heart, the veins, the arteries: ‘Here you have the heart, here [in the aorta] you put the little balloon’. Raphael explains that if the balloon had been properly placed the heart would not have restarted. That was the problem, he says laughing, because ‘legally you can’t say it’s stopped when it hasn’t!’ I reply that, in addition to that, blood was recirculating in his brain.

Raphael (*confidently, to me*): With all the [cardiac] arrests he’d had, all the morphine and with his cerebral pathology, we know that there was no one up there anymore [in his brain].

Me (*to Raphael*): Are we sure?

Raphael: Oh yes, we’re absolutely sure.

Me: So you would do a procurement on someone like that [for whom blood is circulating in the brain]?

Raphael (*confidently*): Yes.

Me (*insistently*): If it were someone you knew [personally] would you do it?

Raphael: Yes, that wouldn’t bother me.

Me: And do a procurement on someone still showing cardiac activity?

Raphael (*uncertainly*): Well, yeah, no … I mean, umm (*Silence*.) With cardiac activity still …? (*Sighs*.) I mean … with cardiac activity still: that wouldn’t really shock me.

I ask him to tell me what does ‘shock’ him then, because judging by his sighs and silences, it seems that something actually does. After a while, he first tells me that if the heart is left beating, it is symbolically more complicated: ‘If there is a tiny something going on in the brain it’s insignificant, whereas if you don’t stop the heart, I don’t think you’ve reached a symbolic limit’. I then recall my conversation with Eric, when the heart surgeon localised the problem in the brain instead, where blood was recirculating (‘the brain arrest isn’t clear-cut’). For Eric, the limit was no less symbolic than for Raphael (‘it’s hypocritical’, ‘we know he won’t survive’) only the symbol was not the heart but the brain. I tell Raphael about this: I tell him my surprise at their different ways of accounting for what constitutes ‘being alive’ and that, for the cardiac surgeon, it seems to be blood recirculation in the brain. The

neuro-intensivist repeats that, for him, it is not a matter of cerebral circulation: ‘From the moment you decide to withdraw therapy, a patient has no future left. And whether he’s in cerebral circulatory arrest or just unconscious, for me, doesn’t really make a difference’. By contrast, for the cardiac surgeon, not having a clear-cut cerebral arrest seemed to have some kind of consequence (‘It’s always a bit disturbing’, he said). Is it because each specialist has learned how to objectify the specific organ they specialise in, the heart becoming a technical object for the cardiologist and the brain for the neurologist, and the other organ—brain or heart—becomes a site for symbolisation precisely because it is outside their domain of expertise?

But after all, one may also wonder, in light of Raphael’s explanations, whether the very question of what remains alive in a person on the brink of imminent death is really the question at stake for either of these doctors during a DCD procedure. Both, in a similar way, explained that from the moment the decision is taken to withdraw therapy, the patient has no future, or, as Eric would put it: the question is ‘a legal matter only’ since we know the patient won’t survive and we know we are going to stop the machine (whatever happens). This would suggest that the notion of ‘irreversibility’, determined well before the procedure begins, renders incongruous any questioning of the criteria of life or death during DCD. The man would have been already ‘socially’ dead, as described by Annette Leibing (2006) and Janelle Taylor (2008) in relation to dementia sufferers. The term social death was initially used by David Sudnow (1967) to define the threshold from which someone, before being physically dead, is no longer considered as a ‘person’. And indeed, as Raphael stated about the man, pointing at his own head: ‘We know there was no one up there anymore’. However, if the man might be considered as socially dead by both doctors and if he is considered physically ‘partially’ dead, with respect to his heart for the cardiologist and to his brain for the neuro-intensivist, I don’t think we can say or conclude from this story that he is ‘just’ dead, nor that he is considered as a ‘non-person’.

I think we cannot do so because the account I just gave of the repeated attempts of the team to silence the ‘swan song’ shows how the transition to death may actually pose problems—from technical issues (finding the right blood pressure number), to uneasiness (Charlotte’s concerns) to moral tensions (it was ‘dreadful’, concluded Elli)—and also points to the efforts, successful or not, to overcome these problems. Furthermore, during my discussion with Raphael in his office, he said this to me too: ‘It would be easy to do a procurement on someone with cardiac activity but there could be abuses. In the man’s case, we went to the trouble of stopping the heart; after that, it started up again. But we made the effort to stop it. We made a real effort to transition from one to the other [from alive to dead]’. He continued, looking vaguely at his computer: ‘But the problem is a symbolic matter

and the way we establish a dividing line between …' He paused, choosing his words. 'Between alive and dead?' I suggested. 'Yup', he smiled.

It is these efforts—finding the appropriate blood pressure value to begin the no-touch, waiting while monitoring the colour and texture of the skin, reducing the oxygen supply and then cutting it off entirely, going to the trouble of stopping the heart—to transition 'from one to the other' that reveal what we actually care for. I thus think we cannot say of the man that before the determination of his death he was considered as a 'non-person', precisely because of the team's concerns in attempting to pin down the elusive boundary between life and death. A dividing line that is symbolic, in the sense that it does point to the force of language, but at the same time has to be established; that is, to be effectively and technically performed. For the brain surgeon, it is effective when the heart stops, whereas for the heart surgeon, it is brain arrest that symbolises this transition, perhaps because it is preferable that it be someone else—the ethnographer included—who is in charge of the question about the dividing line between death and life.

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