Making it happen: data practices and the power of diplomacy among Danish organ transplant coordinators

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Abstract Danish transplant coordinators handle all data and logistics involved with the removal and transfer of organs from the body of an organ donor into several recipients in other Scandinavian hospitals. This entails a wide range of data work, not only in relation to sudden organ donation cases, but also to documenting transplantations, providing feedback on donation outcomes, and facilitating the data needed by surgeons or other health professionals. This article investigates the data practices of organ transplant coordinators through the lens of diplomacy. Based on participant observation and interviews among Danish transplant coordinators, I focus on the cross-disciplinary relations and negotiations characterizing organ exchanges and show how datafication in itself is not enough to ensure smooth transplantation processes. Organ transplantation depends on the diplomatic social skills of the coordinator and the personal relationships between coordinators, surgeons and ICU staff. By bringing into focus the power of diplomacy, I conceptualize these structurally invisible efforts enabling organ donation and its associated data practices. Diplomacy enables us to recognize and understand the relational efforts and aspects of datafication, and the tremendous amount of work and social skill that go into producing and exchanging data in contemporary healthcare.

Keyword Organ transplantation · Transplant coordinators · Data practices · Diplomacy · Data work · Denmark

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Introduction

I love when everything comes together, when everything works, obviously. I spend so much time on preparing. That is actually the most important part of my work: Making it happen. Gathering all the threads with the donor unit and the donor information we have and communicating it to the physicians evaluating the donor potential. Selecting the recipients and communicating back to the donor unit what needs we have regarding the recipients we wish to select. Have the recipients called in in a decent manner and timing it with the surgical teams who travel out collecting the organs, and those who are ready here. That's a tremendous number of people. Therefore, when everything comes together, I'm very close to happiness (laughing).

(Kirsten, transplant coordinator),

Since the earliest days of organ transplant technology, the question of how to obtain enough organs to meet the needs of dying patients on organ transplant waiting lists has been a fundamental issue worldwide. Across nation-states, a variety of different solutions such as changing organ donation legislation, optimizing organ preservation technologies, and implementing new donor death criteria have been introduced (Arshad et al. 2019; Pinezich and Vunjak-Novakovic 2019; Morrissey and Monaco 2014). Across these settings, organ transplant coordinators are positioned in a key role. Their primary responsibility is to make available organs ready for transplantation by producing, exchanging and documenting the needed medical and logistical information among all involved personnel. These data practices, I argue, rest on the power of a particular kind of social diplomacy in these professional relations.

Denmark has performed organ transplantation from brain dead organ donors since 1990 under informed consent legislation, which means that transplantation can only take place with an active consent from either donor or donor family (Jensen and Larsen 2020). The majority of Danes are positive towards transplantation (Nordfalk et al. 2016). Nonetheless, donor rates are low, and the dominant notion of organ shortage heavily affects medical decisions of waiting list admittance (Jensen 2017). It is therefore crucial that all available organs are transplanted. The success of each transplantation depends on a complex infrastructure between intensive care units (ICU) at donor hospitals and transplant centers. Every time a surgeon transplants an organ, it is a result of an enormous network of medical professionals depending on each other, some without ever knowing each other. All they have in common is the transplant coordinator, who suddenly tells them to perform highly demanding medical tasks. Neurosurgeons declare brain death. ICU staff manage the body of the organ donor. Transplant surgeons evaluate organ quality. Laboratory technicians run the necessary tests to ensure a match. Operating teams rush to a hospital to remove the organs. Transplant nurses prepare the anxious recipient. ICU nurses help a grieving donor family say their last goodbyes. Pilots fly across borders to deliver organs and operating teams. Ambulance staff rush with an ice-boxed organ from the airport to the hospital,

and so on and so on. It is in this comprehensive medical structure that transplant coordinators produce, use and exchange the data needed for coordinating organ exchanges. If something fails, the ability to trace and document what and where something went wrong is equally paramount. In this comprehensive infrastructure, coordinators create, exchange, use and store a multitude of patient data and numbers, and collaborate closely with a large number of different healthcare professionals. Keeping and maintaining good relations in these medical networks is of crucial importance.

Like many other areas in healthcare, transplantation has undergone a ‘datafication.’ Policy makers regard the production, collection and analysis of data as the road to a better future (Hoeyer et al. 2019). In this vision, the datafication of transplantation can minimize the shortage of exchangeable human organs, maximize the outcome of every potential donor, and prevent critical mistakes. Such data promises (Hoeyer 2019) have come to govern the political landscape of organ donation and the daily practices of clinicians and coordinators who count and register all potential donors, all realized donors, all available organs, and all transplanted organs; and who, most importantly, monitor and analyze why some transplantations never happen.

Exchanging significant medical data is not a new aspect of transplantation, but the amount of data and the burden of registration have expanded during the last 5 to 10 years in line with the growing fascination with the potential of increased datafication in healthcare (Pine and Bossen 2020; Hogle 2016; Hoeyer 2016). However, no matter how frequently organs are counted and documented, they do not move from the body of the donor into a recipient without the relational capabilities of transplant coordinators, which, further, also involve a significant level of skillful diplomacy. Datafication is not enough. The amount or the quality of available data does not matter if the people involved in the data practices cannot work together. This article investigates how transplantation depends on the meticulous and sometimes mundane relational work of establishing and maintaining the comprehensive medical and social networks involved in exchanging organs and data across hospitals and nation-states. Through my analysis, I foreground the practice of diplomacy—“the art of dealing with people in a sensitive and tactful way” (www.lexico.com)—which I have observed as present in all phases of organ donation; and more generally, I draw out the power of diplomacy in the data practices of contemporary healthcare.

Theoretical framework: data practices and diplomacy

Following recent studies of datafication in science and healthcare (Hoeyer 2019; Leonelli 2016; Ruckenstein and Schüll 2017), this article addresses theoretically what data do, and what data mean, in specific contexts. Inspired by the arguments put forward by Loukissas (2019), I provide an understanding of the local data practices by focusing on data *settings*, rather than on data *sets*—in my case, the special working conditions of organ transplant coordinators, rather than the content of the data sets they handle. In organ transplantation, datafication is not a goal in itself; but getting more data and more numbers about transplant activities is thought to be

to the main issue of how to obtain more organs. To use the vocabulary of contemporary critical data studies, organ transplantation is characterized by a “seduction of quantification” (Merry 2016) and a fundamental data fascination (Kitchin 2014).

Critical data studies have explored datafication as a practice (Middleton 2020) and brought attention to the human work behind data, underlining the social networks and the many actors involved in data production and exchange. (Merry 2016; Pinel et al. 2020). Using the words of Cal Biruk, there has been growing scholarly attention to how data is “cooked” (Biruk 2018). Likewise, studies on data flows, the ethical work in data sharing, and how data are “done” (Hoeyer et al. 2017; Mol 2002) have helped shaped my interest in the social aspects of data exchanges and the variety of medical professions coming together in the data practices of transplantation. Except for a recent study from Spain focusing on the collective achievements of transplantation foregrounding the “complex socio-material arrangements” in the work of transplant coordinators (Bea 2020) little attention has been paid to how the infrastructures underpinning transplantation also depend on all kinds of social relations. From matters of maintenance to the skill to input data accurately, to time pressure and necessary detail, infrastructures built for organ transplantation are deeply human in their work. In this article, I foreground the work of transplant coordinators, framing the kind of work that they do through the lens of diplomacy.

Building on the arguments made in STS that infrastructures are also necessarily social, I develop the concept of diplomacy to shed light on the relational features of organ transplantation data infrastructures. The concept of diplomacy—and its crucial significance in underpinning the practice(s) of organ transplantation—came to me after fieldwork in Danish hospitals. While I was going over my field notes, one word stood out: “diplomat”—the word used repeatedly by several of my informants as an empirically articulated metaphor for their function when coordinating organ exchanges. Being a “diplomat”: this was how the transplant coordinators articulated the challenges and the consequent capabilities they needed to perform their work. Prompted by this image, I have expanded its resonance to relate to a more theoretical attempt to point general attention to the social and relational features of data practices within healthcare, in my case within organ transplantation. According to the Merriam-Webster dictionary, diplomacy has two definitions and means “the art and practice of conducting negotiations between nations” and a “skill in handling affairs without arousing hostility” (www.merriam-webster.com). Based on my fieldwork among transplant coordinators, this is an exact encapsulation of how transplant coordinators manage several surgical teams and medical professionals and how they obtain, produce and share the data needed for all actors in organ exchange to be ready and well informed to enable organ donation to happen. Inspired by recent ethnographic approaches to diplomacy I focus on the “everyday diplomacy” to understand “ways of operating” that are deeply embedded in different forces and social relations (Marsden et al. 2016). Here, diplomacy is understood as a professional skill not confined to the realm of nation-states or to international relations—although relations across international borders are very much a key part of organ transplant coordinators’ work. Rather, it is in general “a wide range of social activities” including getting one’s way, promoting certain interests, and influencing others to do something (Constantinou 2016, p. 24; Ibid.). Within healthcare

and medicine, the notion ‘medical diplomacy’ has been framed as a form of soft power building international relations, commercializing traditional knowledge, and building bridge between spiritual and biomedical healthcare (Castañeda 2015; Feinsilver 2003; Moret 2008). In addition, ‘global health diplomacy’ is widely used to describe how governments and other institutions practice and coordinate responses to improve global health (Ruckert et al. 2016). I take particular inspiration from new studies using the concept of diplomacy to describe a special skill among nurses to achieve goals peacefully, to establish and manage social relations, and to facilitate professional and organizational healthcare development (Bolewski 2018; Marc et al. 2019; Sharafi et al. 2021). As we shall see, organ and data exchanges depend on the diplomacy of coordinators, and—more specifically—on their social abilities to establish, maintain and nurture a wide range of actors in the donation and transplantation community. Coordinators must link actors who do not know each other, and who do not have the same medical and professional interests in mind. This involves a great deal of effort before, during and after the actual transfer of organs and data. By bringing attention to the power of diplomacy, I conceptualize these relational and structurally invisible efforts enabling data practices in contemporary healthcare, and in my empirical case, the data practices enabling organ donation.

Context and methodology

The organ exchange organization Scandia Transplant was founded in 1969 and is placed in Aarhus, Denmark. Scandia Transplant oversees and documents all transplant cases within Denmark, as well as across and between Scandinavian countries, since 2017 including Estonia (www.scandiatransplant.org). In 2020, a total of 2013 organs were made available, transplanted, and documented through Scandia Transplant’s online database YASWA designed (and constantly updated) to enable swift data exchanges across national borders. If, for instance, Stockholm has a donor not matching any Swedish transplant candidates, Swedish coordinators use the database to make an organ offer appear on the screens and smart phones of all 62 Scandinavian coordinators. Organ donors can potentially donate heart, liver, lungs, two kidneys and pancreas. As a result, coordinators sometimes handle six organ transplantations per donor. Despite increased datafication and digitalization, much information must still be exchanged in spoken form by telephone due to regional and national differences in data practices. While data is available about organs, organ exchanges continue to be embedded in social relations through differing data practices. It becomes the role of Danish transplant coordinators to maintain a number of good working relations: with Scandinavian coordinators, with their Danish coordinator colleagues in other hospitals, with ICU staff hosting potential organ donors, and with the many doctors, nurses and surgeons involved with transplant patients at their own hospitals. My argument is that coordinators can be usefully seen as diplomats in these relations when organs and data are exchanged [whether or not international borders are involved.].

Following my decade-long ethnographic interest in organ donation and transplantation (Hoeyer and Jensen 2011; 2013; Jensen 2011a, b, 2016, 2017; Jensen

and Larsen 2020; Jensen and Svendsen 2020), in 2018 I began to follow the data practices in organ transplantation. I conducted participant observation among transplant coordinators in Copenhagen and Aarhus from June 2019 through March 2020, attended 15 day shifts with coordinators, and spent approximately 100 h following their working lives in their offices at the hospitals. I gained access through my existing network of coordinators and their managers, already established in my previous research. Therefore, I was no stranger to the coordinators, and the initial trust-building associated with all fieldwork was easily established. Sometimes during fieldwork there was time to observe coordinators' daily routines of documenting, administering data, chatting with colleagues, following up on cases and preparing for new ones. During ongoing organ donation cases, the coordinator's telephone was ringing constantly, the atmosphere was hectic, and I was literally running alongside them. In addition to observations, I conducted semi-structured interviews with a total of 10 Danish coordinators (two included from previous fieldwork on donor families) and two staff members from Scandia Transplant. I also learned about the data practices of coordinators by reading some follow-up letters from coordinators to ICUs, and from PowerPoint presentations at hospitals and national conferences. In order to comply with the ethical standards in the field, I deliberately refrained from seeing any social security (CPR) numbers or other sensitive medical information of donors or recipients. All data materials are handled according to the GDPR legislation and informants and hospital names are anonymized in this article. By Danish law, qualitative studies are not subject to ethical approval by the National Committee on Health Research Ethics.

All interviews have been transcribed and, together with field notes from participant observation, undergone thematic analysis to identify relevant issues (Attride-Stirling 2001) which led to my focus on the power of diplomacy in data practices. Another significant point emerging from the material was—in a context of organ shortage—the increase in datafication and its consequent implications; this will be the subject of another article. In the following sections, I show how data practices and diplomacy are intertwined at three separate moments in the work of coordinators: when handling sudden organ exchanges, when expressing respect and gratitude after donation, and in everyday structural invisibility as data and donation facilitators.

There is a donor! The diplomacy of handling sudden data and organ exchanges

Human organs can only remain viable without oxygen or perfusion (blood flow) for a limited number of hours before it endangers transplant outcome. For instance, a heart can only be outside a body for 4–6 h, the lungs for 8–10 h, and a liver must be transplanted within 12 h. Therefore, all details in the transplantation process have to be carefully planned, yet with the greatest urgency. Obtaining and using the right patient data and managing the details of the process are literally matters of life and death for suffering organ recipients, many of whom have waited months or years for this opportunity. The system is set up to facilitate what coordinators call 'a match.'

Much can go wrong: if the wrong blood type is entered, the organ will not match the recipient. If the donor has a medical history of certain types of cancer, no organs can be used. If a heart from a 45-year-old male is too big, it will not fit a 16-year-old female recipient, even if they are a match. In addition to handling and exchanging this medical data, transplant coordinators also do a vast number of practical tasks: they book spaces on airplanes for organs, operating rooms for transplants, inform the staff participating in the organ procurement, and ensure that organs are transported and distributed to the correct recipients in time. If there is no plane to carry a human liver from Oslo to Copenhagen, or if no surgeons are ready to receive it, the organ is lost.

A donation case begins with an ICU contacting a transplant coordinator who checks if the patient has registered as a donor, and obtains the patient's medical information and cause of fatal brain injury. If there is donation consent from the patient or the family, and the patient is declared brain dead, the process of finding suitable recipients begins. In order to match donors and recipients, coordinators need to have data on the organ function, its age and size; the blood type and medical history of the donor; and perhaps sometimes the results of various scans for surgeons to evaluate if the organ is suitable. If there is no obvious match regarding blood type and organ size in the local region, the coordinator offers the organ to colleagues in Denmark, before it eventually becomes an organ offer to coordinator colleagues in the rest of Scandinavia, in some cases Europe. In addition to this, coordinators also communicate with the ICU to plan the time of organ removal and make sure they keep the donor stable: brain dead, but with functioning organs. Sometimes coordinators handle the entire donation process, at other times they handle an organ offer from a colleague. One day, during my fieldwork with the coordinator Birgitte, both things happened simultaneously:

I am sitting with the coordinator Birgitte in her narrow and crowded office with three desks and five big computer screens. There are folders on the shelves and papers in piles, and a couple of phones are on the table in front of her. Birgitte is looking in the online file of a potential donor at her hospital where the kidneys might be transplanted to patients on the local waiting list, when the phone suddenly rings: It is the coordinator Susan from the Copenhagen office. They have a donor, a young man with a body mass index of only 13. He has been without oxygen for 20 minutes and has muscular dystrophy. They want to know if Birgitte is interested in the heart. "We have a tiny little lady on the list," Birgitte says. "Okay, let me get back to you." She immediately calls Jakob, the cardiologist at her hospital. "Hi Jakob, how are you? I might have a heart for you. Muscular dystrophy... No, I do not know what kind. He is 172 cm tall, only 41 kilos, BMI 13, blood type A-positive. Okay... yes he sleeps with oxygen usually. Okay, okay ...thanks, I will get back to you." Birgitte calls Susan back, "Hi Susan, yes we're interested but we need to see an electrocardiogram, and we need an echocardiography, and we need to know what kind of muscular dystrophy it is. Our little lady is blood type AB, this might work." After this, Birgitte opens the database and enters the donor information into the section for the potential

heart donor, labeling this as an organ offer. Birgitte also calls Carsten, the anesthesiologist in the operating theater, to plan the organ removal for the kidney donor. Birgitte wants the surgery to happen at 4.00 p.m., but they are not ready until 7.00 p.m. Susan from Copenhagen calls back and explains the kind of muscular dystrophy and adds that the young man also has a history of eye problems and has been followed by cardiologists. Susan says: “If your cardiologist is still interested, we will do the echo and the EKG. They did the first brain death exam an hour ago, but they need to do an angiography as well.” Birgitte calls Jakob back and passes on the information. “Don’t you think this will work? Our little woman receiving the heart is only 150 cm tall.” Smiling at a joking comment Jakob poses about the recipient’s height, Birgitte hangs up and immediately calls the neuro-intensive unit and asks Michael, the neuro-anesthesiologist, if they are okay with the kidney donor patient being picked up at 6.00 p.m. to go to the operating room. The cardiologist Jakob calls back. “We’re interested, but why are Copenhagen not interested?” Birgitte promises to find out, and calls the operating theater to prepare them for the exact time of the organ removal of the kidney donor in the evening, making sure that they have a team ready. After that she calls the nurse Rikke at the neuro-intensive unit, to let her know that they should make sure that the donor family have said their goodbyes before the kidney donor is picked up at 6.00 p.m. Rikke asks if it’s okay the donor still gets noradrenalin and Birgitte says “It’s fine.” Birgitte then calls Susan from Copenhagen back and lets her know that they want the heart. “But I’d like you to dig a little bit into why he was being followed by cardiologists, and we would definitely like a new echo, because we believe our little woman can use the heart.” (From Author’s field notes)

As this case from my fieldwork shows, Danish transplant coordinators handle, exchange and request all kinds of data and medical information among a wide range of medical colleagues. Despite their online systems, the telephone is their most important tool. Some data is in systems, but urgent medical data need to be negotiated and exchanged verbally before decisions can be made, and organ exchanges can be executed. In order to do their job, coordinators are simultaneously in need of data, and the producers of data. In this case, the cardiologist Jakob relies on Birgitte to provide information for him, and they need to have a good and trustworthy relationship. This time, Birgitte has a donor heart for him; at another point in time, she might need Jakob to do her a favor, or work for her, in order to make a transplant happen. Birgitte’s smiling and Jakob’s joking indicate that they are on good terms. The Copenhagen coordinator Susan is willing to provide extra information about the medical history of the heart donor very quickly, and the ICU nurse Rikke trusts Birgitte to discuss the medicine. Since many of these hectic exchanges of medical data happen verbally in person over the telephone, successful data practices rely on the abilities of the coordinator to establish and maintain good relations with all involved. In the hectic processes of organ exchange, data infrastructures depend on both smooth digitalization and the power of diplomacy, meaning the professionalized social skills of the coordinators (Marsden et al. 2016).

Coordinators not only handle data under pressure, they also put pressure on the many people with whom they collaborate. Jakob, the doctor who is receiving the heart, has to decide very quickly in dialogue with his superiors. He also has to put in the extra hours associated with a heart transplant. Susan from Copenhagen must deliver the extra scans needed. Rikke at the ICU is being asked to time the sensitive moment where the family of the kidney donor can say goodbye. Moreover, Carsten in the operating theater has to find time, space and staff for a sudden organ removal. When there is a donor, there is extra work, and extra need for goodwill among the staff. The coordinator Lisbeth explains:

In our job we really have to be diplomats. We demand a lot from others, and we have to make it happen. Moreover, we believe we do a damn fine job, but we also know we're a pain in the ass because we put people under pressure, so our collaborators are not patting us on the back because we had an organ donor. However, if all goes well, they think we're nice to work with. So we can always move forward and return another time. That's what this is about.

As Lisbeth states: "We are a pain in the ass because we put people under pressure." To create and uphold good relations in the medical networks so coordinators can "return another time" is a fundamental and under-recognized aspect of transplant data practices. Birgitte could not have coordinated the case of the kidney and the heart donor, had she not done 'diplomatic' work in the past with Carsten, Michael, Susan, Rikke and Jakob, ensuring she could return with new demanding cases. The power of diplomacy in sudden organ exchanges therefore rests on long-term social investments in the people involved within this professional world. Unlike other structured and automatised data flows and systems in healthcare, the suddenness and cross-disciplinary features of organ exchanges mean that sustainable social relations matter significantly—especially in cases where unexpected incidences or mistakes occur that risk spoiling the meticulous planning.

During her interview with me, the coordinator Simone remembered a case where she was handling several donors at one time and also had to support some rather inexperienced ICU nurses in how to take medical care of the donor in order to keep the organs viable and suitable for transplantation. When everything was seemingly falling into place, something happened:

In one donation case at Fairview Hospital, I planned that we were going to get lungs, liver, and kidneys. I had announced it as I should [to the surgical teams] and I'd agreed with the thoracic surgeon taking out the lungs that I should call and wake him up 30 minutes before he had to be at the Central Hospital. However, in this telephone storm, time ran on, and I had called all the others telling them to be at the Central Hospital at 1.00 a.m. Suddenly, there is only five minutes until the ambulance takes the medical team to Fairview and I remember: Damn, I have not called the thoracic surgeon. I called him and said "Richard I forgot to call you. I am sorry, my phone's been ringing nonstop, and I also have a donor in Middletown" I was devastated and he was so kind and said, "Simone, I spoke to you a billion times already. You had so many calls. I understand that you've been under pressure." He ended up driving to

Fairview in his own car. Then, I called the team and told them: “Just go with-out Richard, he will meet you out there” and I was like “pphheewwww”. The last thing he said was “You owe me chocolate frogs [special Danish chocolate delicacy].” So, then a couple of days after, I brought chocolate frogs and sent them to him by internal mail with a note saying, “Thank you for understanding. From a busy coordinator.” I was under so much pressure. So much!

When listening to this example during my interview with Simone, I realized that on top of the many defined tasks of a coordinator was the task of serving as alarm clock for surgeons. The numerous telephone calls coordinators have to make in order to exchange information on a donation procedure is different work from handling large data sets. Nonetheless, this example serves to tell us about the local setting (Louikissas 2019) in which transplant data are being produced and exchanged. Why is it Simone, and not Richard himself who is responsible for him being awake and ready for organ removal surgery? Why does Simone feel guilty, and why is it her sending the chocolate frogs? Even if Richard is kind and understanding and handles the situation with humor, the example tells us that during an organ donation case in the middle of the night, coordinators run into a wide range of undefined tasks that are not a part of their formal work description. They have to coordinate much more than data and organs, they have to coordinate people. In order to do that, good relations must be established and maintained. As we see, Simone feels guilty about not waking Richard in due time, and she has to ensure she finishes this particular donation on good terms, because, being a transplant coordinator entails feeling confident she can call on surgeons in the middle of the night in the future. The chocolate frogs and the thank you note are expressions of the diplomacy needed to perform acute organ donation cases in the future. Coordinating organs and exchanging medical data is about maintaining good relations with the colleagues needed to remove and transplant them in a medical hierarchy dominated by both profession and gender.

Thank you: the diplomacy of respecting donors, donor staff, and donor data

Once again, I thank all involved in this donation case for great co-operation. Not least, a very special thank you to the family for consenting to organ donation during a very difficult time. Four grateful recipients have been transplanted and all four are doing great today thanks to donor and donor’s family. (Final part of letter to ICU from transplant coordinator)

In Denmark, the clinical infrastructures of organ donation are organized around anonymity: the donor side and recipient side are carefully separated. This means that transplant coordinators know all the medical details of the donors but, unlike coordinators in Spain for instance (Bea 2020), they rarely meet them or their families, and primarily communicate with ICU staff over the phone. In order to be prepared for the speed and the intensity of an organ exchange, the ICUs alert coordinators about a potential organ donor while the patient is still a patient, not yet officially declared

dead. My previous studies among donor families at the ICUs have illuminated that ICU staff do not always like what happens to ‘their’ patient when surgeons remove organs. One ICU nurse even stated that she preferred to get the donor patient *back* at their ICU after “the vultures have taken what they want” (Jensen 2011a, p. 182). Understanding these tensions beneath the surface of organ exchanges is crucial so as to appreciate the kind of diplomacy coordinators perform in order to keep good relations with ICUs, and to secure the ethical and social robustness of the network. If ICU staff do not trust the coordinators, they might be reluctant to reach out next time there is a dying patient who might potentially be a donor, and future organ exchanges might be jeopardized. In order not to be perceived as ‘vultures,’ coordinators, who first and foremost have an interest in handling the exchange of viable organs in order to save lives, must show as much respect as possible for not only the donor and the family, but also for the staff caring for the donor.

When talking a walk with the coordinator Simone on one of her days off, she told me that they had hired Mona, a new transplant coordinator and that she immediately called the large neuro-intensive care unit asking them if they had time for a brief informal visit to meet Mona. “It’s important they know who they’re dealing with,” Simone said. This visit was a kind gesture to let the ICU staff know about the new coordinator. However, it was also a diplomatic investment for Mona. In future donation cases, she will communicate by telephone for information from intensive care nurses, and give them extra tasks to perform in order to secure viable organs. During the walk, Simone also told me about another visit to the same ICU, when she went there to speak to some nurses in relation to her studies. Suddenly, without Simone noticing it, they were in the quiet ward of a young teenage girl who had had her organs removed the night before when Simone was on call as coordinator. Simone explained: “It was death right there. We’re mostly involved with making organs live on. It made quite an impression on me. I never saw that before. I had the image of the girl in my mind the next many times there was an organ donor.” Even if coordinators like Simone are always careful to plan organ removal with the needs of donor families in mind, and always express their respect for donors, their main task centers on obtaining organs and the necessary data for doing so: weight, height, blood type, lung function, blood levels. Donor patients like this girl are usually represented mostly by their medical data in order to find suitable recipients. Silently and ‘coincidentally’ ensuring that Simone saw the dead girl was a tangible way for the ICU nurses to communicate that organ donors are more than numbers and data. They are individuals who die; patients lost in intensive care—despite the huge efforts and dedicated care of the ICU staff. The diplomacy needed to ensure good and respectful collaboration with the ICU involves ‘peeking into’ each other’s worlds, cultivating mutual respect and recognition, and ensuring that there is a ‘personal’ component in the medical facts characterizing donor data exchanges.

Lisbeth, Simone’s colleague in another part of Denmark, also spoke about the importance of connecting to the ICU, not only to enable seamless collaboration, but also for the donation case in general:

We try, as much as we can, to be physically present with the people with whom we collaborate closely. That means that when we have a donor locally

at our hospital, I'm there. I go to the ICU and look the nurses in the eyes. I never speak to families, not at all. Nevertheless, it's important that staff feel that we're not only those demanding people on the phone. Because that's all we do: ask them to do extra work, extra work, and extra work. I believe it matters tremendously that people stay focused and feel that donation is something they want to work with and do all this extra work for. That's hard to achieve if you're too far away.

Here, Lisbeth not only performs the diplomacy necessary for coordinating organ donation, she also somehow represents the concept of donation. In order for coordinators to obtain the necessary data from ICUs, they have to ensure that ICU staff feel comfortable with calling them in the first place, and with collaborating. Making yourself visible to the ICU staff instead of being just 'those demanding people on the phone' is a diplomatic gesture that is fundamental for the exchange of donor data and, consequently, for the exchange of organs. As such, the diplomacy of respectful donor data handling is about seeing the donor firstly as a patient, and secondly as a donor. Coordinators thereby demonstrate the necessary respect and emotional empathy that can build and maintain the social relations that, in turn, enable the mutual trust and recognition needed for future organ and data exchanges. Digital tools, guidelines and standard protocols are necessary, but in this specific data setting (Loukissas 2019), it is such delicate and respectful diplomacy that make organ transplantation happen.

Another crucial part of acting with respect towards the donors is reporting back to the ICU. Five weeks after the donation case, coordinators report to ICUs in a letter with information on how the organ donation ended up, and how many patients were transplanted. By quoting the medical information—that is, the 'data'—from the current health status of the transplant patients receiving the organs in these letters to ICUs, transplant coordinators become mediators of gratitude to the donors, their families and to the intensive care staff collaborating. In these letters, which I position as part of donation data exchanges, coordinators have to be extraordinary diplomatic. Not all transplantations have a happy outcome. Sometimes organs cannot be used, they are not as functional as hoped, or recipients have a difficult post-surgical recovery, or are hit suddenly by infections. This is hard to communicate to ICUs, because staff fight so hard to care for potential donors, and many donor families find great meaning and hope in the fact that organs can benefit others (Jensen 2016). When writing the letters, if explaining why not all organs are used, coordinators deliberately attempt to underline the positive aspects and the difference the donation decision makes in the life of the recipient(s). Here is how a coordinator chose to formulate a letter where many of the donated organs were not used:

On behalf of the transplant coordinators, I once again thank you for good collaboration, this time regarding the donation on (date) where donor was a (age)-year-old woman with intracerebral hemorrhage.

The heart was offered throughout Scandinavia, but unfortunately there was no suitable recipient and it was therefore not used. The lungs were explanted and put on the lung washing machine in order to optimize them. But regrettably, they never obtained optimal oxygenation and could therefore not be used for

transplantation. The liver was evaluated in a biopsy where they unfortunately found some adenomas, which meant that this too was not suitable for transplantation.

However, the left kidney was transplanted to a very small boy with an innate kidney disease meaning he has been in dialysis his entire life. The transplant surgery was rather complicated and kidney function has been lagging behind. However, in spite of this, we are happy to say that the kidney has completely recovered, and the boy is now off dialysis and at home with the rest of his family. So once again, thank you for the co-operation. In addition, special thanks to the donor family from a very grateful recipient and his family.

Previous studies have dealt with the relational nature of data and described how data practices align with care practices (de la Bellacasa 2011; Prainsack 2019; Pinel et al. 2020). Choosing the right words and making sure to inform and share data in a respectful and acknowledging way is how coordinators care for ICU staff. They know ICU staff appreciate gratitude and acknowledgement no matter the donation outcome, and therefore the letters are of great significance. Also, keeping in mind that coordinators never meet donors and their families, the letters constitute a way of caring for the donors and their families. Nevertheless, while being mediators of gratitude, coordinators simultaneously make use of the letters to enable the trust and the good relationships needed in future organ exchanges where they once again will depend on ICU staff and their willingness to collaborate.

In accordance with the recent data enthusiasm in modern healthcare, the work of coordinating organ transplantation is enabled by data exchange on online platforms. But despite this, I observed how the donor form, containing all the relevant information on the organ donor and the whereabouts of the donated organs, was being copied or transferred from the computer screens and collected onto a standard form on paper. After the organs were transplanted, this donor form was carefully stored in an old-fashioned gray filing cabinet. Considering the pervasive overall fascination with data sourcing and digital solutions throughout Danish healthcare, the current use of a huge ancient filing cabinet sparked my curiosity. Why were databases not enough? One day I followed the transplant coordinator Gitte, and we spend the first half hour of her shift running around several wards and offices searching for the right plastic folder to use for storing the donor papers in the filing cabinet. We were not searching for ‘a’ plastic folder; we were searching for ‘the right kind’ of plastic folder. “Why do we not have more of these?” Gitte yelled to her colleague, “We have to remember to order more of these!” Finally, Gitte found one; she took the paper with the donor form and carefully put it in the new folder. Then, she took a sticker with the donor number on it, stapled it with two clips to the folder and put it in the filing cabinet, where it was evident to me that all other folders were stored the same way, with the same care and attention to detail. “It has to be like this,” Gitte laughed. “I don’t know why, I always do this, and the number *has* to be in exactly the same place on all folders. It has to be perfect.” For the coordinators, donor data somehow become a substitute for the deceased donors they themselves cannot care for in the clinic. However, they can express and perform care and respect towards donor patients by ensuring all donor information is stored perfectly in a brand-new folder in the old

filing cabinet. Looking at the material setting of the data (Loukissas 2019), the letters and the filing cabinets, coordinator data practices can be understood as a matter of caring (Pinel et al. 2020). By making sure the donor files are handled with utmost respect, and data on the transplantation are communicated to the donor hospitals in the kindest and most caring matter, these data practices represent the kind of care necessary for maintaining good and respectful relations to donor units.

“Nobody notices”: the diplomacy of invisible data and donation facilitators

Star argued that infrastructures normally have an invisible quality and they only become visible when they break down (Star 1999; Wadmann and Hoeyer 2018). This is also true for the data infrastructures in organ transplantation. Following Møller et al. (2020) claiming that those who do the data work are often unrecognized, I devote this last section of the article to focus on the organizational invisibility of transplant coordinators despite their continuous and irreplaceable contributions before, during and after donation cases.

Sometimes, as we have seen, there are several donors or organ exchanges at once. The giant puzzle of making organ transplantation happen depends not only on the exchange of correct data and information among all actors involved, it also depends on the coordinators' abilities to improvise, as unforeseen events might occur. Kirsten, who has worked as transplant coordinator for 25 years, explains:

Anything might happen during donor surgery and organ procurement, something might extend the process. It might also be that you find something during surgery you have to explore further. There's also great variation in how fast different surgeons work; I need to include all that in my planning. Then something so simple as weather conditions, road conditions, what time of the day, the risk of traffic jams. All these things can mess up my planning, and somehow, it's not my fault, I'm innocent, but everything falls back on me.

In order for organs to be transplanted, many details have to align. If these details, and the associated transfers of information and data, go wrong along the way, coordinators are no longer 'invisible.' Rather, they are the ones to blame. As Kirsten states, it “falls back” on her. On the office door of each Danish transplant coordinator that I met, there was a sign with the text “Nobody notices what I do until I stop doing it” pointing to the amount of work necessary in making organ donation happen, as well as to an invisibility of the function at organizational level. If coordinators do a good job, nobody sees it; only if there is trouble, as Kirsten says, does the criticism fall back on them. The coordinator Astrid elaborated on this.

Look at this sign on the door. This is exactly what it's about. This is how our life is here. We are not here, we are just supposed to be here...(…) When you're at these organ donation meetings and they talk about donation and how fantastic it is, I'm like, “Can nobody see who it is that makes this happen?”

Like Astrid, other Danish transplant coordinators would often say their efforts were easily overlooked, ignored or forgotten by other transplant professionals and policy makers. It is ironic that although they are handling life-and-death matters and medical data of great importance, yet their own professional and organizational importance seem invisible and insignificant.

However, at certain points, specialized coordinator knowledge is needed, and it is often needed right away. Transplant coordinators are also data providers, when surgeons suddenly check in wanting to know about the status of a recipient or to ask the coordinator to recollect a specific medical detail from a transplant case. As Kirsten jokingly said, “They always come running wanting to know something very specific, sooner, rather than later.” To meet these requests quickly, coordinators use alternative data practices, such as keeping a special little paper notebook for the kinds of information they know surgeons need. In the book, they would note down facts related to specific cases, patients, incidents and treatments. If the coordinators were the additional external memory bank of surgeons, the little book was the additional memory of the coordinators. Because such ‘data exchanges’ are not part of official protocol, nobody officially acknowledges their efforts to provide such sudden and delicate data. However, these exchanges served as yet another way of easing the relationships between coordinators and surgeons: enabling coordinators to have better relationships and thereby better access to surgeons when they needed their professional skills suddenly at 3.00 a.m. in a hospital in another part of the country. Such reciprocal exchanges of data are needed in order for the vital data exchanges of sudden donation cases to succeed.

Another feature of these diplomatic exchanges between surgeons and coordinators is the enabling of scientific research based on data from the databases managed by transplant coordinators. These databases were established in order for surgeons and medical professionals to be able to publish scientific articles. One of the coordinators, Simone, was particularly involved in the data collection facilitating this scientific work. When asking if she had been part of any publications based on the data material she had collected through the databases, she replied:

Well, you know. I’m a nurse so that’s not my strength. I’m good at making things happen but not quite as good at getting my name on things. I’ve gathered a lot of data, and built a lot of databases so they could have the data. But I haven’t written the articles. I’ve read them and given feedback. But... No authorships yet. In the beginning it was fine. I just thought the work was funny. I didn’t see the recognition I would have gotten with a co-authorship. Later, I realized they could not have done it without me.

Simone clearly provides the data, but when it is time for publication, nobody notices her—even if the study could not have been done without her. Incidences like this during fieldwork made me think that there are no limits to what coordinators will provide and endure, and how hard they will work to ensure good relations when exchanging organs and data, even if it means they remain invisible, unrecognized data workers (Møller et al. 2020).

Adding to this, it is a fundamental characteristic of coordinators to make sure that all personnel in an organ exchange are comfortable with the circumstances of

the donation case. When an operating team arrives at the hospital where coordinators are located, they often greet them in person. “We welcome them in order to make sure things happen in a good way,” the coordinator Lisbeth explained, illustrating an additional aspect of the coordinator’s working life, that was crucial for ensuring good relations, yet structurally unrecognized. This responsibility of making sure the organ removal runs smoothly also relates to the local surgical teams. According to protocol, the organ form containing all data about the surgery and the condition of the organs has to follow the donor patient all the way into the operating theater. After organ removal, this paper is physically sent by internal mail to the coordinators but sometimes, as Lisbeth told me, coordinators deliberately choose to go to the surgical ward and pick it up themselves. She explains:

Sometimes after we’ve had a donation case, I walk by the surgical department. They do have some papers we need, and it’s such a good way to see them. You cannot enter without someone having something they want to talk about. Something always comes up when I arrive which you have not gotten to write on an email or take to the management. Visiting them, helps pour oil on troubled waters. “I was wondering Lisbeth, why did you do it like that?” It is because we can talk and explain our considerations. Occasionally, you put out fires by being there.

Given the contemporary need in Danish healthcare to streamline and digitalize all data (Wadmann and Hoeyer 2018), this seems rather irrational and time consuming, but the physical presence of the coordinator is yet another diplomatic performance in order to ensure good collaboration and avoid future conflicts that might jeopardize the cross-disciplinary network needed to execute organ exchanges. Lisbeth’s strategy of showing up speaks to the focus of this article: namely, that datafication in itself is not enough to ensure smooth organ exchanges. If the many people involved with organ surgery do not actually meet, in person, the ‘Lisbeth’ or ‘Simone,’ they can easily build up resistance to the coordinator function—and to their demands that the transplantation be performed at 4.00 a.m. instead of 8.00 a.m. in order to ensure viable organs and the increased likelihood of a successful transplant.

But the diplomatic efforts do not end with the operating teams. Sometimes, in the months and years after the donation, donor families call transplant coordinators to find out about the status of the recipients who received the organ from their family member. The coordinator Jytte explains:

Many families call wanting to know how it’s turned out. You have to be relaxed and let them do the talking. Just listen to what they have to say. Then you can briefly offer them an update on the status of the recipients. If they are in Denmark, I can figure it out and call them back. It’s clearly an extra service, and it’s a time-consuming service.

Listening to the stories of donor families and offering them information on the status of recipients is not a formalized part of the data practices in organ

transplantation. Nobody notices—except for the grateful families. But insisting on listening, and providing this “extra service” is another way for coordinators to practice the diplomacy needed for the sustainability and legitimacy of organ donation. By providing the data needed by both surgeons and grieving families, and the service of welcoming surgical teams and following up on the operating staff, coordinators move way beyond their official tasks of managing organ donation cases. Nonetheless, it is this invisible and unrecognized work that enables organ donation to take place in a timely and decent manner every day.

Conclusion: attention to the power of diplomacy in data practices

In order to comprehend the data practices of organ transplantation, it is fundamental to realize that the definitions of ‘data’ go way beyond digitalized medical information and numbers and the local settings in which data are exchanged (Loukissas 2019). My study has shown how data comprise phone-calls, letters, collegial conversations, notebooks and carefully curated donor forms, all of which include and rely on actors across many settings. In line with the arguments recently put forward by Rachel Douglas Jones and colleagues (Douglas-Jones et al. 2021), we must “attend to data’s multiplicity and particularity.” In addition, I have argued for increased attention to the diplomacy needed to establish and maintain data practices. Based on empirical insights from the working lives of Danish transplant coordinators, I have shown how data depend on these coordinators’ relational ability to work together with a wide range of different health professionals under ethically challenging and hectic circumstances. Framing this as diplomacy, I point attention not only to how data are exchanged in the moment when transplantation takes place, but also to the work that has to be done before and after data exchanges in order to enable these critical moments. Data cannot be produced, used and exchanged without the meticulous work and the diplomatic capabilities of the people involved—especially in the case of organ transplantation, where data themselves are not the goals, but, rather, data are essential tools in a long complex process of detecting, preserving and removing organs from one body to another. Transplant coordinators maintain and preserve the social network of medical actors who are fundamental for making organ transplantation happen. Data exchanges must be carefully prepared and followed up upon in order to ensure the ethical and relational sustainability of future data exchanges. As such, this article points attention not only to the data flows, the data workers, or the data settings, but to the importance of keeping the social infrastructures of data exchanges ready and well-functioning and willingly collaborative: through what I frame as ‘diplomacy.’ In an area like organ transplantation, this entails making sure that ICU staff continue to find the practices of donation legitimate and decent, and that they trust the people calling them in the middle of the night asking them to run another test, provide a new scan, or adjust their timing of donor family goodbyes. It also entails making sure operating theater staff and surgeons receive the attention and care that make them willing to step up and appear in an operating room when they thought their shift had ended. Moreover, it entails delivering the many invisible services of providing data for research and reports,

and uphold the practical and ethical sustainability of organ exchanges. As such, all these examples from the working lives of transplant coordinators serve to suggest that future studies of datafication in healthcare must pay attention to the power of diplomacy: the ability to avoid conflict and maintain good social relations between the people involved in the data work. Through the lens of diplomacy we are able to observe and unpack new dimensions to studies of data practices. Diplomacy enables us to recognize and understand the often invisible relational efforts and aspects of datafication, and the tremendous amount of work and multiple social skills that go into producing and exchanging data in contemporary healthcare.

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Declarations

Conflict of interest The corresponding author states that there is no conflicts of interest.

Ethical approval The study is conducted in Denmark, where qualitative studies by Danish law are not subject to formal ethical approval.

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