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# No Heroics, Please

Mapping Deceased Donation  
Practices in a Catalan Hospital

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PhD in Science Technology and Innovation Studies  
The University of Edinburgh  
2016



# Declaration

I declare that the thesis has been composed by myself and that the work presented is my own, except where explicitly indicated otherwise in the text.

*(Sara Bea)*



# Abstract

This thesis presents an in-depth ethnographic mapping of deceased donation in a Catalan hospital. A unique site in terms of leading edge technoscientific practices, high rates of donation and its consolidated specialised team of transplant coordinators (TCs). The thesis situates donation as an embedded medical practice and traces the practicalities and specificities of making donation a possibility at the hospital. The empirical accounts offer a distinctive contribution that complements and challenges existing social sciences literature about donation. The latter have predominantly focused on donation as a controversial practice through highlighting the emotional experiences of donors' families and individual medical practitioners involved. This empirical investigation mobilises, and further develops, STS material semiotics tools to provide an account of donation enacted as both procurement and healthcare. Ethnographic insights illustrate the shifting processes of mutual inclusion and exclusion that underpin the trajectory of integrating donation as a routinized hospital practice, along the recurring set of enduring tensions. This is achieved by following the work of TCs along the stages of donor detection, evaluation, maintenance, consent request and organ extraction. Crucially, the analytical focus decenters the individual actors' perspectives, broadening the scope of the inquiry and making visible the complex sociomaterial arrangements that take place, inside and outside the hospital, which are rendered as a gradual process of assembling donations. Families' consent to donation is essential but it is decentered, it is neither that which starts a donation process nor the only factor that contributes to the assembling of a donation process. Unlike available anthropological and sociological studies of donation this work is not about documenting the reductionist transition from patient to donor, whole to parts, person to thing and denouncing the fall from subject to object reified in donation practices. The emphasis here is on tracing the overlap between donors as patients, thus the analysis shows the shifting enactments of the embedded donor/patient configuration, which includes the donor/body, donor/person and donor/corpse figures simultaneously along the donation process. The intervention of bodies as active entities is examined through a speculative and pragmatic elucidation on the situated and relational enactments of responsive bodies and organs. This thesis contributes to contemporary re/articulations of materiality and agency through the lens of distributed joint action and entangled actors from a nonanthropomorphic stance. The research also contributes to current policy debates in the UK, and in Scotland in particular, that propose to tackle the national problem of low donation rates with a legislative move to an opt-out system for donation. It offers robust empirical evidence to contest the dominant organ shortage problematisation that is reduced to the legal polarity of either opting in or out of donation. I suggest that questions about increasing donation rates cannot be restricted to the domain of individual choice as this excludes the situated medical practices that enable the choice of donation in the first place.



*If there is a sense of reality, there must also be a sense of possibility. To pass freely through open doors, it is necessary to respect the fact that they have solid frames*

*'The man without qualities'*

Robert Musil



# Acknowledgements

This thesis would not have been possible without the five-year funding from the ESRC. I remain greatly indebted to the TC team at the Hospital Clinic in Barcelona. They have showed an unconditional acceptance of my research project from the very beginning till the end of it. I am particularly grateful for the times we shared in the hospital whilst I was doing fieldwork. They not only attended to all my demands for information, but they also made the difficult time spent at the hospital more bearable. I hope that soon I will be able to present this work to them and have another opportunity to continue our ongoing conversations.

My academic tendency to unintelligibility and disperse interests have benefitted greatly from the work of my supervisors Gill and Steve. Their joint demands for clarity, consistency and justification have pushed this thesis to completion. And that they have conducted such challenging task in the most gracious and warm manner is something that I also thank them for.

During the PhD I have spent quite a long time away from the STIS group at the University of Edinburgh, fieldwork, maternity leave and the final year of writing in seclusion. Nevertheless, whether in presence or in absence being part of such a remarkable group of people has been a constant source of great comfort and inspiration. It has been a great journey and one that I have been lucky enough to share with my fellow PhD students with all our pains and joys. I am particularly indebted to Meritxell, to our long-standing friendship and shared commitment to think with the STS lens, and to her firm belief that whatever I ended up writing would certainly be worth reading.

Other friends have also contributed to this thesis, Josep Maria who took on the arduous task of transcribing interviews when I became just too pregnant to continue working. And more recently, Jessica, who not only proofread the thesis at the speed of light but also provided plenty of insightful and encouraging comments. Steph has, over the years and from the other side of the academic fence, also been of great help, both in celebrating the good times and being there for the not so good ones.

Sam, my partner, and Oliver, our son, my dearest life companions know more than anyone else about the work that has gone into this thesis. I am thankful to Sam who has made it easier for me to concentrate on this project, and to Oliver, who on the contrary has made it more difficult by reminding me on a daily basis that doing a PhD is only one of the things I do in life. Oliver, my only hope is to persuade you one day that I have not been writing a book about dinosaurs all along! I like to believe that one day I will be able

to produce a much more accomplished piece of work, and that it will unquestionably be dedicated to the two of you. For the time being, this thesis is, and will remain, the last product of my student life, thus I want to dedicate it to my parents, Dolors and Annibal, the ones that started it all. I am thrilled to think that even if this thesis will not travel much, besides from the examiners offices, I will soon be taking it to my parents' home. It will sit and gather dust in a bookshelf, next to my sister's thesis in biology, and my brother's thesis in chemistry. Three not so different academic works and three people who are profoundly indebted to our shared family life, to the enduring world of thought and laughter that our parents have created for us. I have learned from my dad that eccentricities can come with a great deal of common sense, and that cultivating an inventive nature and a sense of wonder for the ordinary is an ongoing life task. My mum's allergic reaction to any convention paired with a wild imagination and a sharp sense of humour has nurtured an instinct of inquiry that runs through the family and that now expands to a growing third generation. This thesis is also a product of your legacy and so it is dedicated to you, the family that I come from.

# List of Acronyms

A&E – Accident and emergency department

CPR – Cardiopulmonary resuscitation

DBD – Donors or donation after brain death diagnosis

DCD – Donors or donation after circulatory death diagnosis

ECMO – Extracorporeal membrane oxygenation machine

EMS – Emergency medical services

ER – Emergency room

HCP – Healthcare professionals

ICU – Intensive care unit

OCATT – Catalan transplant organisation

ONT – Spanish transplant organisation

OPO – US organ procurement organisation

OR – Operating room

PMP – national donation rate measured in donors per million population

TC – Transplant coordinator



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# Chapter 1 – Introduction

## 1.1 –A Thesis about Mapping Deceased Donation Practices



Figure 1<sup>1</sup>

In 1983 Tapies, a Catalan artist and a leading exponent of European abstract art, was commissioned to design a poster for an international conference on kidney transplantation that was to be hosted in Barcelona. The image he produced (figure 1) depicted a circulation of kidneys across a kidney-shaped pattern. This thesis is also about this circulation of organs across bodies. It interrogates the conditions of possibility for such circulation of body parts that goes from the dead to the living. It presents an in-depth mapping of the medical practices that make donation a possibility, an option that some families of deceased eligible donors will be given, but nevertheless, an option that first needs to be enabled. This thesis is not about from whom the organs come, or to whom they are transferred. Neither is this work about the feelings and symbolic meanings that donors' families and recipients might attribute to the act of donation or the organs, nor about the reasons that might underpin the choice of consenting or refusing at the hospital. This research departs from the premise that for donation to be a choice it first needs to be made possible. Thus, the question addressed is: *how is donation being done as a situated medical practice?* This thesis tells about the complex sociomaterial arrangements that bring together multiple medical professionals, things and politics in the making of the choice of

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<sup>1</sup> Tapies' Poster for Kidney Transplant Conference at Barcelona 1983 in Valls E. (2009)

donation. It shows the unfolding of such collective practices through a mapping of the process of assembling donations at the Hospital Clinic of Barcelona.

## **1.2 – The Organ Shortage Problem: Clinical Practice and Policy Debates in the UK and Spain**

The main challenge of transplantation is said to be that the quantity of available donated organs is never sufficient to cover the number of patients waiting for a transplant. The deficit has never been resolved and nowadays it is commonly referred to as the organ shortage crisis in medicine (Quigley et al. 2008). This research project emerges from a specific articulation of the problem of organ shortage and the proposed ways to tackle it that encompass the situations in the UK and Spain.

The starting point for the research was the UK's low rates of deceased donation. Even though there has been a significant increase over the past years, the national figure still remains one of the lowest in Europe<sup>2</sup>, and it is often cited that around three people die each day waiting for an organ (NHS 2016). In 2006, the Westminster government proposed to tackle the organ shortage with the implementation of presumed consent legislation for deceased donation (Department of Health/DoH 2006). The move was said to make all organs available unless an objection had been registered in life. Thus the current opt-in policy – individuals state their wish to donate in the organ donation registry- would be reversed to an opt-out system. It was described as 'soft presumed consent' because the donors' families would have the right to refuse, unlike in the hard version of the policy that is based on automatic conscription of organs. The British Medical Association (Bird and Harris 2010) publicly endorsed the move but the Organ Donation Taskforce's independent report (DoH 2008) advised against a move to an opt-out policy. The reasons there stated were that presumed consent could endanger the concept of donation as a gift and it could create an anti-donation backlash and diminish the UK public's trust in the NHS medical institution. Further to that, it was also reported that the levels of evidence of the policy's efficiency to increase donation rates remained insufficient. As well as that, the report argued that the legislative change would not give enough certainty about the individual's wish to facilitate donation, which could undermine the legitimacy of the system. Thus, the taskforce's report recommended continuing to promote organ donation

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<sup>2</sup> UK's donation rate is currently at 19.9 deceased donors pmp; per million of population (UK Transplant 2016). See Appendix I for a Map with International donation rates pmp. (donors per million of population).

within the current opt-in model of informed consent for donation. The report indicated that the key aspects to improve on were at the level of organisation and infrastructure, in particular the detection of potential donors in the hospitals. It recommended ensuring that donation was integrated as a routine part of end of life care (DoH 2008). However, presumed consent became the centre of debate once more, with the Welsh government proposal to implement the opt-out policy following the devolution of health competencies (Brennan 2015) and, as will be explained in next chapter, with the policy being currently considered in Scotland as well (Scottish Parliament 2016). The main arguments professed that the legislative shift could result in a 30% increase in donation rates (Rithalia et al. 2009), and that, since surveys confirm that 90% of the public already endorse donation – although registrations do not usually exceed 29% - it would help to make donation the norm rather than the exception, and it would further promote a favourable public attitude towards donation (English 2007). The proposal met with opposition and the counterarguments labelled the policy as authoritarian and manipulative, arguing that it would represent an appropriation of bodies by the state rather than donation being a matter of individual choice, and that organs would thus be ‘taken’ rather than ‘given’ (House of Commons 2011).

Supporters of presumed consent, as well as detractors, have looked to Spain to evidence their claims. Spain introduced presumed consent in 1979 and nowadays holds the world’s highest rates of deceased organ donation<sup>3</sup>. Thus, some claim that the success of the so-called ‘Spanish model’ rests mainly on the enabling legislation (English 2007), whilst others argue that it is due to institutional factors and, in particular, the role of the ONT<sup>4</sup>, the nation-wide transplant coordination network that oversees the work of procurement professionals in hospitals (Wright 2007). Proponents of the latter view claim that legislation alone would not be as effective if it was not for the work of transplant coordinators (TCs), who are in-hospital medical professionals specialising in donor detection, evaluation, maintenance and approaching the potential donor’s relatives to request consent to donation – in practice consent is not presumed (Quigley et al. 2008). Thus, as Murphy et al. (2010) claimed, “what Spain has shown is that the highest levels of organ donation can be obtained while respecting the autonomy of the individual and family, and without presumed consent” (924).

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<sup>3</sup> Spain’s donation rate for 2015 is 39.7 pmp. It holds the world’s highest deceased donation rates for the past 24 years (ONT 2015).

See Appendix I for a Map with International donation rates.

<sup>4</sup> ONT: Spanish Transplant Coordination Network.

The Spanish case is also relevant since the European Union approved a directive<sup>5</sup> to boost organ availability by following the Spanish model of procurement. European states were given a two-year period to implement the required changes at the level of a national system that regulated donation and transplantation, as well as the appointment of specialised donation professionals at hospital level (Watson 2010). In addition, the World Health Organisation global consultation on organ donation and transplantation (WHO 2011) urged countries to work towards achieving national self-sufficiency in respect to available organs for transplantation. The report highlighted the relevance of the ONT, Spanish national transplant network, and the formal appointment of specialised coordinators within hospitals who could identify potential donors. The improvements were urged as ways to increase donation rates and thus combat worldwide problems of organ trafficking and transplant tourism (Delmonico et al., 2011).

Despite the growing relevance of the Spanish model and the increasing prominence of TCs, there is a significant lack of literature and research on the latter topic. In the UK, a systematic review (Rithalia et al. 2009) was conducted to analyse the impact that presumed consent could have for organ donation rates. Although it concluded that the measure had the potential to increase currently low rates, it was also noted that more information was needed to understand the work of TCs in hospitals with regards to organ procurement. More recently, a social policy evaluation study (Manzano and Pawson 2014) that compared the UK and the Spanish systems of deceased donation also indicated the need for more information on the practice of donation in hospitals. The authors claim that the variability in donation rates could be explained in terms of organisational factors, such as coordination of material and human resources, rather than by reference to individual behaviours like altruism. Thus, they contend that more studies that focus on the 'social production of donation' are needed, so that the relevant organisational factors and institutional agents involved in the system and their interconnections can be identified. In short, the study suggested that if the Spanish model is to be replicated, then its mechanisms and circumstances need to be further explored to assess if current structures and staff relationships in the UK clinical setting could absorb the proposed changes (Manzano and Pawson, 2014).

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<sup>5</sup> EU directive (2010/45/EU) set up to regulate organ donation in Europe to increase the EU average 18 pmp to approximate that of Spain 34 pmp.in 2010  
([http://ec.europa.eu/health/blood\\_tissues\\_organs/docs/directive\\_2010\\_45\\_en.pdf](http://ec.europa.eu/health/blood_tissues_organs/docs/directive_2010_45_en.pdf)).

## The Initial Pilot Study and the TC team at the Hospital Clinic

This thesis originated from an initial pilot study I conducted for an MSc in Social Research in 2010. It subsequently developed into an ESRC-funded MSc and PhD in Science and Technology Studies. The pilot study addressed the aforementioned organ shortage problem with a focused study of a TC team in a Catalan hospital. It provided situated accounts of donation practices, and delineated the figure of TCs as in-hospital procurement-specialised professionals. The Hospital Clinic in Barcelona<sup>6</sup> was chosen given that it presented the highest donation rates for Catalonia, and because the figure of TC was pioneered there in 1982; the TC role was later replicated across Spanish hospitals and integrated as a keystone of the Spanish model (Valls 2009).

The first incursion into the hospital – a three-week period of observations of the TCs' daily activities and in-depth interviews with all the members of the team – brought forward an initial mapping of donation practices. This suggested that donation is a complex multi-stage process that is made possible by the work of the TC team, a host of other healthcare professionals in the hospital, enabling legislation and supportive public health policies and hospital protocols, as well as the contribution of donors' families that consented to the donation request when approached by TCs. The main finding of the pilot was that consent is not that which starts a donation process but rather is a necessity within the trajectory of the whole process. That is, that even though the bereaved family's decision is essential to proceed to the organ extraction stage, it is nevertheless subsidiary to other initial stages of the process of donation, namely donor detection and evaluation of eligibility. Thus, the PhD research was premised on the objective to further study the practices of donation along all the hospital stages, the phase of consent being decentered, and to map the intervening factors and actors that contribute to the making of donation processes in this particular hospital.

### **1.3 – The Research Outline: A No Heroics, Please Proposal**

The design of the PhD research project responded to the pilot's primary pull of giving an account of the TCs' practices of donation in the Hospital Clinic of Barcelona, to further investigate how donation was made possible at the hospital. Crucially, the aim was to focus on collective sociomaterial practices, entangled actors and distributed action. The

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<sup>6</sup> See Appendix 3 for OCATT (Catalan Transplant Coordination Network) Statistics and the Hospital Clinic of Barcelona.

initial move to decenter consent and to map the whole process of donation – across the stages of donor detection, evaluation, maintenance, consent request and organ extraction – was expanded so as to encompass the decentering of any intervening actors, from donors and families, to TCs and other participating medical professionals. Hence, the project developed along the theme of decentering individual actors encapsulated in the thesis's general narrative of '*No heroics, please*'. The latter is divided into five interrelated propositions that define the scope and objectives of the research.

*No heroics, please I* proposes to study embedded *donation* practices. It responds to the fact that transplantation is no longer heralded as the heroic medical science of saving lives. Sixty years have passed since the first successful transplant and nowadays transplants have become routinized in most developed countries. In the Hospital Clinic of Barcelona both transplants and deceased donation have become integrated and ordinary hospital activities. This thesis tells the story about institutionalised donation practices that are thoroughly embedded, and thus enabled, by existing healthcare activities at the hospital.

*No Heroics, please II* proposes to decenter *donors* and consent. This research deals with the sociomaterial processes and decentered actors that make possible the choice of donation. This is not a work about heroic donors that save the lives of others, or about their families' emotional experiences or reasons for their choice. Donors, families and the stage of consent are decentered in these accounts of coordinated medical practices. The focus is on the activities that compound to the process of assembling donations, to map the complex and interrelated trajectory of different stages from donor detection, evaluation and maintenance to the consent request with families and the subsequent organ and tissue extraction.

*No Heroics, please III* proposes to decenter *TCs*. They might well be the key to increase organ donation rates, as the Spanish model boldly claims, nevertheless they do not work alone. This thesis shows how their procurement work is made possible by the collaboration of multiple professionals, inside and outside the hospital, and it demonstrates how such local practices are deeply entrenched within a particular regulatory landscape, which spans from specific hospital protocols to Catalan public health policies and Spanish presumed consent legislation.

*No Heroics, please IV* proposes a theoretical inquiry into participating *bodies and organs* that mobilises notions of ontology, agency and materiality which do not presuppose

autonomous actors and agency as individual property. Both subjects and objects are active, and the question pursued here is how is the action distributed and how do different decentered actors enable and constrain different affordances for the process of assembling donations.

And finally *No heroics, please V* is derived from the grounding of this research in its long-standing purpose to produce relevant knowledge that can contribute to current discussions about how to increase deceased donation rates. However, the interventionary commitment of this thesis is not about delivering the answer to *the organ shortage*, rather the analysis of hospital practices with high donation rates will be employed to interrogate whether the questions that dominate the debates in the UK are sufficiently attuned to the specificities and practicalities of donation as a situated hospital activity.

The *No heroics, please proposal* will be presented in chapter 3 and related to the thesis' theoretical approach. The first four propositions will be illustrated and expanded throughout the empirical chapters 5, 6 and 7, and lastly in chapter 8, the general discussion will bring them together to form a discussion on responsible donation practices that will in turn convey the last of the propositions.

This mapping of donation practices is firmly grounded in the STS domain, and it makes use of a material semiotics approach to the empirical study of technoscientific practices. The latter is premised on the study of heterogeneous relations that are simultaneously semiotic or discursive as well as material and that continuously generate all kinds of entities. I will be drawing on the works of Haraway (1988, 1991, 1997, 2008), Law (2002, 2004), Law and Mol (2008), Latour (1983, 1988, 2000, 2004, 2005), Mol (1999, 2002, 2008), Mol and Law (2002, 2004), Mol, Moser and Pols (2010). This thesis seeks to make visible the sociomaterial practices of assembling donations whilst decentering both subjects and objects that intervene and interrelate through the shifting stages of collective and situated accomplishments. It responds to the ontological turn in STS to study enactments in practice, to examine how various phenomena are being made in and through specific and local practices. Chapter 3 will explain the theoretical underpinnings of the thesis and it will specify how these have translated into the methodological direction of the research project. In particular about the use of ethnographic methods that were employed during the nine months fieldwork period in the Hospital Clinic of Barcelona. During that time I followed the work of the nine TCs along the different stages of the donation process, observations of their daily activities were then coupled with extended interviews with the

nine members of the team with the intention to further delve into the practicalities and contingencies of their work. In Chapter 4 the methodological discussion will highlight the demands and intricacies of a challenging ethnographic task, for donation processes are neither linear nor easily observable, rather they are different actions taking place simultaneously at various sites and involving a myriad of practitioners inside an outside the hospital. Thus, the ethnographic gaze was focused on documenting what the TCs, as the coordinating figures of such decentralised processes, are responsible for in each stage, hence, making visible the various intervening entities and professional interdependencies that enable their objective to procure organs and tissue for transplants.

This thesis offers a novel approach to the topic of deceased donation, both at the theoretical and methodological level, and consequently, the accounts produced differ substantially from existing social sciences literature on organ donation and transplantation. Chapter 2 will present an extended review of available studies on the topic, mostly from the disciplines of medical anthropology and sociology. The ethnographic work of prominent authors such as Fox and Swazey (1974, 1992), Hogle (1995, 1999), Lock (2002) and Sharp (2006) has characteristically provided interpretative accounts of the social meanings of donation, it has sought to give voice to those they saw as excluded from heroic accounts of transplants as life-saving medical feats, namely, donors and their families. In doing that, the authors have taken a critical stance towards the practices of procurement, especially in the US, where donation is mostly defined as a technocratic, utilitarian and dehumanising practice (Fox and Swazey 1992, Hogle 1995, Lock 2002, Sharp 2006). Ultimately, as I will be arguing, these medical ethnographies have focused exclusively on highlighting the controversial side of donation, to identify the characteristics that make procurement different from healthcare, and to denounce the alleged objectification of donors through commodifying medical practices. In contrast, this thesis has approached donation as a highly institutionalised practice in a hospital where it has become an integrated hospital activity. Instead of tracing the dividing line between procurement and healthcare, this empirical investigation will show that in practice donation is both procurement and healthcare; an integrated hospital activity albeit with enduring tensions. This is because donation, unlike healthcare, is not directed at treating the individual living patient, it deals with deceased patients, the potential donors from whom organs and tissue will be procured and circulated to other patients, the transplant recipients.

Another point of disconnection with extant studies of organ donation is that this research does not document the problematic transition from patient to donor, a ubiquitous theme in the reviewed literature on the topic. The latter is extensively dealt with by contemporary social studies, that like this thesis, also give an account of integrated donation practices in the hospital and that encompass European sites with public healthcare provision (Hadders and Alnaes 2013, Hoeyer and Jensen 2011, 2012, Hoeyer, Jensen et al. 2015, Jensen 2011, Paul, Avezaat et al. 2014, Cooper and Kierans 2015). The aforementioned authors have predominantly examined the individual attitudes and experiences of ICU nurses in regards to the problematic transition from caring for a living patient to maintaining an organ donor. The main difference is that this thesis has dealt with an altogether different medical professional; the TCs are full-time procurement specialists whose responsibilities do not include the care of critical patients. Moreover, this research deals with a unique site with high donation rates, thoroughly institutionalised donation, and professionalised TCs. This is in contrast to the abovementioned European-based works that focus on countries with lower donation rates (Denmark, Norway, England, the Netherlands). Ultimately, the empirical investigation decentered donors and rather than seeking to examine how patients become donors, it explored how donors remain patients, before, during and after assembling a donation process. Drawing on the STS theoretical framework to study ontologies being made in practice, the donor figure is unpacked by tracing the overlap between donors and patients, and it interrogates how, under which conditions, and to what effects are donors enacted as patients? The empirical chapters will present the multiple, shifting and simultaneous enactments of donors as patients, bodies, persons and corpses through the different stages of the donation process.

This thesis' primary pull to account for situated donation practices is also entangled with another pull that has largely intervened and shaped the type of accounts of donation presented. That is, to engage in empirically theorising the body as a participating entity in the practices that it emerges from. Chapter 3 will present the STS material semiotics tools that were put to use in order to give an account of active donors *qua* bodies. This research follows Mol (1999, 2002), Mol and Law (2004), and Law and Mol's (2008) call to study how the body is being done in particular practices. The latter advance that bodies are not extrinsic and coherent singularities but rather their wholeness is accomplished in practice, through the intervention of many people, things and politics. This empirical investigation has responded to Mol and Law's (2004) incitement to theorise the body as an effect and intervention of particular medical practices, and it has thoroughly deployed

their theoretic-methodological position to inquire into participating bodies outside the constraints of the subject/object dualism. According to Mol and Law (2004), and Mol (2002) and Latour (2000, 2004), the question of the body within the social sciences has been constrained by the polarity of either studying the body as subject and thus espousing a phenomenological approach, or the body as object from a social constructionist stance, the latter has predominantly focused on denouncing the objectifying medical practices that reduce subjects to objects. Thus, the aforementioned authors, and Mol and Law (2004) in particular, argue for extending the remit of the social sciences so that bodies can be rethought of as both enacted and acting in practice. This move entails a re-crafting of key notions of ontology, materiality and agency, and as I will be explaining in the forthcoming chapters, it is a pursuit deeply entrenched within an STS material semiotics shared quest to find ways to extricate agency from intentionality, to decenter individual actors and to broaden out the scope of the inquiry so as to encompass distributed action and entangled actors. To do that, this thesis has also mobilised Haraway's (2008) nonhumanist notion of response-ability, which encapsulates a relational and nonanthropomorphic rendering of interrelated entities that simultaneously but asymmetrically respond, and thus enable response to and from each other through multidirectional interactions. Ultimately, the combination of the tools of enactment and response-abilities in technoscientific practices has enabled this research to offer a nuanced examination of how the various situated and relational actors— from TCs, other practitioners, and families, to donors *qua* bodies, and organs - intervene and thus condition the process of assembling donations in particular ways.

This theoretical approach also represents another major divergence with existing literature on organ donation. As I will be expanding on in coming chapters, the reviewed organ donation studies have addressed the question of the body within the limitations of the hierarchical binary of acting subjects versus passive objects. The latter has been ubiquitously reified in the anthropological works of Fox and Swazey (1974, 1992) Hogle (1995, 1999), Lock (2002) and Sharp (2006). These authors share a critical stance that denounces the objectifying practices of procurement that reduce patients into donors, or in other words, that demote persons into things. In contrast, this research has sought to explore the exclusion effected in the cited works, namely the relegating of the body to brute materiality without capacity to act, and it has done so through a pragmatic inquiry into the ways in which response-able donors/bodies participate in and affect the TCs' activities of assembling donation processes.

## 1.4 - The Process of Assembling Donations in Three Chapters

Chapter 5, 6 and 7 will present the empirical accounts from the Hospital Clinic and the TCs' practices and associated responsibilities in each stage of the process of assembling donations. The ordering responds to the research's objective to map the making of the choice of donation. However, rather than a temporal reconstruction of the process of assembling donations, which in practice does not necessarily follow a determinate pattern, the empirical chapters are divided into: 1) An overview of *the process* of donation in chapter 5 about the practices of detecting and evaluating eligible donors; 2) A focused analysis about *the body* in donation practices in chapter 6 about maintaining donors and extracting organs; and 3) A scrutiny of the situated practicalities of the choice of donation that focuses on the main *actors* -TCs and bereaved families – and their distributed responsibilities in chapter 7 about the consent request.

Chapter 5 will start to give shape and depth to the *No heroics, please I* suggestion to study donation as a routinized and integrated hospital practice. It will trace how TCs carry out their responsibility to detect the totality of potential donors amongst critical or deceased patients at the hospital. The figure of the donor/patient will articulate these accounts, the overlap between donors and patients will further situate donation practices in the hospital's healthcare activities, and it will demonstrate the *No, heroics, please II* point to decenter consent, treating it as a necessary but not sufficient condition for a donation process to be assembled. Chapter 5 will also introduce the different types of donors, and hence processes, that are included in the Hospital Clinic's donation programme, that is, organ and tissue donors after brain death diagnosis (DBDs)<sup>7</sup>, donors after cardiac death diagnosis (DCDs), and tissue donors. The complex sociomaterial arrangements that enable TCs to detect these three types of donors and to evaluate their eligibility will exemplify the *No heroics, please III* proposition to decenter TCs. The latter posits that TCs do not work alone; rather their procurement responsibilities are thoroughly embedded in, and thus enabled, by existing hospital mechanisms and protocols that bring together the collaboration of various medical and non-medical professionals in the assembling of donation processes. Donation processes being assembled follow a gradual trajectory that remains at all times underdetermined, there are various factors and actors whose intervention, or lack thereof, can lead to a disassembled donation. The latter refers to the occasions in which an initiated donation process becomes halted altogether, a possibility that can take place at any given stage of the process. The ethnographic accounts from the

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<sup>7</sup> See Appendix 2 for Glossary of terms DBD and DCD.

hospital will offer multiple instantiations of disassembled processes during different stages, these will also help to define the scope and above all limitations of TCs' practices and highlight the specificities and contingencies that intervene and differently enable or preclude the progressive assembling of donation processes.

Chapter 6 will cover the stages of donor maintenance and organ extraction and it will launch an analysis based on the responsive donor/body figure. It will largely be dedicated to the *No heroics, please IV* proposition to examine the situated and relational ways in which bodies and organs are enacted and acting within the practices of donation. It will nevertheless also encompass, and add to the discussion when relevant, the figure of the donor/patient and the first three of the *No heroics, please* points about embedded donation, decentered donors, and decentered TCs respectively.

Chapter 7 will define the distribution of responsibilities during the stage of the consent request in which TCs approach families of eligible donors and give them the choice of donation. Donation is enacted in these interactions as an end of life choice, an integrated part of healthcare and also a decision for eligible donors' families to consider based on the known or presumed preferences of the deceased donor/person. Bereaved families are by then also responsible for the subsequent funeral arrangements because the donor/patient who TCs have identified, the responsive donor/body under maintenance, and the donor/person whose preference is to be ascertained, is also a donor/corpse to be buried or cremated within a short time. These are the contingencies and specificities that define how the choice of donation is enacted at the Hospital Clinic when TCs discuss the possibility with the bereaved families. Their final decision can either enable the donation process to continue to the extraction stage, or otherwise the initiated process will become disassembled.

Chapters 5, 6 and 7 mapping of the stages of assembling donation processes will lead into the concluding chapter 8, in which the arguments presented empirically through the four *No heroics, please* propositions will be brought together under the theme of discussing responsible donation practices. Chapter 8 will thus convey the meaning of the *No heroics, please V* and it will articulate the ways in which this thesis mapping of donation practices offers timely and relevant knowledge that can be called upon to intervene in the political considerations about deceased donation rates. In particular, the research contribution is directed at contesting and sharpening the prevalent questions that define the organ

shortage problem in the UK, which as I will contend, are unnecessarily restricted to the legal polarity of opt-in or opt-out policy and neglect the situated practicalities of donation.



## Chapter 2 – Literature Review

### 2.1 – Introduction

This chapter will present the selected literature on the topic of organ donation. The first section will continue to map the background problem that underpins this research project, the organ shortage problematisation and the strategies to increase deceased donation rates discussed in the UK that refer to the Spanish model. Initially, the existing literature defining the Spanish model of organ procurement and the figure of the TC will be introduced, and this will then be linked to the UK's efforts to increase national donation rates and associated deliberations on what type of lessons can, or can not, be adapted from the Spanish case. It will be explained that the latest policy proposal in Scotland, a legal move to presumed consent, has spurred heated discussions in which the Spanish example of high donation rates figures prominently. The evidence for the policy's efficacy remains contested and the example of Spain is mobilised by both supporters and detractors of the proposal. The second half of this chapter will provide a broad overview of the existing social science literature on organ donation and transplantation; this topic has received considerable attention in the areas of medical anthropology and sociology. The works reviewed in section 2.4, studies in economically developed countries from 1970s onwards, will present both the variability in scope of the literature, and issues covered, as well as their points of connection. Given that this research project is a study of hospital practices of donation, the literature chosen mostly addresses the situated dimension of such medical practice. Finally, section 2.5 will discuss the distinctive angle this thesis advances for the study of donation practices, and how this research's aims and objectives prompted the work to differ from other social studies of donation and to mobilise an altogether different theoretical approach.

### 2.2 – On the Spanish Model of Organ Procurement

The Spanish transplant coordination network's (ONT) longstanding director, Matesanz, and some of his close colleagues, Dominguez-Gil and Gomez, are the authors of most of the literature that covers donation practices in Spain. They are all health practitioners who have had clinical experience with procurement practices and in addition they also hold organisational and public policy roles. The literature produced is mainly in Spanish

but some of it has also been translated or written for international journals with the purpose of offering strategies to increase donation rates in other countries<sup>8</sup>. The ONT has been described as ‘the Spanish health system crown jewel’ and it is praised for both its ‘lifesaving’ effects, in terms of number of transplants carried out every year, and for its cost-effective rationale. Matesanz (2006) claims that it significantly reduces the financial expenses associated with the treatment of chronic conditions with the use of only 3% of the national budget.

The principles of the Spanish Model of donation are 1) A national transplant coordination network; 2) Appointed transplant coordinators at national, regional and hospital levels; 3) Audits of brain death cases for early detection of potential donors; 4) The pivotal work of the central office that coordinates all the processes of donation and transplantation; 5) Emphasis on continuous medical training, including donation eligibility criteria to identify potential donors and family approach strategies to increase consent to donation; 6) Hospital reimbursement to incentivise donation activity at the institutional level; 7) A close relationship with the mass media to promote a positive image of donation and educate the public on transplantation matters.

The role of TC is undertaken on a part-time basis by ICU intensivists and anaesthesiologists, and increasingly by nurses, who have the responsibility to develop a proactive programme of donor detection as well as overseeing all activities of donor evaluation, maintenance and approaching potential donor families and forensic authorities to request consent and finally to coordinate the process of organ extraction (Matesanz and Dominguez-Gil 2007). Much emphasis is given to the identification of potential brain dead donors in hospitals with the use of retrospective audits of all cases detected and undetected. Matesanz (1998) conducted a comparative study of international deceased donation rates and concluded that the role of TCs is essential since “the non-detected donors constitute the major cause of loss of organs” (1635). Hence, educating medical professionals on donor eligibility criteria is a paramount feature of the model. Nevertheless the aspect of TCs’ work that has deserved more national and international attention has been their role in the ‘donation interview’ or family approach to request consent to donation.

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<sup>8</sup> Matesanz and his team at the ONT have also served as advisors to several countries and have liaised with the foreign health delegates and health professionals that attend their workshops at the hospital Reina Sofia in Madrid where they teach the Spanish model of donation.

### 2.2.1 - TCs' Protocols for the Family Interview

ONT-based studies claim that the success of the Spanish model is mostly due to the professionalism of the TCs' approach towards the potential donors' relatives (Domínguez-Gil, B., et al. 2010). This approach depends largely on the context of the interview, the attitude of the TC and the reasons provided to consent to donation. About the context it is said that the TC should be present when the diagnosis of brain death is communicated to the families by the neurologist, along with the medical team that treated the patient. Once the medical team leave, the TC is responsible for all communication with the bereaved families. It is recommended that further interactions should take place in a private room, and there should be enough chairs, water and tissues (Matesanz 1996). The TC's attitude should be empathic, and express their condolences to the grieving family, as well as further clarifying about the finality of the brain death diagnosis and resolving any doubts families might have, prior to the TC initiating the donation request. A set of strategies is suggested to increase consent and to reverse refusals to donation, such as providing families with the reasons to consent to donation. The latter can be such as appealing to altruism, solidarity and even utilitarian arguments (the organs are not useful for her anymore and they could save others in need), above all the objective is to extol the positive moral values of donation (Gomez 2008).

The emotional support TCs offer to families is said to be beneficial both for the families and to increase consent rates, hence, donation interview protocols put much emphasis on guidelines to build a supportive relationship with the potential donors' relatives; such as showing a 'transparent and empathic' manner and helping them to begin the grieving process. With regards to the family's response to the donation request, a set of communicative skills is offered in order to deal with objections and attempt to reverse a refusal to donate, as well as dealing individually with any members of the group who have a negative attitude and increase group discrepancy (Gomez 2008). The ONT has worked extensively in the 'benchmarking' of donation interview protocols, which are to be used for the on-going training recommended for TCs, and are to be implemented in the hospital practices of donation after brain death (Matesanz et al. 2012). An ONT-based study analysed the decrease in refusals to donate in contrast with the unchanged attitude towards donation of the surveyed population; it concluded that the reason behind Spain's lowest rates of family refusals in the world (16.4%) was the use of donation interview protocols. Thus, the authors suggested that training health professionals to develop a strategic approach to families was more effective than the legal principle of presumed

consent or financial incentives to increase national donation rates (Domínguez-Gil et al. 2010).

A different study confirms the ONT's claim of the pivotal role of TCs and the use of family interview strategies to decrease family refusal rates (Caballero and Manzano 2012). It is a report about the TC team of a hospital in Barcelona<sup>9</sup> that developed a 'family interview guide' to request consent for donation to the relatives of potential brain dead donors. The study claims that consent rates increased to 100% since its clinical implementation. Similar to the Spanish model guidelines, it is recommended that a professional TC conducts the interview, and that the TC should be empathic and emotionally supportive towards the bereaved families. However, Caballero and Manzano's guidance differs from the Spanish model protocols as there is less emphasis on the supportive relationship that TCs build with families. Instead, the authors argue that 'bereavement counselling' should not be offered by TCs and instead families should be referred to the psychological support services in the hospital. With regards to the specific consent request, the recommendation is that it should be done in a respectful, clear and brief manner; informing families that their deceased relative 'can help others'. The authors state about the importance of such approach in that "emphasis on the social and health benefits for patients on the waiting list for organ transplantation is recommended. Death is hard, not donation. And there is no transplantation without donation" (Caballero and Manzano 2012, 165). A follow-up study (Caballero, Leal et al. 2014) assessed the positive results of the family interview guide during a two year period in the same hospital. Results indicated that refusal rates had dropped from 17.5% to 1.9%. The authors specify that 80% of the refusals were reversed with the use of the guidelines, but added that even though some strong refusals cannot be reversed it is nevertheless important to let families know "that they can choose to donate and the significance of donation for other patients" (Caballero, Leal et al. 2014, 123).

### **2.3 – Organ Donation Rates in the UK: The Current Situation and Proposed Strategies**

Murphy et al. (2010) analyse the differences between the UK and Spanish deceased donation rates and argue that British donation rates could be improved without changing the legislation to presumed consent. The key lesson from Spain is said to be the professionalization of appointed TCs inside hospitals along with the training and

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<sup>9</sup> Hospital de la Santa Creu i Sant Pau is another large hospital in Barcelona. This research studies the Hospital Clinic i Provincial of Barcelona.

implementation of family interview protocols to decrease refusal rates. However, it is noted that even if refusals were lowered from their current average of 42%, to 15% like in Spain, donation rates would still be half of the Spanish ones. Other factors involved are identified, such as the UK's lower numbers of potential donors, less traffic mortality rates and different end of life practices like withdrawal of life support, as well as low capacity of ICU beds and different admission criteria. The authors strongly argue against presumed consent and claim that its appeal resides in the fallacious rationale that if consent is problematic then the solution should be to remove the need for it. A negative consequence of such legislation would be to neglect the fact that "death is not an isolated event, but a profound family matter" (Murphy et al. 2010, 923), as it would exclude the primary role of the family's decision to consent to or refuse donation. Thus, the authors suggest that further training is needed in order to equip appointed TCs with the relevant communication skills to deal with bereaved families.

The British Medical Association's (BMA 2012) progress report<sup>10</sup> on donation policy identified aspects of the Spanish system of donation, and in particular about the family approach, that would raise ethical concerns if applied to the UK due to a different 'general culture of care'. Of particular concern was the training that TCs receive on strategies to reverse families' refusals and their active role in 'persuading' relatives to consent to donation. Similarly, an anthropologist consulted in the Nuffield Bioethics report, argued that the Spanish model is unsuitable because of a common assumption amongst UK health professionals that the Spanish approach is a relatively 'aggressive' stance towards the family, and that if protocols were to be adapted they should incorporate 'a greater allowance for resistance and refusal' (McDonald 2010).

### **2.3.1 - Current Clinical Practices of Donation**

The Department of Health (2011)<sup>11</sup> and the British Medical Association (2012), in their respective reviews of donation activity following the implementation of the Organ Donation Taskforce report (DoH 2008), announced that the practical changes have increased donation rates by 25%. The key principle to integrate donation as a usual part of end of life care is said to have been achieved throughout the NHS areas. The changes at the level of clinical practice include 1) the appointment of specialised nurses in organ

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<sup>10</sup> British Medical Association Report 2012: 'Building on progress. Where next for organ donation policy in the UK?.'

<sup>11</sup> Department of Health Report 2011: 'Working together to save lives. The Organ Donation Taskforce Implementation Programme's final report'.

donation (SNODs) in all the hospitals who are responsible for donor care, family approach and organising the donation procedure; 2) A system of ‘minimum notification criteria’ has been implemented to enable early detection of potential donors by clinical staff and subsequent alert to SNODs; 3) Monitoring of all donation activity, including potential donor audit and missed referrals; and 4) Reimbursement to hospitals has been introduced to cover donation practices costs. The areas identified that need further work on are said to be to increase referrals, these are numbers of detected potential donors, so that donation is considered whenever possible and hence that donation becomes a usual rather than an unusual event. And to decrease family refusals, the work of SNODs is reportedly associated with an increased consent rate to donation. Other recommended measures to increase the availability of organs for transplantation include donation after cardiac death programmes (DCD<sup>12</sup>), use of ‘higher risk’ donor organs with extended acceptance criteria for age and disease history, and the practice of elective ventilation that allows for the intubation of patients to become donors when consent has been granted. In the public sphere it is recommended that donation should be further promoted as ‘the gift of life’ and that more recognition should be given to donors. The latter would be addressed with national memorials and local initiatives and events that would allow donor families to gather and share their experiences, and for transplant recipients to express their gratitude to their anonymous donors.

### **2.3.2 - Current Policy Changes and Proposals: Presumed Consent**

Wales officially shifted to presumed consent legislation or ‘soft opt-out’ for donation in December 2015. Individuals can register their expressed consent or their objection to having their organs removed after death for transplantation, in case of lack of objection their consent will be ‘deemed’. The legal shift is proclaimed as a ‘revolution in donation’ that will shorten transplant waiting lists and hence reduce mortality rates amongst patients. Under the new system, two of the primary problems are reportedly addressed, firstly the persistently low rates of registrations of consent and secondly, the need to gain family’s approval even when the deceased person was on the donor registry. It is stated that many organs are lost due to the families’ right to veto the decision of previously registered donors, the Welsh opt-out system still grants families the right to object but only if evidence can be provided about the objection of the deceased person. Both Northern Ireland and Scotland are currently considering moving to an opt-out system, Wales is portrayed as taking the lead in donation and hence results of early evaluations of

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<sup>12</sup> DCD: donation after cardiac death. See Appendix 2 for Glossary.

the policy's outcome will inform proposals in the other devolved parliaments (Brennan, 2015).

In February 2016, the Scottish Government rejected the 'transplantation bill report' that advocated a move to presumed consent. However, given that the proposal fell short by only three votes<sup>13</sup>, it was decided to launch a public consultation on the matter and to reintroduce the bill in 2017. The opt-out policy proposal aimed to increase donation rates whilst respecting the choice of the individuals – it would be possible to opt in, opt out or appoint up to three proxies that could make the decision – and supporting families faced with such 'tough decisions'. It identified an authorized investigating person (AIP) with the legal responsibility to contact proxies, prior to next of kin, to ascertain if organ removal is lawful. The BMA Scotland supported the move for its potential to make donation 'the default position' which "could lead to a change in the philosophy within society where donation becomes seen as the norm" (2016, 20). Some of the objections to the policy referred to the policy's neglect of the individual's right to freely consent, and argued that this would contravene the 'European Convention on Human Rights and Biomedicine' that stipulates consent should be required prior to any medical intervention. Thus, it was argued, the policy would shift control from the individual to the state, which would be given ownership of people's organs. Objections have also been voiced about the negative impact of organs being 'taken by force or by default' rather than freely given, and the move was said to endanger donation as an altruistic gift and to threaten public trust in the medical profession. The diminished role given to families has also been contested, some of the opponents argued that proceeding with donation without authorization from the next of kin would pose serious ethical concerns as well as leading to a decline in organ safety. The AIP role and overlap of competencies with SNODs was also highlighted as problematic, it was further stated it could delay the decision-making process and thus being the cause of lost donors. The efficiency of the proposed policy as a measure to increase organ donation rates has been hotly debated; the example of Spain's high donation rates is used both by supporters as evidence of presumed consent positive results, and by detractors who argue that Spain does not follow presumed consent in practice, as there is no opt out registry in place and thus families are always asked for consent, and that instead its increased donation rates have been associated with changes within the donation and transplantation system.

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<sup>13</sup> Scottish Government Transplantation Bill Report, 59 MSPs voted against and 54 in favour.

## **2.4 – Social Studies of Organ Donation and Transplantation**

Section 2.4.1 will present the major ethnographic works on the topic of organ donation and transplantation. Some of the salient themes that are there analysed – conceptualisations of body and individuality, death and personhood, and different characterisations of donation and organs across the lay and the medical professional spheres – will also be present in section 2.4.2 that will cover smaller studies that have taken the perspective of the public in general or the views of donor families and transplant recipients in particular. Even though the literature that focuses exclusively on health practitioners is rather scarce compared to the former social studies, the topic has received a growing attention over the recent years. In section 2.4.3 I will present the works coming from the European setting, which, like this project, analyse donation practices within a public health system, in contrast to US-based work (presented in section 2.4.1 and 2.4.2) that features organ procurement organisations (OPOs) within a private healthcare system. Most of the works presented analyse the local clinical practices and trace the interrelations with the broader context. For some this is described as national or cultural, and for others, (the works included in section 2.4.5), is referred to as the organisational, political and economic context.

### **2.4.1 – Medical Ethnographies of Donation and Transplantation**

The works in this section are presented in a chronological order as they build upon each other's knowledge claims and can be located within the same discipline of medical anthropology. They are all long-term ethnographic projects (some spanning over decades), and follow a multi-sited methodology that includes not only different actors, from donors' families, recipients, medical professionals to policy-makers and legislators, but also different sites, US predominantly but also Japan, Germany and Denmark. The comparative approach is used in these studies to back up different interpretative claims about the phenomena of donation and transplantation; mostly cultural differences and predominant ideologies are identified as the underlying mechanisms for different meanings attributed to the medical practices under study. Each author, some of them with an extensive corpus of work on the topic, follows a particular line of analysis and consequently the different themes highlighted and concluding claims diverge. However, the following medical anthropology studies share a critical stance towards the practices of donation and transplantation, and thus aim to unveil the power differential between the medical and the lay spheres for the purpose of making visible the exclusions this

engenders. There are several axes of contention: the commodification of the body in medical practices broadly, the largely problematic association with brain death diagnosis, and the ambiguity of donors as 'living cadavers' within particular clinical practices. Much attention is also given to the differential meanings attributed to donation, donors and organs, these are portrayed by setting mechanistic medical conceptions of bodies against social understandings of body and death as related to notions of personhood and individuality.

The medical sociologists Fox and Swazey's ethnographic studies on donation and transplantation in the US were the first to open up the biomedical practice for social analysis (1974). They argued that Mauss' gift-exchange theory (1954, 2002) could explain the symbolic and emotional meanings that lay at the core of both the act of donating and of receiving such an 'extraordinary gift of self'. In their accounts, both donor families and transplant recipients attributed anthropomorphic qualities to the gifted organ – it carried the donor's identity – and thus novel bonds and reframed kinships were enabled through the act of transplantation. Donation for bereaved families represented a way to turn a 'senseless tragedy' into a meaningful act of extreme generosity. This symbolic power of donation was also the cause of the anxieties experienced by recipients, (what Fox and Swazey (1974) named 'the tyranny of the gift'), as they dealt with feelings of guilt and indebtedness due to the unidirectional and thus unreciprocated nature of such altruistic donation. Fox and Swazey's (1974, 1992) work denounces the underreported negative consequences of transplants and blames the professional culture of triumphalist science and medical hubris. The latter mechanism is epitomised in the transplant surgeons' 'courage to fail' attitude; their 'fervour and zealotry' to procure more organs for transplants is said to have led them to underestimate the risks that such medical acts entail for both donors and recipients. Fox (1996) claimed that such unfettered medical assumptions resulted in "the profanation of the meaning of giving, taking and receiving human organs, and of the reverent respect for the dignity of human life and death that ought to undergird these acts" (262). The work spans across a period of forty years and states that the exponential expanse of organ transplants deflects attention from its most salient controversial features. Firstly, the disputed legitimacy of brain death, to Fox and Swazey a heart-beating brain-dead donor is a 'live cadaver' suspended in a twilight zone between life and death (1974, 1992). And secondly, donation and transplantation advance a medical view of the body, as Fox put it, as "an ensemble of interchangeable spare parts" (1996, 265).

This medical view poses severe challenges to the integrity and identity of the individuated body and Western notions of personhood, self and other (Fox and Swazey 1974, 1992, Fox 1996). Both authors decided to abandon the field, Fox in particular reproached that the progressively routinized practice of transplants had 'de-gifted' donation; in that it effaced the "unparalleled nature of what is still involved when physicians remove the gift of organs entrusted to them" (Fox 1996, 260). Above all, Fox and Swazey's critique is ultimately directed at the technocratic and instrumentalist ethos of such medical practices, and they see these as going hand in hand with the commodification of the human body, that becomes reduced to a 'mere thing' or a 'useful precadaver' rather than a person (1992).

Hogle's (1995) research in the US can be aligned with Fox & Swazey's critical stance and it further contributes to it by presenting an in-depth examination of hospital practices conducted by 'organ procurement organisations' (OPOs), that operate in the US private healthcare system. The author situates the clinical practices within a broader framework of 'late capitalist society'; her work shows the links between the commodification of life in the practice and the dominant transplant industry financial interests and pursuits. The main argument proposes that different 'technoscientific phenomena', such as the use of life-supporting ventilators, enable the newly defined medico-legal concept of brain death, which in turn functions as a cultural mechanism to make possible the ambiguous entity of the 'living cadaver'. The latter represents a blurring of boundaries "between life and death, human and technology, natural and artificial" (1995, 206) that Hogle aims to capture with the hybrid figure of the donor-cyborg. The ethnographic accounts of the procurement process focus on the transition from patient to donor, Hogle claims that health professionals' actions, protocols and technologies are geared towards reducing the ambiguity of the donor-cyborg, and for that "it is necessary to deconstruct the subject (the person), and reconstruct an object (the production unit)" (1995, 206). These processes of donor objectification are said to strip the patients' human identity and personhood away and turn their bodies into 'incubators of organs', a valuable source of usable materials. The reductionist transition remains nevertheless problematic as the brain-dead donor-cyborgs still retain 'a residual essence of their humanity', in that as Hogle writes "the organic material in the rest of the body retains its ability to function; to "live", body parts can die at different rates" (1995, 210). The preservation and enhancement of donors' organs that takes place inside and outside the body, through several technical and chemical means, is described by the author as the transformation of organic 'body parts' into therapeutic tools.

These become mechanised as universal parts so as to enable their redistribution to other multiple 'end-users'. The growing entwinement between organism and technology, Hogle explains, inevitably steers the dehumanisation of the donor-cyborg as a docile body, while at the same time, donor families and recipients take part in the construction of a narrative about the donor's personal transcendence through the act of organ transplantation (Hogle 1995). The author contrasts the relatively unproblematic procurement practices in the US, as a testament to its highly technocratic society, to those encountered in Germany, where brain death legitimacy and the use of body parts is widely contested and bears the stigma of the abuses of Nazism. Thus, German organ procurement practices strive for minimal invasion of the dead body and organs are perceived as natural products in accordance with cultural ideas of the body's integrity and inviolability. The work also compares the way in which organ donation is conceptualised differently in East Germany, linked to notions of solidarity, and in West Germany where it is said to rest on the Christian notion of charity (Hogle 1999).

Lock's anthropological work also develops a comparative approach; the analysis is based on the contrast between the silent institutionalisation of brain death in the US and the controversy that surrounds it in Japan where it is still heavily contested. The comparison focuses on different conceptualisations of personhood, body and the relational self and advances the main argument that death is a social construct that encompasses biological, personal and social dimensions (Lock 2002). Thus, as Lock elucidates, death cannot be pinned down and objectively diagnosed like an event located in time but rather it is a slippery gradual process – this is what ultimately confers the ambivalent nature of the donor, described as a 'living cadaver', and additionally, the author explains, it exemplifies the blurring of a previously unchallenged dichotomy between nature and culture. The transgression of other foundational boundaries in Western notions of personhood and the body are also examined through the notion of 'living cadaver', Lock speaks of 'bodies that outlive persons', donors as hybrid entities suspended between life and death, cyborgs breathing with technological assistance but forever unconscious. The gradual death process is epitomised in the 'twice dead' notion that separates the brain death diagnosis from the subsequent cardiac death of the rest of the body. Lock articulates the concept to present her critical take on the legitimacy of a death diagnosis based on neurological criteria, and the assumptions it entails, such as that death as irreversible loss of consciousness restricts 'the seat of life' to the brain exclusively. The work contends that the medico-legal redefinition of death emerges from, and further enables, a utilitarian

procurement of organs, especially in an increasingly technocratic US culture, where transplantation is enshrined as a heroic medical feat and donation is actively promoted through the gift of life rhetoric by a profit-oriented transplant industry. Lock provides rich accounts of medical practices and shows the entanglements between brain-dead diagnosis and the need to procure organs for transplants. The trouble with ‘jumping the gun’ or thinking about donation too quickly “to salvage hope from disaster”, Lock states, can only be balanced by adequate clinical experience to ensure that “care of the patient comes before an interest in his or her organs” (2002, 102). Once the death diagnosis is official then the practitioner’s attention is said to shift from the patient to the organs. Lock examines the conflicts experienced by practitioners who deal with breathing and heart-beating brain-dead donors, their task is troubled by the occurrence of ‘observable signs of life’ in maintained donors. The inevitable paradox is that “if organs are to be transplanted, then circulation and organ function must be kept as close to “normal” as possible” (2002, 243).

Thus, the author argues, procurement professionals have to grapple with the dissonance brought about by ‘bodies that outlive persons’ and ‘living organs inside brain-dead bodies’. The work also documents extensively the emotional distress and conflict experienced by relatives after brain-death communication, and their reactions when medical professionals approach them and tell them how the donor’s gift could save many lives with transplants.

The difficulties are said to be due to the friction brought about by the trespassing of the life and death boundary that donation and transplantation entail, and the discrepancy of discourses articulating the event: “the language of medicine insists that human body parts are material entities, devoid of identity whether located in donors or recipients. However, in the rhetoric promoting donation, organs are animated with a life force...living on in other bodies” (2002, 319). The work offers accounts of both donor families and recipients’ experiences that attest to the ‘social life’ of donated organs, far from being ‘mere biological organs’, they become ‘personified’, donation is thus construed as a way to give meaning to an otherwise ‘senseless’ death, or “a technological path to transcendence” (2002, 319).

Juxtaposing the case of Japan with that of the US allows Lock to distil the main differences of ideologies and how these intervene in the medical and social accounts of donation and transplantation. The dispute, as Lock puts it, is that whereas in the US “the gift metaphor has had the effect of representing the act as a personal choice – one that “fits” with dominant ideology in North America of having the right to dispose of one’s property as

one wishes” (2002, 318) – in Japan, both death and the body are embedded in strong family ties, they do not belong to the individual alone nor are they dominated by medical professionals’ definitions. Hence, donation cannot be captured within the individual domain of the gift discourse, and medical authority recedes as “death in Japan remains above all a social event; the family is in control, and death with dignity requires family participation” (2002, 369).

Additionally, Lock’s work (2001, 2003) has amply dealt with critical issues around the commodification of the body for medical purposes along with Scheper-Hughes’ work denouncing the global traffic in organs as ‘scarce commodities’ (Scheper-Hughes, 2001; Scheper-Hughes, 2000). Both authors have condemned the dubious medical practices that prioritise utilitarian uses of body parts at the expense of the dead and the dying whose suffering goes unacknowledged. Their research has exposed that the transplant industry (elsewhere mostly characterised about the heroics of transplants and saving lives), has created the so-called ‘organ shortage crisis’ by expanding the eligibility criteria and thus the number of recipients in the waiting lists and by the unreported practice of re-transplants in patients whose first graft failed. Lock’s research in Japan and the US is mobilised along with Crowley-Makota’s (2008) work in Mexico to further expand on the limited purchase of the gift of life as a ‘premodern trope’ to capture organ donation as a situated practice in different countries. Lock and Crowley-Makota (2008) claim that when donation is constrained within the ideal of autonomous choice, then the familial, social and cultural contexts are neglected. They believe that in order to understand the reasons why people refuse or agree to donate, the focus should be instead on “the social context that shapes how people decide whether to donate organs...which make transplantation possible” (157). Thus, the authors call for further accountability of the different contexts to explore the reasons for family refusals, which they feel they are too often overly simplified as lack of education or altruism (Lock and Crowley-Makota, 2008).

Sharp’s ethnographic work (2000, 2006) takes the main tenets of the previously reviewed work of Fox & Swazey (1974, 1992), Hogle (1995, 1999) and Lock (2001, 2002, 2003) as the starting point for an in-depth mapping of donation and transplantation in different parts of the US, encompassing the accounts of donor families, recipients and medical professionals. Her critique is also directed at the technocratic and utilitarian approach to transplantation that medicine and in particular the transplant industry sustains. Sharp’s method is to juxtapose contradictory discourses to expose the paradoxes that underpin organ transfer in the US; her work claims that the transplant industry creates and sustains

‘a complex array of euphemistic constructions’ – such as coating donation with the gift of life, heroism and altruism – as an instrumental move to cover up the highly ‘lucrative’ and hence commodifying side of organ transfer (2006). Similarly, she argues, the dehumanisation of donors that procurement entails, reducing them to ‘medicalised cyborgs’, is dealt with powerful narrative strategies that emerge from a medical conception of death, the body and personhood, in an effort to silence the doubts and discomfort that such practices pose to both professionals and relatives involved. The paradox here, as the author indicates, is that even if transplant professionals describe donated organs as ‘replaceable parts’ or ‘inert objects’ and “thus, denaturalized parts incapable of harbouring traces of their once human origins...transplanted organs are perceived instead as fragments of beloved individuals who live on and grant new lives to others” (Sharp 2006, 24).

Sharp offers multiple stories of novel kinships that emerge between donor families, recipients and their families and contrasts it with the transplant industry’s insistence on the anonymity of organ transfer. She argues that such stories exemplify the public resistance to dominant medical narratives and the ‘aggressive work’ they mobilise to prevent communication between donor kin and recipients. A different set of paradoxes emerges from the clinical practices of procurement, Sharp intends to contribute to the existing corpus of critical work about the legitimacy of such practices albeit from a different perspective, instead of looking for controversy elsewhere, like Lock (2002) in Japan and Hogle (1999) in Germany, she unveils the controversy underneath, that is, the personal accounts of health professionals, their private doubts about brain death and ambivalence towards donors are offered as a direct route to the “wondrous counterreality to the official rhetoric and public face of organ transfer in America” (2006, 47). Especially the practitioners’ reluctance to shift their attention from caring for a living patient to maintaining a brain dead donor, Sharp argues that their dissonance is further exacerbated by the contrast between the depersonalising practices that turn brain-dead donors into ‘passive objects’, and the occurrence of “disconcerting reactions not considered to be characteristic of dead bodies...spinal reflexes...blood pressure and respiratory changes” (2006, 88). The author explains that the practice of anaesthetising the donor prior to surgery responds to the need to address the professionals’ worries about the donors’ ‘troubling signs of life’ and their attributed capacity to experience pain.

The work of medical professionals, and especially transplant surgeons, is said to be heavily under pressure due to the perceived organ shortage, and following Fox & Swazey

(1974, 1992), Sharp denounces the consequences of such procurement-oriented conduct in that it neglects the moral dangers that underpin their actions of transforming dying patients into potential donors or “repositories of reusable parts” (2006, 25) as well as the safety of recipients that she sees put at risk due to the “aggressive and liberal acceptance criteria”(2006, 20) implemented to increase organ availability. Above all, Sharp’s highly condemnatory work, aims to bring forward that which she feels is excluded from dominant triumphalist and gift-based discourses of donation in the US, in particular the role of donor families because ultimately, she explains, “the vast majority of organs are offered by donors’ surviving kin to anonymous strangers; procurement specialists help to negotiate the transfer of these body parts to surgeons” (2006, 13). Thus, she wishes to make visible the stories of “the unsung heroes of donation” (2006, 25), who do not receive any financial compensation even though the organ transfer is highly profitable for the OPO involved, and who remain unacknowledged in an individual-based rhetoric of heroic donors and personal redemption (2006).

Jensen’s (2010, 2011a, 2011b) ethnographic work with OPOs in New York and donor families builds on Sharp’s approach but offers some variations in style. The main premise put forward is, following Sharp (2006), that American OPOs actively manufacture a positive discourse of donation as gift-giving, and offering hope and redemption out of meaningless losses, to promote and encourage the public to support it. To Jensen, “the hero stories of organ donation act as yet another deliberate organizational tool to control the experiences of donor families” (2010, 68). It is claimed that the concept of the donor as a hero living on in others was constructed so as to offer some emotional therapy to the suffering of donor families who have to deal with the tragedy of their loss as well as with the doubts and fears prompted by the ambivalent brain death diagnosis. Jensen’s work departs from Sharp’s accusatory style as she contends that procurement is not dehumanising per se, rather that the objectification of donors is a necessity in order for them to become subjects again; through donation and transplantation donors live on in other people as absent yet present heroes. Similarly, in her thesis Jensen (2011b) borrows a concept from Sharp’s work, that of donation as ‘orchestrating death’, to present ethnographic work in one Danish hospital and the stories of donor families’ experiences, but rather than exposing the dubious practices of medical professionals, her work shows that the procurement of organs is compatible with treating donors with respect. In her accounts, the health practitioners strive to orchestrate a good death for donor families by making it both beautiful and infused with gifting-meaning. The author asserts that such ‘extraordinary deaths’ and the suffering and sacrifice they involve in both donors and

their families are far from being properly acknowledged and 'honoured' in the public domain, as well as not being reflected in Danish public health policies which aim to normalise donation by presenting it as the default choice to be taken (2011b).

#### **2.4.2 – Social Studies about the Public, Transplant Recipients and Donor Families' Views and Experiences of Organ Donation**

The following works belong broadly to the discipline of social sciences, most of them are short and focused projects, as opposed to formerly reviewed comprehensive ethnographic studies, and rely on public survey or interview methodology. They all inquire into the social realm of donation, mostly on the reasons and emotions behind people's decision to donate or to refuse, and they aim to contribute to long-standing debates on ways to increase donation rates and identify the main obstacles that are said to cause low levels of public endorsement of donation. Similarly to the aforementioned ethnographies, much emphasis is put on the divide between medical objectification of the body as 'collection of spare parts', and the views of the public and donors' families and recipients. The divergence between those is seen to be the cause behind low donation rates, and in particular the different conceptualisations of the body/self, personhood and individuality espoused.

Joralemon's (1995) work deals with the organ shortage problem, or what he calls the 'organ wars'. His US-based anthropological analysis delineates the then current strategies of the medical community to combat the 'cultural resistance' to transplantation that the author sees as the cause of low donation rates. The main problem, Joralemon explains, is that transplantation advances conceptions of the body as fragmentary, 'a collection of replaceable parts', and of personhood associated only with consciousness. Thus, it transgresses commonly upheld notions of self/body integrity, which he says cannot be restricted to the brain. Like other previously reviewed authors, Fox & Swazey (1992), Hogle (1999), Lock (2002), Sharp (2006) and Jensen (2010), Joralemon also identifies the gift discourse of donation as an instrumental construction to address public apprehension and to increase numbers of available organs for transplants. The author indicates that the gift ideology of altruism is directly opposed to the other narrative mobilised to deal with public rejection, that of individual rights and a market in organs. Hence, he contends, the two approaches differ in the attributed reasons to donate, if organs are gifts then they are donated out of altruism, the heroic donor's sacrifice is directed towards the community. Conversely, if organs are commodities then they are sold by a rational autonomous

individual acting out of self-interest. Neither of the two opposing ideological strategies can ever be entirely successful in combating public resistance to transplantation, Joralemon (1995) argues, because deceased donation lacks the social ties that ground any gift-exchange system, as the work of Ohnuki-Tierney (1994) and Lock (2002) in Japan contend, and body parts cannot be considered alienable objects one can sell. After all, the analysis concludes, 'cultural resistance' will not be easily fought because as the process of rejection of a transplanted organ exemplifies "the intuition of bodily integrity has a solid biological foundation" (1995, 347).

Siminoff et al. (2004) claimed that in order to increase the supply of donated organs for transplants more was to be known about the US public's attitudes and beliefs on the two cornerstones of donation; that is the concept of brain death and the dead donor rule, the latter states that procurement will only take place after death diagnosis has been confirmed. The results showed that a significant part of the respondents were either misinformed or unaware of the concepts. The authors conclude that the knowledge gap between lay and medico-legal conceptions of death and donation should be addressed with more education on the matters to address the problem of low donation rates.

In a previous study, Siminoff and Chillag (1999) had already scoped US public attitudes towards donation and had similarly concluded that the reasons for low donation rates are to be found in the inconsistencies between 'the biomedical establishment' conceptualisations of death and the body and those of the public. Primarily, they highlight the inaccuracy of the gift of life metaphor to describe donation, they claim it is fallacious as it lacks the reciprocity dimension, as other authors have stated (Joralemon 1995, Ohnuki-Tierney 1994, Lock 2002, Shaw 2010), and that even though it is commonly used to promote donation in effect it does not lead to increased consent to donation. Ultimately families donate, as their data suggests, out of non-altruistic reasons "to see their loved one live on in the recipient" (Siminoff and Chillag 1999, 40). On the subject of reasons to refuse, the study identifies low acceptance of the concept of brain death in the public domain, fears that the patient will not receive the same life-saving treatment if considered a potential donor, and concerns over the treatment of dead bodies and the visible impact of donation on the body. About the latter, the authors claim that even though 'the transplant community' considers organs from the deceased as spare parts, the public hold strongly opposing views as the predominant concern over the dead body's integrity is reflected in the US common practice of open-casket burials and low rates of cremation. Additionally, Siminoff and Chillag's study offers the views of transplant

recipients, too often neglected as the authors contend, that testify to the damaging effects of the gift discourse, Fox & Swazey's (1992) notion of the tyranny of the gift, that places recipients under feelings of obligation and guilt for the death of the donor, is here further extended and identified as a controlling strategy used by medical professionals to ensure the recipients' adherence to the rigorous post-transplant treatment.

Sanner's (2001) study on people's attitudes to donation and transplantation in Sweden, also responds to the need to understand people's reasons to consent or refuse to donation. It explores issues related to the body and individual identity, and the results show two different conceptualisations, one is 'the body-as-machine' or a collection of spare parts, and like other commentaries upon the increasing commodification of the body, Sanner claims that medical practices of transplantation are actively advancing such mechanistic view of the body. The other conceptualisation is 'the influenced body' in which "body parts are conceived as segments of the whole and also express the being in its totality" (2001, 1497). The latter refers to the public's view that receiving an organ also implies the transfer of the donor's subjectivity, which in turn alters the recipients' identity. Sanner (2001) argues that conceptions of 'the influenced body' are excluded in medical professionals' discussions with prospective recipients and suggests that a more holistic view of the body, as opposed to the mechanistic spare parts conception, should be espoused within the medical establishment. In another study, Sanner (2003) further develops her critique of the medical objectification of the body. Interviews with actual recipients of a transplanted organ aim to show that even though medical professionals reinforce the body-machine conception, as in talking about the function of the organ and the need to supervise it, recipients can never fully embrace a view of their bodies "in this rational and depersonalised way" (399), even though some of them actively try to in an attempt to 'naturalise' the transplant and ease their feelings of discomfort about it (2003).

Sque and Payne (2007, 2008) conducted interviews with UK donor families, their work is focused on understanding the reasons that underpin family refusals to donate and the experiences undergone by families that had consented to it. Mainly, the difficulty of 'letting go', seeing their deceased relative being taken to organ extraction surgery, and the fears associated with feelings of "violation and desecration of the donor's body and their prolonged suffering" (2007, 114). Thus, the authors conclude that the gift discourse is not applicable to deceased donation as it effaces the sacrificial nature that it entails for donor families. Another study that criticises the poor fit of gifting metaphors to donation and that instead highlights its closer association with the notion of sacrifice, is Shaw's (2010)

work with health professionals involved in donation practices in New Zealand. In their view, gifting terminology is not applicable in the hospital when conducting the donation request with potential donors' families, and as Shaw argues, it is only useful to emphasise the positive moral values of altruism in public campaigns to promote donation. This compares to the arguments made by Joralemon (1995) and Siminoff and Chillag (1999) Sharp (2006), Jensen (2010) and Lock (2002), and further adds to a conceptualisation of the gift narrative as a rhetoric device to separate donation from the sale and commodification of body parts.

### **2.4.3 – Studies of Hospital Practices of Donation and Practitioners' Views**

The topic of deceased donation has been amply studied through the perspectives of the public, donor families and recipients, as the last section showed. In contrast, the sphere of health practitioners has been significantly less scrutinised. Even though, (as noted in section 2.4.1) the medical practices and views of the professionals have been incorporated in ethnographic works, there is a scarcity of social science literature that focuses exclusively on the professionals' practices and views. A clear exception is the influential study of (Youngner et al., 1985), cited in all the anthropological studies of donation and transplantation coming from the US (Fox & Swazey 1992, Hogle 1995, Lock 2002, Sharp 2006), that puts forward the 'disturbing effects' that organ extraction surgery had for intensive care unit (ICU) and operating room professionals. The main difficulty, as identified by the study, was the dissonance between the brain death diagnosis and the 'visibly not dead' appearance of the patient turned donor; the professionals' concerns were linked to wider public's resistance to organ donation. The study argued that ultimately donation practices are the opposite of healthcare practices in that it "goes against the welfare of the patient, mutilated, it violates the rule of treating human beings as ends and not mere means to other ends" (1985, 321), as well as a being a breach of respect to the newly deceased. Thus, and with the objective of facilitating the work of health professionals, Youngner, Allen et al. suggested that professionals should be better informed about brain death, in that the patient is definitely dead and that the fact that "tissues and other organs are merely functioning is essentially different from a living human being" (1985, 323), and thus dead patients cannot be harmed during surgery. It was also claimed that it would be beneficial to inform healthcare personnel about the positive results of transplants and the stories of patients who have received 'the gift of life', hence it was contended, their endorsement of donation will increase and their discomfort about taking part in procurement activities decrease.

The following list of works to be presented will shift the attention from the US to the European setting, there are many differences but the one I wish to emphasise is that the donation practices under study are located within the broader framework of national public health systems, as opposed to the privatised health organisation and the work of OPOs in the US. They are all quite recent studies that use ethnographic or interview data and that work at the intersection of anthropology, sociology, policy studies and STS. They emerge from countries with low donation rates, and they similarly put great emphasis in mapping the areas of friction that the contested practices of donation entail for clinical practitioners. The troubling transition from patient to donor, a theme present in all the previously reviewed works, is addressed by highlighting the difficulties that the transition entails for practitioners, as well as the ambiguities of brain death diagnosis that the authors see pervading both the clinical practices of end of life care and of organ procurement.

Hadders and Alnaes' (2013) study is based on fieldwork conducted in two ICUs in Norway, it focuses on the differential processes of 'enacting death', drawing on Mol's (2002) ontology multiple in practice approach. It focuses on the different ways of performing clinical practices around death diagnosis depending on whether donation is a possibility. It highlights the necessary interdependence and coordination of a variety of health professionals that take part in a donation process and their different ways of handling the difficult issues of the contested practices. Such as the 'troubling' transition from patient care to donor maintenance for ICU nurses that demands a shift from person to 'insentient body' or 'an incubator of organs'. The authors, like in Youngner, Allen et al.'s (1985) study, suggest that the practitioners' concerns could be addressed if they received more feedback on the 'goodness' of donation and the 'life-saving' results of transplantation. Nevertheless, the work states that donation will remain a 'contested practice' because the nurses' duty of patient care and respect continues after brain death diagnosis, they see this exemplified in the nurses' behaviour of talking to donors and to continue to nurse them, because as the study argues "safeguarding their patients' embodied integrity remains a cornerstone for patient care in general" (2013, 253).

Hoeyer and Jensen's (2011, 2012) interview work with health professionals involved in donation practices in Denmark has focused on documenting and engaging a productive dialogue about the problems professionals face in a national context of low deceased donation rates with growing transplant waiting lists. Denmark was the last country in

Europe to legalise brain death criteria<sup>14</sup>, and as the authors argue, deceased donation from brain dead patients is still a highly controversial practice and donation rates are amongst the lowest in the European area<sup>15</sup>. The researchers' stance (2011) is that norms and ethical standards are developed in practice as opposed to abstract guiding principles that are applied through processes of rational decision-making. Hence, Hoeyer and Jensen pay careful attention to the complexities and practicalities of everyday decision-making in the hospital setting, the choices of individual health practitioners are analysed and the authors provide their own interpretation of what the underlying justification mechanisms are said to shape their views and organisational practices. The data are drawn from interviews with neurosurgeons that perform brain death diagnosis and approach bereaved families to discuss donation, with ICU nurses in charge of donor care, and with anaesthesiologists who supervise the medical treatment involved in donor maintenance (2011). These are put together to map the conflicts embedded in the transition from caring for patients, 'an end on their own', to dealing with donors that 'serve as means to others'. In particular the research focuses on an aspect of donation practices which further exacerbates the difficulties associated with the dehumanising and objectifying practice of reducing patients to 'a stock of spare parts', that is, the occasions when a brain-dead donor, whose family has already consented to donation, goes into cardiac arrest and a 'violent and brutal intervention' is necessary to restart the heart and avoid losing the donation. The authors explain that such physical action interferes with common practices and upheld ideals, as the previous work of Jensen (2011b) highlighted, the importance of values of respect towards the dead and about the dignity and tranquillity of the dying process feature largely in the health practitioners' work towards 'orchestrating' a peaceful and dignified transition from patient to donor. The practitioners' moral dilemma, Hoeyer and Jensen explain, is to be understood within the realm of practical work ethics, on the contrary to previous characterisations of medical professionals as 'mere instruments for procurement' that are put forwards in denunciatory work on 'aggressive organ harvesting' (Fox & Swazey 1992, Sharp 2006, Lock 2002 and Schepper-Hughes 2001). The difference is that the professionals under study show little interest, let alone motivation, to increase the supply of donated organs for transplants. Rather, their prerogative is to be understood as part of the 'transgressive ethics' that are part of ICU practices; in that cardiac arrest treatment is not unusual in an ICU but that ultimately "it is the changed parameters of benefit that make physical procedures into a form of violence" (2012, 613). The analysis moves on to examine the strategies deployed by individual practitioners to deal with the

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<sup>14</sup> 1990

<sup>15</sup> Denmark donation rates: 10.2 p.m.p. See Appendix I for Organ Donation Rates Map.

ethical quandaries experienced when performing cardiac arrest treatment to donors. These may include appealing to the wishes of the bereaved family to proceed with donation or describing the action as a medical necessity, and the authors highlight the absence of appeals to the potential transplant recipients as noteworthy. The practitioners' shared demands for a policy to regulate the practice, is deemed paradoxical by Hoeyer and Jensen (2012), in that it would sanction actions that are perceived as 'violent and immoral'. The explanation the study puts forward is that regulating the practice would shift the issue towards a work ethics domain, hence, it would diminish moral discomfort by removing individual responsibility about the practitioners' choices of action by deferring it to higher authority, and thus the policy would 'close the case'.

In a more recent study (Hoeyer, Jensen et al. 2015), the same topic and interview data are scrutinised from a slightly different angle, the objective is to unveil the social mechanisms that underpin different moral valuations undertaken by practitioners in order to legitimise the controversial practice of cardiac arrest treatment for donors. Three valuation processes are identified, the needs of recipients, respect for donors' autonomy and the needs of donors' relatives. With regards to recipients, and noting their absence in practitioners' accounts, the study claims that the cause is to be found in self-imposed deliberate ignorance that "facilitates a form of abstraction in which organ donation can be associated with the abstract moral values of doing good rather than being assessed in the light of actual benefits for actual people" (2015, 590). Discursive strategies about respect for the autonomy of the donor body refer to the practitioners' interpretations that cardiac arrest is akin to the body 'opting out' of donation, in these accounts the failing heart is identified as 'legitimate decision-maker'. The study argues that practitioners' valuation practices are primarily directed at attending the needs of donors' families, and that these trump both those of the recipient and of the donors in case of conflict. The mechanism of deliberate ignorance is also said to explain the nurses' decision about not telling the donor family about the treatment, "she foists her ignorance on others to uphold her sense of integrity and as an act of caring for the relatives – not to acquire the organs or to uphold her power" (2015, 586). The authors conclude that even though the identified deliberate ignorance mechanism plays a part in deceased donation practices, the general public should be better informed about 'increasingly aggressive modes of organ procurement' to preserve the public legitimacy of the donation system.

The policy studies work of Paul, Avezaat et al. (2014) focuses on interviews with healthcare professionals involved in donation processes in the Netherlands. The study was originally

government-assigned to identify the 'technical problems' in clinical practice that could be addressed by means of policy so as to increase the country's low donation rates. However, the authors contend that their results contradict the original premise of the study, in short, that policy-making practices, such as design and implementation of standardized protocols to regulate donation processes, neglect the most salient dimension of clinical practice, which are the ambiguities that such 'controversial' work entail for practitioners. These are encapsulated in the concept of 'transition work' that refers to the trajectory 'from losing a patient to 'gaining' a donor'. The difference is that unlike protocols emphasis on standardization, transition work implies 'tinkering with existing resources' and is not reduced to the domain of institutional knowledge but incorporates local and experiential layers as well as emotion-management processes. The primary tension between policy discourse and clinical practice is said to be that protocols render donation as a normalized practice, a routine procedure in the hospital, whereas in practice this view is contested as practitioners continue to struggle with various ambiguities that relate to the brain death diagnosis, the gradual shift from patient to donor care and the donation request with the bereaved families. Paul, Avezaat et al. (2014) conclude that instead of looking for a 'technocratic fix' to increase donation rates more work should be done on understanding the type of work and ambivalences donation practices pose to health professionals.

Cooper and Kierans' (2015) ethnographic work conducted in a hospital in the UK addresses the effects of incorporating organ donation processes into end of life care practices through the notion of 'negotiation of death'. It aims to highlight how the possibility of donation influences the communication of brain death to families of potential donors. Similarly to Hadders and Alnaes (2013), the authors argue that even though death communication and the donation request are decoupled, in practice they are highly intertwined. This is mainly because the 'brokering of death' will be done in a manner so as to enable a subsequent donation request and to optimize a positive answer of consent, especially in cases dealing with black and minority ethnic groups that are associated with high refusal rates. Cooper and Kierans' (2015) ethnographic work, much like other anthropological work on donation practices, intends to make visible the interrelationship between situated local practices, such as making brain death a clear and meaningful event for families of potential donors, and the larger 'biopolitical' context. The latter is characterized by the UK's persistent efforts over the years to increase low donation rates, which the authors see being reified through the policies and protocols that

put the practitioners under pressure to increase numbers of available organs for transplantation.

#### **2.4.4 – The Institutional Dimension of Deceased Donation Practices**

Some works have dealt with the broader institutional framework of donation exclusively, unlike those in the former section that addressed the larger context but only through the individual practitioners' views or the details of situated local practices. The two sociological studies that follow have advanced some relevant themes on the political and economic dimension of donation practices, such as the interrelationship between organs as gifts and commodities, and on the structural as well as the moral effects that donation practices are said to have on the public domain.

The sociological work of Healy (2004, 2006) is based on the premise that altruism should be understood in its organizational context and not merely in terms of individual behaviour. The work examines the potential problems and possibilities that the introduction of a market in human blood and organs could present to the current voluntary system in the US. Healy (2006) analyses the changes over time in deceased donation rates in several states in the US and argues that those can be explained by the structural and institutional patterns of the organ procurement organisations that regulate donation activities in the different areas. The main argument advanced is that it is precisely these organisations that produce and sustain altruistic behaviors like organ donation; OPOs provide the logistical and institutional context where gifting behavior like donation can take place. Healy claims that the 'social organization' of donation ought to be further acknowledged given that "the study of altruism generally, and the case of human goods in particular, has neglected these processes and focused instead on heroic individual altruists" (2006, 22). Transplant advocates and OPOs, in their attempts to normalize donation and highlight its moral value, are said to have fostered an account of donation based on the gift of life and the generosity of donors and their families. Healy explains about the performativity of the official gift discourse, in that the institutional account about the meaning of donation has permeated in the public domain and it now shapes that which it initially intended to describe. Thus, OPOs are said to operate both in the structural and the moral landscape of donation in the US; they provide the organizational context in which to give but also the reasons for doing so and the meanings attributed to it. Such claim about the instrumentality of the gift discourse that Healy (2006) advances can also be found in the work of Lock (2002), Sharp (2006), Jensen (2011),

Siminoff and Chillag (1999) and Joralemon (1995) amongst others. Healy concludes that it is precisely this moral account of altruistic donation – which was created to increase the public's support towards it and lower high rates of refusals – that now represents the main impediment to the introduction of financial incentives for donation as a proposed strategy to increase deceased donation rates.

Waldby (2006) has also looked into the broader political and economic context of donation practices, her notion of 'tissue economies' underpins a sociological analysis of the transfer of human tissue; blood, organs, and cell lines. The author presents a new take on the contentious issue of defining organs as either gifts or commodities that has populated the previously reviewed literature; from critical anthropologists that denounce the commodification of the human body and the lucrative side of donation like Sharp (2006), Lock (2002) and Schepper-Hughes (2001), to the work of Joralemon (1995) and Healy (2006) that look at the opposition between gifts based in altruism and commodities associated with financial markets. The concept of 'tissue economies' is articulated by Waldby to examine the interrelatedness between gifts and commodities in a 'late capitalist' global landscape. Thus, the analysis identifies the various social and ethical issues raised by specific processes of inserting the productivity of the human body within current social, political and economic milieu. The work draws on Foucault's concept of 'biopower' that defines the function of the state as administrator of its population's health and vitality, and that characterizes the sphere of health governance as structured according to the imperative of health or the 'biopolitics' of raising the level of health of the social body (1978). Waldby contends that the political economies and health policies that regulate human tissue distribution rest on the concept of 'biovalue'; in short, that a surplus in vitality – human tissue from the deceased – can be redirected to the living to improve the levels of national health. And that ultimately such global tissue circulation enhances the production of health as well as wealth and that it engenders a redefinition of moral values that are said to change the individuals' sense of embodiment and the perceived regenerative capacities of the social body (Waldby 2006).

## 2.5 – An STS Study of Practices of Donation in a Catalan Hospital and the Need for a Different Theoretical Approach

This research project responded to the preliminary aim to map the hospital practices that make donation processes possible at the hospital. In addition, much like social studies of organ donation reviewed above, I was also interested in examining how concepts like donation, donors, bodies and organs were articulated in the medical practices under study. However, and given that the scope of the research was reduced to the TC team, this project departed from prevalent social literature on the subject in that it didn't wish to contrast different discourses about donation, namely the alleged rational account given by the medical profession, versus lay understandings based on emotional meanings. Rather, the focus was exclusively the practices of TCs in a site where donation had become routinized and was part of the healthcare system. This represented another point of disconnection with available literature that solely focused on documenting the controversial side of organ procurement. The enquiry moved to scrutinising the overlap between procurement and healthcare in practice, to examine how donation processes were enabled by existing healthcare practices in the hospital, and to trace the integration of donation as another healthcare practice, as well as identifying the prevalent tensions. Thus, even though I wished to address the patient to donor transition, which featured prominently in reviewed studies, the point of departure was different. The TC team conducted only procurement-oriented tasks; hence the transition was featured differently than in previous studies that focused on the accounts from healthcare practitioners that had to shift their attention from patients to donors. The guiding questions were: 'How are donors enacted as patients in TCs practices?' and 'In which other ways are they rendered in the practice?' The way to go about it was to follow the shifts in practice, along the whole process of donation, from donor detection, evaluation, and maintenance, to consent request and organ extraction. Since this project became inscribed within an STS domain, another search started, looking for ways of theorising the body in medical practices, to account for the intervention of materialities like bodies and organs but also beds, pumps or blankets. This is the other defining pull that has shaped this research and consequentially this thesis. Throughout the PhD trajectory both pulls have become entangled, mapping the specific practices and accounting for the intervention of bodies have developed as parallel and mutually inclusive processes of figuration, and they amount to the following account of donation practices in a Catalan hospital. The empirical stories I will present, like other social studies of donation previously reviewed, also attempt to make visible a given set of exclusions and to assess what their

incorporation changes in the actual panorama of international debates about deceased donation rates. Nevertheless, the exclusions I will be addressing are of a different kind and thus a shift in the theoretical and consequentially methodological approach has also been necessary.

In the following chapter I will explain the set of theoretical tools that underpin this research. Their implementation has allowed me to study local practices of donation from a perspective that decenters both subjects and objects and that instead focuses on processes. The objective has been to map the given donation practices, to identify the shifts in the differential distribution of responsibilities along the intervening factors and actors and the interdependencies amongst them. I contend that much of the previously reviewed literature rests on the anthropomorphic divide between subjects and objects and inevitably on associated notions of ontology, agency and materiality. The two guiding forces that shaped this research have steered it away from these conceptualisations and instead other renderings of these foundational concepts articulate this project. The next chapter will present them along with its points of dis/connection with previously reviewed social works of donation practices.



## Chapter 3 – Theoretical Approach

### 3.1 – Introduction

This chapter will present the theoretical notions that underpin the research project by drawing on the work of four key authors in the field of STS: Haraway, Latour, Law and Mol. They are all leading figures in the field and share a non-essentialist ontological approach that can be broadly referred to as material semiotics, an orientation they apply to the study of technoscientific practices. A material semiotics sensibility is grounded on the premise that both the ‘social’ and the ‘natural’ are being done and generated as effects within particular webs of relations. Relations can be both semiotic – and include conceptual or discursive elements – and material as they also encompass the intervention of numerous materialities. Thus, the methods of analysis seek to map “the enactment of materially and discursively heterogeneous relations that produce and reshuffle all kinds of actors” (Law 2009, 141). Haraway’s influential work has mobilised, and further developed, material semiotic tools and sensibilities to map the domain of technoscience. In her words: “Technoscience extravagantly exceeds the distinction between science and technology as well as those between nature and society, subject and objects, and the natural and the artifactual that structured the imaginary time called modernity” (1997, 4). It is a shared pursuit of the aforementioned authors to contribute to existing contestations within the social sciences that articulate the difficulties that thinking with modernist polarities entails.

The primary focus will be on literature that has dealt with studies of medical practices; thus, the work of Annemarie Mol will take a central position in the following account. It will be deployed as a binding agent to amalgamate the different authors’ works; the emphasis will also be on tracing the partial connections amongst the different studies reviewed. The chapter is divided into three sections that will deal respectively with the following themes: 1) the ontological turn in STS and the study of sociomaterial practices 2) theorising the body outside the subject/object dichotomy through nonanthropomorphic renderings of agency and materiality 3) the political responsibility of doing social research and intervening in the problem studied. Each section will be followed by one or more subsections that will define this thesis along a ‘*No heroics, please*’ proposal. The latter encapsulates five core propositions that situate the aims, scope and objectives of the research. The gist of ‘*no heroics, please*’ resides in opening up a novel way to give an account

of donation practices by decentering subjects and objects and focusing on sociomaterial processes, collective action and entangled actors. The *No heroics, please* proposal will be unpicked drawing on the theoretical approach presented and signalling the points of divergence with previous studies of organ donation. The five propositions will also be articulated in the three empirical chapters where they will be iteratively resurfaced and illustrated with ethnographic accounts from the hospital practices. The final discussion chapter will take stock of the contribution and implications that this *No heroics, please* proposal represents for the study of deceased donation as a situated medical practice.

### **3.2 – Doing STS and Taking the Ontological Turn**

Mol's studies of medical practices have covered diseases such as anaemia (with Law 1994, Mol 1999), atherosclerosis (1998, 2002), hypoglycaemia and diabetes (with Law 2004, Mol 2008). The works represent rich empirical investigations that simultaneously foreground local and specific medical practices and address theoretical questions on the nature of reality, knowledge, agency and materiality. Along with other influential social studies of medicine, such as those of Hirshchauer (1991), Singleton and Michael (1993), Casper (1994), and Cussins (1996), Mol's work has pushed for a serious engagement with medical practices and practitioners that leaves behind the restrictive binary choice of either being in favour or against medicine (Waldby 2000). The move has been sustained through ethnographic work on situated and specific medical practices, thus, the 'so-called hard core of medicine' – the making of biomedical facts and contents of diagnosis – has become unlocked and scrutinised as an object of study for the social sciences. Medicine studied from within is no longer a coherent set of rationalities but rather an assemblage of different practices that intervene and shape the ways that bodies are performed, disease handled and technologies incorporated. Medicine under scrutiny loses its apparent unity and it becomes diverse medical practices where politics, differences, incoherencies and tensions abound (Mol & Berg 1998).

Mol's work advances a distinct ontological move and purports to decentre knowledge to focus on reality-in-practice. That is, it enlarges the focus from the actors' meanings and perspectives on the object studied, in order to encompass the doing of reality in specific sociomaterial practices. The principle is that there is not just a singular object known differently by different actors, but rather that the reality of the object is being done differently in various practices, and thus reality itself becomes multiple. Anaemia, for example, becomes multiple as it is enacted differently in clinical, statistical and

pathophysiological knowledge practices (Mol and Law 1994, Mol 1999). The different versions of the disease are not “mutually exclusive perspectives, discrete, existing side by side, in a transparent space. While in the centre the object of the many gazes and glances remains singular, intangible, untouched” (Mol 1999, 76). Rather, the different versions of crafted reality are interdependent; they might collide at some points but nevertheless coalesce in others as they depend on each other. The ontological turn implies that multiplicity, contradictions and uncertainty are integral to any knowledge practice. Closure cannot be expected, and thus it becomes a matter of grappling with complexity and inherent tensions (Mol 1999). This style of doing research is indebted to a poststructuralist sceptical position about the singular and extrinsic character of reality, with its consequent denial that knowledge can offer absolute certainty about it. It draws on notions of performativity of knowledge practices, as developed by Foucault, and performativity of gender practices, in Butler’s work, and as Law (2008) claims, it emerges within an actor-network-infused STS environment.

Knowledge is not purely referential as it partakes in the doing of a particular reality. It interferes and intervenes in the multiplication of realities. Mol’s work can also be understood in correspondence with Haraway’s critique of objectivity and subsequent elaboration of the partiality of ‘situated knowledges’ (1988). As well as resonating with Latour’s (1983) claim that reality is ‘secreted’ from laboratories. In that nature and society are no longer two incommunicable spheres but rather distinctions are made in and through sociomaterial practices. Hence, Latour’s incitement is to study ethnographically the ‘down there’, rather than participating in fruitless disputes between the ‘up there’ – social explanations – and ‘out there’ – pre-given natural facts (1983).

Mol studies the multiple doings of atherosclerosis and bodies in a Dutch hospital empirically. The ethnographic approach is redefined as ‘praxiographic’ given that it foregrounds the study of situated practices with decentered actors. Activities, sites, technologies and bodies are all participating in the enactment of multiple realities. The knowing subject is thus decentered, as “the knowledge incorporated in practices does not reside in subjects alone, but also in buildings, knives, dyes, desks. And in technologies like patient records” (2002, 48). It follows that different ‘atheroscleroses’ are brought into being through several located processes: an internist’s version of the disease is different to that of a pathologist, or that of an X-ray machine or a Doppler scan. However, this multiplicity does not translate into fragmentation; processes of coordination, distribution and inclusion that take place in the hospital hold it together as a non-coherent whole. The

enacted object is more than one but less than many (Mol 2002). The different versions of the disease coexist and overlap and are, sometimes, in tension, and others in peaceful coexistence. The ubiquitous processes of mutual inclusion foreground the interrelatedness amongst that which is different but partially connected.

Both Mol (2002) and Law (2002) developed Strathern's (1991) notion of partial connections along with Serres' (1982) topological thinking. In them, Euclidean renderings of spatial integrity are challenged and replaced by relations of intransitive interrelatedness amongst mutually inclusive spheres. The emphasis is on tropes of 'locatedness', multiplicity, simultaneity and complexity. It is an intellectual move that allows them to circumvent the restrictions imposed by binary dualisms that so often permeate Western thought, such as subject/object, self/other, singularity/plurality, and local/general. The strategy is to focus empirically on the specific ways that different domains are entangled rather than on tracing boundaries amongst mutually exclusive dichotomies. Mutual inclusion and exclusion might coexist in practice, on occasions different domains might include each other, others they will be in opposition and thus in a mutually exclusive relation, and even sometimes relations of inclusion and exclusion will take place simultaneously.

Law (2002), in parallel with Mol (2002), has contributed to the ontological move with his work on decentering the object in technoscientific practices. Objects (in this case it is an aircraft in the making), are multiple, they come in different versions that are partially connected and interfere to cohere into a single assembled object. Wholeness or singularity is an achievement and thus it cannot be attributed as a property of the object in question. As Latour put it, "there are acts of differentiation and identification, not differences and identities" (1988, 169). The question of ontology thus becomes an ethnographic enterprise, and both Mol's (2002) and Law's (2002) works represent elegant and rigorous exemplifications of how to go about this. The main pursuit of the investigation is to make visible the conditions of possibility or the processes by which things are drawn together to assemble a decentered more or less coherent whole. The following sub-sections will articulate the links between my research's objective and the aforementioned theoretical notions along the first three versions of the 'No heroics, please' proposal.

### **3.2.1- No Heroics, Please I: Routinised Transplantation and Embedded Donation**

This research project emerges from a particular setting, a hospital in Barcelona with high volume of transplantation and donation activities. Over sixty years after the first successful transplants, the aura of miracle science and medical heroics of saving lives has lost its glare. Transplants have become routinized, and in the hospital studied here, so has deceased donation. This is a story about donation as an embedded hospital practice, an ordinary practice that is carried out in a business as usual manner. In this hospital site it is an uncontested, uncontroversial domain of activity inserted within existing healthcare services. Donation is located within the public health sphere, an institutionalised practice with a long trajectory of protocol development and implementation. Furthermore, it is a site that stands as an international referent to examine and follow so as to increase the national rate of donated organs. Nevertheless, tensions abound as the inevitable frictions brought about by donation practices can never be effaced. It is an intervention on an individual who does not gain any benefit from it. It is a practice that involves dead patients in the hospital site where healthcare practices are always directed at living patients. It is aimed at the procurement of organs for transplantation. Thus, the ultimate patients that are cared for are the patients in the transplant waiting list. Donation as the procurement of organs for transplants is an integrated healthcare practice in the hospital under study, albeit with various inherent tensions. The purpose of this research is to attend to both the similarities and differences. On the seamless integration of procurement within healthcare practices, as well as to the inherent frictions that separate procurement from healthcare. Donation is both procurement and healthcare. Donors are enacted as patients in the hospital. Sometimes procurement collides with healthcare and then donors are not like other patients. Drawing on the theoretical framework previously presented, and plunging into the unravelling of processes of mutual inclusion and exclusion, the following empirical investigation will analyse the interrelatedness and shifts in which procurement and healthcare overlap and separate.

### **3.2.2- No Heroics, Please II: Decentering Donors and Consent**

This thesis brings forward the medical practices that make possible the choice of donation for the families of eligible donors in the hospital. Thus, in the following empirical accounts donors become decentered, they are neither the heroic individuals that save the lives of others, nor are their families the forgotten heroes that should receive further

acknowledgment. It is often said that there would be no transplants without organ donors, this thesis advances that there would be no deceased donors without transplants either. The objective is to scrutinise the practices that take place in the hospital, interrelated processes, intervening actors and factors that make donation a possibility for some. In a similar vein to Healy (2006) and Manzano and Pawson (2014), this investigation contends that accounts of donation as an individual choice located within the moral sphere of altruism, have neglected the institutional practices that make the choice about donation an option in the first place. In the hospital studied here, organ and tissue procurement becomes a complex sociomaterial process of assembling donations. There are different stages from detection, evaluation and maintenance of eligible donors to the consent request with their families and final organ extraction. The stage of consent is decentered, as it is not the start of any donation process, nor is it the only factor that contributes to the assembling of a donation. In short, this work is not about donors and their families and the reasons behind their choice, neither is it about their personal experiences and the emotional aftermath of it. Instead, the focus is on donation as a situated hospital practice, and thus the objective is to map the making of the choice along the different interrelated stages of the process of assembling donations.

The following empirical chapters will follow the trajectory of the process and illustrate that donation is both procurement and healthcare. Chapter 5 will cover the stages of detection and evaluation, and through the accounts the figure of the donor/patient will be articulated. Above all, interrogating 'how is the donor enacted as a patient?', and, 'when does a donor become somehow different from a patient?' The emphasis on enactment is not about distilling an ontology multiple for the donor. I refrain from using the term 'ontology' as I believe it imports essentialist notions that deflect the attention away from processes of embeddedness and relationalities that first need to be examined in practice. Thus, the following empirical chapters will trace how the embedded donor/patient figure unfolds and shifts within and through the donation processes. Chapter 6 about donor maintenance and organ extraction, will add the donor/body figure that becomes the centre of the analysis, and in chapter 7 about the consent request it will be the relational donor/person and donor/corpse that will be unravelled. In short, the examination will be on how donors are enacted simultaneously as patients, bodies, persons and corpses with the purpose to apprehend the situational character and effects of donation as a medical practice.

### **3.2.3- No Heroics, Please III: Mapping the Practices of the TC team**

In this account of donation practices there are no heroic transplant surgeons that bring dying patients back to life. The medical professionals at the centre of this story are the transplant coordination team at the Hospital Clinic in Barcelona. Their work starts after the death diagnosis has been confirmed and their responsibilities do not extend to the healthcare domain of transplant patients. They are procurement specialists; they are responsible for the whole process of assembling a given donation case. Nevertheless, they do not work alone; their task would simply be impossible without the intervention of a myriad of other hospital practitioners. TCs are decentered as well. They are part of something larger, institutionalised practices of deceased donation inscribed within a specific regulatory landscape that includes legislation, public health policies and hospital protocols. The focus of the investigation is on the TCs' practices, what they do in the hospital, not what they think about it at a personal level. Much of the reviewed literature that engages with medical professionals involved in deceased donation practices (Hadders and Alnaes 2013, Hoeyer and Jensen 2011, 2012, Hoeyer, Jensen et al. 2015, Jensen 2011, Paul, Avezaat et al. 2014) has been concerned on their individual views on what they do; their choices and the decision-making processes that sustain them. Above all, they have focused on identifying the axis of frictions brought about by donation, in short, that which separates it from healthcare. This thesis departs from a different place altogether, as noted previously, in that donation will be analysed as a healthcare practice with its inherent tensions. The work of TCs embedded in the hospital will be mapped along with the scope and limitations of their responsibilities. Much emphasis is put on limitations, constraints and that which intervenes in their work requirements and obligations beyond any personal choice of action. It is important to note that other cited literature on the topic deals with a completely different set of donation practices and national context. They are studies from sites with low donation rates (Denmark, Sweden, Norway, England, the Netherlands) and a history of public controversy about brain death (Denmark, Germany, Sweden). Furthermore, the literature deals with a different type of medical professional, most of whom are ICU nurses whose individual patient-centered job clashes with procurement-oriented practices. In contrast, this research project deals with the work of the professional figure specialised in procurement in the hospital. And moreover, it addresses the TC team practices within a situation of high donation rates and heavily institutionalised donation protocols. Thus, the objective of this investigation is not to study TCs at an individual level. Nor to focus on their choices as happening in the void, neither determined by moral factors. Instead, this research scrutinises the practices. The

practices obviously include the work of individual practitioners, but these are not taken to be moral subjects of free choice but rather embedded in a particular donation landscape with some affordances and many constraints.

### **3.3 – Incorporating Materialities: Enacted/Acting Bodies**

Studies of medical practices have greatly contributed to crafting new ways of rethinking the body as a theoretical and a political category. STS studies, with a shared material semiotics disposition, have responded to Haraway's (1991) call to account for the discursive and material configuration of bodies as active agents or 'generative nodes'. Theorising the body from this perspective is premised on the notion that the body, as any other materiality, is embedded, relational and enacted as both process and performance. Thus "it presents the body as being shaped, brought into being, transformed and known through interactions with other entities" (Berg & Akrich 2004, 9). There is no essentialist definition that can capture what a body is, rather it is the very relational ontology of bodies that is at stake in any empirical investigation. Bodies as singularities are not taken to pre-exist the practices that they are part of, as Haraway put it, "their boundaries materialize in social interaction" (1991, 208). Hence, the researcher's gaze moves to the body-in-action, to account for the situated and specific practices from which it emerges as well as for its intervening role as mediator. Bodies are both effect and intervention. Taking this empirico-philosophical route to rethinking the body-in-practice offers a productive way out of the constraints imposed by worn out dualisms such as subject/object and agency/structure. It releases the body from being studied either as thinking and feeling subject – a phenomenological approach – or as mute externality to be defined from the outside – a constructivist approach (Mol and Law 2004). The exclusion that both approaches reified is to leave the materiality of bodies out of the question altogether. Mol (2002) has suggested that this has restricted the role of the social sciences to 'merely' adding subjectivities – patients' experiences and meanings – to medicine's unquestioned objectification of bodies and disease. Hence, leaving unexamined the scientific representations of the body and their articulations within medical practices. In a different vein, but also addressing the social sciences' exclusion of materialities, Latour (2000) has argued against the division of labour that separates that which can be studied only by the natural sciences – nature or the external world of objects – and that which belongs to the social sciences domain – subjective representations of the former. Instead, he claims, our investigative efforts should 'get back to things' to circumvent the limitations of the subjective or objective binary choice that separates culture from nature. Latour's call

draws on a rendering of things as assemblies, hence, not pre-existing entities but assembled in complex heterogeneous practices that must be in the first place unravelled and opened up for examination. Unity and wholeness is an effect not an attribute of the thing in itself, hence, it can only be found at the end of several processes of assemblage (2000).

Haraway's contestation to essentialist notions of individuality and self resonates with Latour's claim in that, as she posited "any objects or persons can be reasonably thought of in terms of disassembly and reassembly...what counts as a 'unit', a one, is highly problematic, not a permanent given" (1991, 212). Mol's work develops many partial connections with both Latour's and Haraway's intellectual programs, as well as adding her own style of empirical philosophy: 'telling philosophical tales with empirical stories' (Mol 1998). It is through very detailed empirical investigations, case studies of situated practices, that she gives shape and depth to particular insights such as the ontology multiple of the body in medical practices (2002). Mol's work, along that of other influential authors – as Hirschauer (1998); Casper (1998); Moreira (2006); Law and Singleton (2005); Singleton (1998), Cussins (1996), Van Der Ploeg (2004) – has spurred into action the proliferation of social studies that address the body-in-practice. A shared approach is to problematize the bounded and singular nature of the body by showing how the body being done in medical practices is multiple. Mol (2002) illustrates how the different versions of the body that coexist in and through different treatments for atherosclerosis are not in opposition, even though with internal frictions, the body multiple hangs together as a non-coherent whole. The wholeness of the body is thus a situational accomplishment not a given; a series of specific and interrelated processes ought to take place for it to be assembled in practice.

STS has taken the challenge of incorporating materialities, accounting for their intervention in the technoscientific practices under examination, both as agents and product. Theorising the body in practice has also been a great platform to discuss notions of agency alongside materiality. Once we take the ontological turn and we focus on enactment, we leave behind social constructionist accounts of bodies as passive objects, waiting to be defined by a plurality of actors. Mol and Law (2004) argue that the constraining but pervasive subject/object dualism emerges from a knowledge-centred version of reality characteristic of the Western modern predicament. On one side we have the active knowing subject, and on the other side, and a few steps down the hierarchy, we have the passive object of knowledge. The authors cite Sullivan's historical work on

Bichat – that claims that modern medicine’s subject/object divide is premised on the life/death dichotomy as it separates knowing physicians from known ‘silent corpses’. The problem this entails is that any inquiry that starts with the question ‘what is a body?’ will inevitably bifurcate into polarised accounts of either the medical experts or the patients’ definition of the body. To avoid reifying such knowledge-centred accounts that exclude the active participation of bodies, Mol and Law suggest ‘shifting the grounds’ and posing the preliminary question differently. If instead we ask ‘how is the body being done in practice?’ then our attention turns to actions rather than differential knowledge of various actors.

This onto-methodological strategy affords a way out of the subject/object binary; bodies being done in practice are both enacted and acting. Both active and passive, acting and being acted upon are two interrelated and coexisting modes of being. Bodies as active agents are to be understood within material semiotic notions that “disentangle agency from intentionality... an entity counts as an actor if it makes a perceptible difference” (Law and Mol 2008, 58). Latour’s actor-network theory notion of ‘actants’ conveyed this message already, in that while action is distributed and thus both human and non-human entities may act, an actor never acts “by itself, but always by others” (1988, 161). Similarly, Haraway’s long-term project to make space for ways of thinking outside anthropomorphic paradigms that reify subject/object polarisations, has greatly contributed to the reshaping of agency as intervention and interference (1991, 1997). Mol and Law (2004, 2008), in resonance with Latour’s on-going amodernist project and Haraway’s nonhumanist body of work, have offered empirical ways to go about extricating both agency and materiality outside the shackles of human exceptionalism; an enduring legacy of the rationalist doctrine of the Enlightenment. Nevertheless, mobilising alternative notions of agency is never an end in itself, as Law and Mol put it: “more interesting than the fact that things may act is what they do. Anything is, or might be, or might be said to be, an actor. So the point is not *who* has done it. Instead, what become more urgent are questions about *what* is happening. What do actors *do*?” (2008, 74). And the best way to study the enacted-acting body is by focusing on specific practices.

### Empirical Studies of Acting/Enacted Bodies

The example of hypoglycaemia is examined by Mol and Law (2004), and in this study the authors pay careful attention to the practicalities involved in doing bodies with diabetes. The method is simple, thorough ethnographic description to persistently foreground the

practices in which the hypoglycaemic body is being done and acting. The result is making visible that indeed, action moves around, and bodies, like other participating entities in the practices, do things. However, what is at stake is that “these active bodies are not isolated. Instead their boundaries are leaky. They interact and sometimes partially merge with their surroundings” (Mol and Law 2004, 53). One cannot disentangle human and technology – the active body that measures sugar levels from the measurement machine. Or the inside from the outside – a feeling of an impending sugar level drop and the restorative effects of eating an apple. Neither the division between self from other can be constrained within individual body boundaries – a diabetic person’s partner might be quicker to detect a hypo on its way and intervene to avoid it. The body-in-action has semi-permeable boundaries; it is not singular or limited by one stable and resistant boundary. The body-with-diabetes hangs together as a non-coherent whole, with internal frictions, such as the tensions between the interests of different organs. Ultimately, Mol and Law write, the wholeness of the body is achieved through a lot of work. The embodied person and a myriad of other entities need to intervene for a body to hang together in practice (2004).

The wholeness of a singular body becomes less self-evident when the focus is on bodies that live with disease. Their situational and relational character comes to the fore as “the single human being that forms the heart of humanism gives way to a composite picture involving many measurements, numbers, intuitions, habits, humans – not to mention dead ends and (often unresolvable) contradictions” (Mol and Berg 1998, 7). In the same way, Haraway, writing about the history of immunology, asserts that individuality is a matter of self-defence given that “disease is a process of misrecognition or transgression of the boundaries of a strategic assemblage called self” (1991, 212). She deploys her well-known trope of the cyborg – that blurs the boundaries between bodies, organisms and machines – to challenge the assumption of organic wholeness that underpins the dominant notion of individuality: “the cyborg is also the awful apocalyptic *telos* of the “West’s” escalating dominations of abstract individuation, an ultimate self untied at last from all dependency, a man in space” (Haraway 1991, 150-151). Thus, a material semiotics approach – espoused and reflected by the work of all authors here cited – lends itself as a valuable tool to theorise the body in specific practices without assuming a singular and bounded intrinsic character of the body. Hence, affording a way out of the pervasive dualism that bifurcates into either studying the body as a subject or object. Either being a body or having a body. Both options are restrictive if one wishes to explore how bodies are

enacted and acting in the practices under study, as they both carry the risk of importing reified notions of the body as external materiality without agency.

STS incitement to engage with practices and professionals that deal with bodies – medicine and biology being the most widely researched domains – to encompass the active participation of materialities, is also a move to embrace the political dimension of social science. Writing about bodies can never be disentangled from discussions about values, about rights and wrongs, and how to address and intervene in the particular issues under analysis. Furthermore, as Latour reminds us, to move away from a distinction between subjective and objective bodies “is not to abandon the difference between badly and well-articulated propositions. On the contrary, it is to push the frontlines of the struggle *inside* the sciences themselves” (2004, 227). Therefore, incorporating materialities and examining the practices in which bodies are being done, is a crucial necessity in order to advance a version of social science and STS that aims to make a difference and intervene in the situations that it studies. Such political endeavour cannot come into full force unless we find ways of writing bodies outside the subject or object dichotomy. Ways of doing research that are not confined to the domain of the social, the individual actors’ perspectives, but that also encompass the sociomaterial complexities of technoscientific practices. After all, such practices are the conditions of possibility for particular enactments of bodies, and if we leave them unexplored, their workings will remain unarticulated and thus not amenable to discussion or change. Or in Latour’s own words: “if what is to be assembled is not first opened up, de-fragmented, and inspected, it cannot be reassembled again” (2005, 250). The quest for political relevance will be further discussed in section 3.4. First, I will expose how theoretical notions of agency and materiality in relation to the study of bodies in practices are mobilised in this empirical research.

### **3.3.1 – No Heroics, Please IV: Including Participating Bodies and Organs**

This thesis aims to contribute to studies in the social sciences that engage in theorising the body outside the subject/object dualism and that reconsider notions of agency and materiality. In short, it includes the intervention of both bodies and organs in the practices of donation under study. That is, foregrounding the practices in and from which the figure of the donor/body emerges. Drawing on Mol and Law (2004), chapter 6 starts by posing the question ‘how are donors *qua* bodies being done in these hospital practices?’ Above all, it is a speculation of how to articulate notions of agency and materiality,

rendered as distributed and relational action, from a nonanthropomorphic stance. The challenge is to avoid reifying once more the polarised and hierarchical binary that divides entities into either subjects or objects. In particular, the entrenched distinction between acting subjects versus passive objects. I contend that much of the literature reviewed in the previous chapter, social studies of organ donation, has approached the question of the body within the limitations that are inherent to the application of the subject or object dichotomy. This stance will be clarified and discussed in prospective empirical chapter 6, however, here I wish to briefly point to Lock's work as an exemplification of the issue at stake. Lock, along with Schepper-Hughes (1987), advanced the notion of 'the mindful body' as a prolegomenon to medical anthropology work. The purpose was to move away from rationalist renderings of personhood that neglected the body and restricted human life and individuality to the neurological domain, the brain or mind-self. Her influential work on brain death disputes takes the issue further, as it deals with a very particular entanglement between persons and bodies. In her own words: "although rarely referred to explicitly, knowledge, particularly from the Christian tradition, buttressed by the Enlightenment philosophy, contributes to a tacit understanding that makes it appear rational to think of brain-dead bodies as objects that can be commodified" (Lock 2004, 144).

Lock's concept of 'living cadavers' acts as a dispositif to bring forward the troubling nature of organ procurement from brain-dead donors. Mainly, the ambiguities that emerge as foundational boundaries like those of life or death and person or thing are being trespassed. Bodies feature at the centre of her analysis; to her they are bodies that outlive persons. However, corporeal activity identified in brain-dead donors is described as 'observable signs of life', both in donor families' and medical professionals' accounts. Thus, the action that takes place within the body is ultimately attributed to the disputed dead person. Bodies might be acting, but they only do so within the parameters of autonomous anthropomorphic agency. This means that her accounts of acting bodies epitomise her stance that brain death – defined as death reinvented for transplantation purposes – does not equate to an irreversible death diagnosis but rather to the troubling category of 'good as dead' (Lock 2002). Thus, I sustain that as much as bodies become active agents, they are still oscillating between either acting subjects or passive bodies. The donor figure as 'living cadaver' fluctuates between either being a dying person, a legal subject entitled to human rights, or a corpse, no longer a person and hence dispossessed of former individual rights, that becomes objectified within medical practices of organ procurement.

The purpose of this analysis is not to point at Lock's works shortcomings. As made clear in the previous chapter, her work is deeply rooted in the discipline and style of critical medical ethnography. Theorising the body by mobilising other notions of ontology, materiality and agency has never been part of her intellectual pursuit. Nevertheless, her work and that of other reviewed medical ethnographies (Fox & Swazey 1974, 1992, Hogle 1995, 1999, Sharp 2006, Jensen 2010, 2011b) effect some significant exclusions that I wish to address in the following empirical investigation. Mainly the claims that donors, described in Lock's work as cyborgs or hybrids, are subjected to reductionist practices of procurement that turn the patient into a donor, demote the person to a thing, and fragment the whole into parts. Those are all processes that are undergirded by the ultimate transgression, the fall from subject to object. Lock's work is crucially concerned with this problem as her critique of commodifying medical practices advances. In my view, her work, amongst that of others cited above, deploys antagonistic renderings of subjects versus objects as it seeks to unveil and denounce the practices that reduce patients from ends to means. And it is precisely this critical stance that I crucially wish to deviate from, for I sustain, this approach only enables an analysis based on exclusively foregrounding the controversial side of donation, and moreover pinning it down to the brain death disputes. Instead this project advances under the pressing need to re-craft notions of agency and materiality outside the subject or object binary, and to advance an account of donation practices embedded within healthcare, routinized and uncontested but with several axes of frictions. The following empirical chapters will develop this line of argument through an articulation of donation practices that are both procurement and healthcare, and that encompass some donors declared dead following neurological criteria and some others declared dead by cardiac criteria. Brain-death diagnosis is neither more controversial, nor less 'credible' than cardiac death diagnosis. All donors in the TCs' practices are considered equally and irreversibly dead. The objective of this research is to examine how donors/bodies participate in the given donation practices outside the subject or object ethical quandary, alive or dead, patient or donor as mutually exclusive dichotomies. To do this, it is necessary to shift the attention to bodies-in-practice, and to leave behind, as Mol and Law (2004) suggest, knowledge-based accounts that inevitably bifurcate into either objectified rendering of the body in medical professionals accounts or subjectified accounts of patients' perspectives.

In chapter 6 I will present the theoretical tools more in-depth and I will argue that accounting for bodies as actors is not a case of simply extending agency to the domain of

materiality, as this would also entail trading in humanist notions of autonomous agency. Rather, the enacted/acting donor/body-in-practice will be studied mobilising nonanthropomorphic notions of agency and materiality, with a clear focus on embedded actors and entangled action. This approach represents a major digression from previous social studies of donation; particularly on the front of opening up novel ways to account for organs outside social constructionist takes. Previously presented accounts have defined organs along the polarity of either gifts or commodities (Sharp 2006, Lock 2002, Hogle 1995, Joralemon 1995 and Healy 2006). Once more, it is the normative splitting violence of the subject or object hierarchical binary that is at work here. On one side we have the medical accounts of ‘mere biological organs’, and on the other, personified organs that carry the identity of the donor. Organs are defined according to two opposed meanings corresponding to medical or patient’s discourse, depersonalised materialities or spare parts, versus, anthropomorphic living parts that embody the donors’ identity. Such accounts exemplify rather fittingly the division of labour that Latour (2000) refers to, social sciences that deals with the social only – representations or meanings as secondary qualities – and that inevitably excludes primary qualities or things in themselves. I presume that it is these works’ focus on discourse – with a clear loyalty to representing the patients’ perspectives so as to draw attention to ‘the social lives of organs’ that they see excluded from medical accounts – that pre-empts any possibility to address the materiality and agency of organs. And moreover, it only grants organs the privilege of social lives. They are still mute objects, singular and extrinsic, amenable to different definitions that acting and knowing subjects might adhere to them.

The shadow of Lock and Schepper-Hughes’ ‘mindful body’ (1987) looms large in these accounts along with the anthropomorphic exclusions it entails. I contend that such an approach is limiting in that it only considers organs as mute externalities devoid of capacity to intervene in the donation practices where they emerge, and it entails normative prescriptions that are only fit to build a critique to the powerful in the name of the disempowered. I suspect a Marxist spectre is haunting the aforementioned works, with its critique of commodification of human life and the body, their denunciation of doctors considering organs as alienable goods, and their unmasking of practices that turn humans into means rather than ends on themselves. All in all, a humanist framework that heralds sovereign subjects with subservient docile bodies and organs as objects, narrows down the scope of the analysis to a critical take on the asymmetrical struggle between who gets to attach which value to the given goods and who can lay claims about ownership on the property. It still leaves the question ‘what is going on in the medical

practices' unexplored. On the contrary, this STS investigation drawing on a material semiotics framework, is about mapping the hospital practices, the making of the choice about donation; the conditions of possibility for organs to become donated and transplanted to someone else. Thus, in empirical chapter 6 I will be asking 'how are organs enacted and acting during the maintenance and extraction procedures?' The focus will shift to emerging organs-in-practice along the processes of assembling donations in the hospital.

### **3.4 – On Political Relevance: Intervening to Make a Difference**

Doing STS after the ontological turn, and advancing detailed studies of specificities and practicalities around the topic under study, is also premised on a committed long-standing aspiration within the social sciences to produce relevant knowledge, which can be mobilised to make a difference in the situation under examination. The shift to foreground the political responsibility of doing social research is crucially concerned with broadening up the scope of action and intervention afforded to the social sciences. Mapping technoscientific practices and incorporating materialities grants the given investigation the possibility to engage with "this assembly in charge of composing the common world that should rightly be called politics" (Latour 2000, 121). Latour's notion of politics is very much aligned with that of cosmopolitics advanced by Stengers (2005). The latter appeals to a common world in the making, where notions of ultimate truth and goodness cannot be taken as pre-given. Rather, the call is on questioning, creating a space for hesitation, on what we mean when we say 'good'. It becomes a matter of collective thinking, with all the possible agreements and disagreements those will generate, around particular political issues. Stengers' cosmopolitical proposal does not strive to provide generalist answers that apply to all contexts but instead pays close attention to specific settings where practitioners operate, where the relevant questions are to be posed and jointly deliberated (2005).

Latour incites us to move beyond a 'sociology of the social' to avoid further reifying exclusionary frameworks that neglect objects, defined in his work as things or assemblies. To him any knowledge inquiry that is restricted to the domain of the social inevitably leads to explanatory accounts based on a limited repertoire of social causes, which mostly hinge upon worn-out stories of power, domination or exploitation (Latour 2005). The consequence is that social science's purchase rests mainly on its critical power, understood as the ability to denounce or criticise that which it brings new knowledge

about. Along parallel lines, Mol, referring to social studies of medicine in particular, has affirmed: “our theoretical frameworks seem to be exclusively adapted to the task of ‘criticism’. They unmask. They tend not to explore or build ideals but to undermine them” (2008, 103). In order to go beyond the limitations of denunciation, the urgent task at hand, as Law (2002) has argued, is to foster new ways of doing research that are more attuned to material semiotics’ conceptions of partial knowledge and situated understanding. Doing research in a world full of uncertainties, ambivalences and complexity can no longer give the researcher the privileged position of the knowing outsider: “the luxury of standing outside, criticizing, and correcting is no longer available...the hands of the storyteller are never clean” (Law 2002, 11). Thus, the reflexive stance of the researcher ought to attend to the performativity of her accounts, to cultivate a heightened awareness of her intervention in the current state of affairs that she is already giving visibility to, and hence opening it up for discussion. To Law, a rigorous and interventionist social science must be reliant on methods that enable ‘fractional ways of knowing’, that is, that depart from centered accounts of knowledge infused with certainty and that advance explanatory frameworks about an extrinsic and singular reality (Law 2002). Knowledge is always partial, but never innocent, hence, the matter at stake is to learn to produce knowledge that strives to become politically relevant. There is no solid ground upon which one can erect normative statements, neither matters of fact nor ethical principles can be appealed to in order to close any account and declare who is to be blamed and who to be defended. As Mol put it, “many elements are balanced and they will never come to a standpoint...tolerating open-endedness, facing tragic dilemmas, and living-in-tension sound more like it” (1999, 83). The key is to be found in thoroughly detailed empirical studies that foreground the practicalities and specificities of the topic under study. This is because, as Latour argues in his plea to move away from denunciation, “one’s own actions ‘make a difference’ *only in a world made of differences*...critical proximity, not critical distance, is what we should aim for” (Latour 2005, 253). Thus, the incitement is to develop an ethnographic gaze that provides thorough descriptions of particular cases studies. The resulting product never amounts to an all-encompassing explanation, or to easily generalizable answers. In fact, it will most likely be “a fragile intervention consisting only of text” (Latour 2005, 256). Nevertheless, case studies will help to open up questions, to interrogate available answers and to contribute to more nuanced ways of approaching and performing the particular topic under study. To Mol and Law (2002), case studies hold instructive potential about the particular site, as well as being able to travel and sensitise the study of other sites, where similarities and differences will abound but deserve further investigation.

Mol (2008), and along with Moser and Pols (2010), has further reflected on the purchase of empirical science studies to engage seriously with the question of values – of goods and bads in practices. Referring to the domain of medical practices specifically, the authors explain that a theoretical and practical focus on care can help to move away from polarised portrayals of paternalistic doctors versus disempowered patients. The latter can be found copiously within disciplines such as medical sociology and anthropology, and it is heralded as the trademark of their critical edge. Mol, Moser and Pols (2010) elucidate that critical social scientists have tended to approach medical practices espousing a normative position deeply rooted in the principles of medical ethics. Those can be encapsulated in the protection and enhancement of patient autonomy and the right of the patients to take their own decisions. Hence, social science “evaluated care practices as either respectful (good) or undermining (bad) of patient autonomy” (2010, 12). However, the individualised and rationalist ideal of patient’s choice has proven to fall short in grasping the intricacies of care practices that deal with disease. Complex sociomaterial entanglements, unruly bodies and vulnerable patients have not been included in what Mol calls the ‘logic of choice’ (2008). Furthermore, a critical stance that defends patients’ rights does not contribute to the necessary task of unravelling the given practices in the first place. Thus, it becomes a normative position whose intervention ends with denunciation. This makes a very small difference to the lives of those affected. Seeing the wrongs identified will not improve their lives as patients, because ultimately, they cannot choose not to be patients and remove themselves from the problematic situation. Their relational lives, bodies and disease condition are thoroughly interdependent with the care practices in question. Thus, Mol (2008) proposes instead to cultivate the logic of care, which proceeds from the preliminary question ‘what is happening in the practices?’ so that a better mapping of their complex issues can be advanced. The purpose is to address the difficulties and to try to improve them. In contrast to the logic of choice – deployed as a measuring standard to pass judgement on the practices – investing in the notion of care foregrounds that any practice will encompass different goods and bads. Some of them might peacefully coexist whilst others might clash (Mol 2008). Tension and frictions are an inherent part of any practice. They represent an element to be explored, in practice, rather than to attempt to erase them in the name of overriding humanist principles. It is not about finding an answer about which good is to be fostered above all: “rather than using large brushstrokes to cast the care we come across as either good or bad, we give detailed descriptions in the hope of opening up questions to do with qualities and values in new ways” (Mol, Moser and Pols 2010, 11). Thinking with the notion of care demands an innovative attitude to researching and writing about healthcare practices and living with

disease. Above all, the researcher is expected to become attuned to specificities, practicalities and to cultivate sensitivity to “persistent tinkering in a world full of complex ambivalence and shifting tensions” (Mol, Moser and Pols 2010, 14).

Haraway’s (2008) multispecies work on instrumental relations between humans and laboratory animals shares Latour, Law and Mol’s joint proposition to move away from denunciatory critique and instead cultivate a serious engagement with the complexities of the practices under study, to explore and address the difficulties directly so that better ways of going about them can be fostered. The main issue at stake with experimental research practices, as Haraway explains, is that the suffering of animals can neither be eliminated nor legitimised appealing to regulations and practical necessities. Such instrumental relations between humans and animals cannot be vilified since “use, instrumentality are intrinsic to bodily webbed mortal earthly being and becoming” (Haraway 2008, 71). The relevant question thus becomes, the author posits, what responsible research practices might look like within the affordances and limitations inherent to our historical coordinates. It becomes a matter of encompassing the suffering of animals; an approach of ‘sharing suffering’ is based on a relational living-with stance that proposes that:

“... entities with fully secured boundaries called possessive individuals (imagined as human or animal) are the wrong units for considering what is going on. That means not that a particular animal does not matter but that mattering is always inside connections that demand and enable response, not bare calculations or ranking. Response, of course, grows with the capacity to respond, that is, responsibility. Such a capacity can be shaped only in and for multidirectional relationships, in which always more than one responsive entity is in the process of becoming. That means that human beings are not uniquely obligated to and gifted with responsibility; animals as workers in labs, animals in all their worlds, are response-able in the same sense as people are; that is, responsibility is a relationship crafted in intra-action through which entities, subjects and objects, come into being” (70-71)

The notion of responsibility here extends the capacity to respond, response-ability, to animals rather than restrict it to participating human actors. Nevertheless, the distribution of responsibilities in research experimentation practices is inevitably asymmetrical. Haraway notes that this is a point that is missed out by extant polarised approaches on the subject of animal experimentation. Both positions, either animal rights defenders that condemn the practices, or those who justify them by appealing to the human good, are based on taxonomic calculations that draw upon individual-based

definitions of self-similarity and equality in order to support their claims about the 'greater good'. The trouble with such dichotomised approaches is, firstly, they are grounded on atomised notions of liberal individuals as 'autopoietic wholes', and secondly both sides ignore that "the claim to have Sufficient Reasons is a dangerous fantasy rooted in the dualisms and misplaced concreteness of religious and secular humanism" (2008, 89). Thus, Haraway in a similar vein with Stengers' speculative philosophy, states that any necessary articulation of the matters of concern at stake will have to proceed without "the god trick of self-certainty" (2008, 88). Reasons are necessary but not sufficient when one wishes to address the complexities of intrinsically asymmetrical instrumental relationships. An appeal to reasons "does not end the question; it opens it up. Maybe that's all *nonhumanism* means" (2008, 92). On the whole, attentiveness to interrelated vulnerabilities and 'shared suffering' also carries an obligation to care, to nurture responsible practices with and for other animals. Haraway concludes that this cannot be achieved within an ethical framework based on humanist principles. Instead, "multispecies flourishing requires a robust nonanthropomorphic sensibility that is accountable to irreducible differences" (2008, 90).

Haraway's call to move away from an anthropocentric normative stance and to decenter the human as the individualised sovereign subject of Reason, is in symphony with Latour, Law and Mol's extensive work, and it is premised on an iterative probing of established notions of the human, a contestation to universalising notions that efface the fact that after all the very same notion of human is what is produced, as the expression 'the abstraction of the Human' neatly encapsulates (Haraway 2008). The incitement of the aforementioned authors is to produce relevant knowledge that can intervene in the task of composing a common world, which has to proceed without the enlightenment of humanist rationality and a fixed normative stance based on individualising ethical principles. It is an uncertain and unpredictable world and our entangled existences are part of it. The task of the researcher is to grapple with this complexity, to exercise a speculative approach, an inquisitive take on the specific practices under study. In order to enable the cross-examination of existing answers and the emergence of novel questions with the purpose to sharpen the political engagement with the prevalent tensions that are to be tinkered with. This is the necessary path to becoming politically relevant and making a difference that pulsates under this research project and that the next section will further articulate.

### 3.4.1 – No Heroics, Please V: Mapping Donation Practices and Becoming Politically Relevant

The previous theoretical discussion will be mobilised here to examine the different normative approaches that underpin existing studies of organ donation. I argue that the diverse ethical allegiances have contributed to shaping the ways in which the topic has been previously rendered. I will also examine how this work sits within the available approaches and what type of account about such medical practices and practitioners this thesis advances. This has been a constant source of reflection throughout the development of the PhD, as this research has evolved whilst navigating the polarised moral landscape on the topic. Maybe the struggle could be summed up as a process of finding other ways to narrate donation practices outside the antagonistic ethical normativities that populate the literature; either those that take a denunciatory critical angle on the practices of procurement or those that justify and praise organ donation as legitimate healthcare practice.

The first position has been advanced within medical anthropology under the critique of aggressive procurement practices and the commodification of the body in medicine (Youngner, Allen et al. 1985, Fox & Swazey 1974, 1992, Fox 1996, Hogle 1995, 1996, 1999, Lock 2001, 2002, 2004, Schepper-Hughes 2000, 2001, Sharp 2006). As noted previously, the denunciation is directed at the objectifying, reductionist and dehumanising aspects of organ procurement that turn patients into donors or persons into things. It identifies the ethical transgression posed by such practices that demote subjects to objects; individuals are no longer treated as ends in themselves but as ‘mere means’ to other ends. It is a critique that purports to unveil the wrongs committed under the morally prevailing ‘gift of life’ rhetoric, which is seen to obscure the workings of powerful financial interests in the transplant industry that has progressively routinized donation practices. The authors have undermined the unquestionable goodness of transplants, arguing that this must not be invoked as the reason that can silence any problematic issues that emerge from procurement practices. They explicitly bracket off the dominant accounts about the ‘gift of life’ and the goods of transplants, as Lock explains, their focus is on unveiling what has been left out from dominant heroic accounts, that is, the rights of the donors and the suffering of their families (Lock 2003). The accusation is directed at the corporate interests of procurement organisations, their “chilling utilitarian ethos” (Sharp 2006, 12) is thus vilified in the denunciation of increasingly commodifying practices. The conflict is between the medical professionals’ objectification of human bodies and organs, as

alienable commodities, and the discrepancy of discourses with donor families and recipients' subjectified accounts of the former. I contend that this mode of critique is deeply entrenched within the US private healthcare setting and the profit-oriented OPOs that operate outside the hospitals; it entails an account of donation as procurement and it effaces its healthcare dimension as it leaves out the domain of transplantation.

A second approach to donation practices can be identified in contemporary works that move away from critique and that instead praise the goods of donation as embedded healthcare practice. Crucially these are works that emerge from countries with public healthcare universal provision; wherein the commodification critique seems to lose its sway. A clear example is Jensen's ethnographic accounts of donor families and medical practitioners in a Danish hospital (2011), and her later work with Hoeyer (2012, 2015). They not only take a step away from accusations of objectifying practices, but moreover, they advance that organ donation also has its goods, that donors are treated with respect, their deaths become extraordinary, and that medical professionals' conduct is above all caring towards the families; their interests lie in 'orchestrating a good death' for the families not in procuring organs for transplantation. This version of donation defends that donors are not objectified but treated as subjects, not reduced to 'mere means' but ends in themselves. The deontological ethical principle that the US critique of commodifying procurement saw disrespected is here preserved, the goods of donation heralded and praised without recurring to the ultimate justification of saving lives with transplants, which is absent from medical practitioners' accounts (Hoeyer, Jensen et al. 2015). I speculate that such normative positioning and account of donation is also shaped by the type of practices and practitioners under scrutiny, that is, ICU nurses that are responsible for critical patient care and whose work is largely dissociated from transplantation. Ultimately, or so I would claim, this version of the goods of donation as caring practice is enabled by downplaying that donation is directed at the procurement of organs for transplantation.

A third type of approach to donation, that in contrast to the former one, does account for its dimension as procurement for healthcare, can be found in the Spanish model policies. They are praised as a referent to follow in order to alleviate the organ shortage crisis by the European Union regulatory framework (Watson 2010) and World Health Organisation's recommendations (WHO 2011). They offer the solution to the organ shortage; the practices and protocols advanced are geared towards increasing the numbers of donated organs, legitimised by the commendable good of saving lives. The

shortcomings of deontological ethics, or the bads of procurement become neatly glossed over in the official rhetoric of world leaders and the heroics of transplants; an example is the ONT director's book 'the miracle of transplants' (Matesanz 2006).

This thesis opens up a fourth way to narrate organ donation, encompassing the practices and practitioners involved. It does not seek to denounce the bads of procurement, as in US-based critique, nor to justify them by their associated healthcare-related goods, either those concerned with donors and families, such as in Danish works, or those that foreground the needs of transplant recipients as in the Spanish model discourse. It is an investigation deeply committed to accounting for the complexities and specificities of the medical practices of donation, which include many goods and bads and in-betweens. Donation is studied as an integrated hospital practice but with a set of enduring frictions that can neither be removed, nor justified or vilified with an appeal to reasons and ethical principles based on an individual rights-based normative stance. In donation, the centered subject of humanism, endowed with rights of autonomy and integrity, is thoroughly disrupted, as the practice is ultimately directed at procuring organs and tissue to be circulated to other patients. This thesis is grounded on the premise that even though donors as patients do become means rather than ends in themselves, this is not necessarily wrong, but it entails inexorable difficulties in practice. Hence, this study will interrogate empirically the question 'what type of situated medical practice is donation?' The accounts will above all trace the partial connections, and disconnections, of donation as both procurement and healthcare. Drawing on the joint incitement from Haraway (2008), Latour (2000, 2004, 2005), Law (2002), Mol (2002, 2008), Mol, Moser and Pols (2010) to extend the remit of the social sciences beyond denunciation so that political intervention can become enabled, this research also moves within, and expands, the interstitial spaces between critique and justification. The political purpose is to produce relevant knowledge that can be called upon to intervene in the current organ shortage problematisation. Crucially, and so I will be arguing in the next chapters, a scrutiny that focuses on the complex sociomaterial entanglements that constitute the practices of assembling donation processes, is a primary condition to foster new questions to emerge and to interrogate the validity of existing answers to the problematisation of low donation rates.

The aim of an in-depth mapping of donation practices is not to offer the solution to increase low donation rates, as in the Spanish model protocols and prescriptions, but to foreground the practicalities and specificities that are contingent to situated practices of

organ and tissue donation in a hospital with distinctively high rates. This empirical task will be carried out by careful attention to the distribution of responsibilities in the TCs' practices along the different stages of the process. It is an investigation that heavily invests in the notion of responsibilities, as advanced by Haraway (2008), given its potential to foreground multidirectional relationships and the differential response-abilities of the various participating entities in the medical practices. Distribution is another major theme in the analysis that follows, in which the theoretical approach presented will be put to use to decenter the autonomous subjects and objects to broaden out the scope and encompass collective action, entangled actors and relational interdependencies. The question to be addressed throughout the analysis and duly examined in the final chapter will be: from a thorough mapping of the particular hospital donation processes, how can this research contribute to a discussion on fostering responsible donation practices? Or in other words, to inquire about collective practices of procurement for transplantation that are responsive to donors, families, recipients, medical professionals and policy-makers involved.

## 4 – Methods

### 4.1 – Research Aim and Objectives

This chapter will defend the methodological approach that was chosen and operationalized to address the research aims and objectives. It will firstly provide a discussion of ethnographic methodology that will trace the connections between anthropological and STS' approaches to doing ethnographic work. Special attention will be given to issues such as prioritising a focus on actions with decentered actors' personal perspectives, tropes of visibility and the anthropological prerogative of 'being there', and conducting an ethnography 'at home'. The former issues will be further articulated and related to my particular use and experience of ethnographic methodology to study donation practices at the Hospital Clinic. The chosen research methods of non/participant observation and in-depth interviews will be defined prior to introducing a discussion on the practicalities and specificities of their use to address the research questions whilst conducting fieldwork. An extended section about research ethics will combine and connect relevant literature on the topic and this project's trajectory of dealing with various ethical issues, such as gaining ethical approval from the University of Edinburgh and the Hospital Clinic, negotiating consent, anonymity and disclosure with participants prior to, during, and after fieldwork. Finally the process of data analysis and writing up of the thesis will be briefly explicated.

As the research outline has already been introduced in the preceding chapter along with its theoretical underpinnings, here only a brief summary of the project's primary aim and key objectives will be provided to set up the forthcoming sections on ethnographic methodology. The specific research questions will be introduced at the start of each empirical chapter.

- *Research Aim:*
  - To map the hospital practices of deceased donation in a Catalan hospital with particularly high donation rates and a consolidated TC team.

- *Research Objectives:*
  - To provide an in-depth scrutiny of the practicalities and interdependencies between different actors and factors that intervene in the trajectory of assembling donation processes at the given hospital.
  - To trace the TCs' distributed responsibilities throughout and in each stage of the donation process, from detection, evaluation and maintenance of eligible donors, to the consent request with families and the final organ and tissue extraction.
  - To examine how the donor figure is embedded along the medical practices of donation.
  - To interrogate empirically how bodies and organs are enacted and acting in the process of assembling donations in the hospital.

## 4.2 – Ethnographic methodology

This research project draws on ethnographic methodology to study hospital practices of deceased donation. As previously noted, the site where fieldwork was conducted is the University Hospital Clinic of Barcelona. The choice of a single case study design is consistent with the theoretical and analytical framework presented in former chapter 3. I make no claims on the generalizability of this thesis' findings to the whole of the Catalan territory, let alone the Spanish one, or as a representation of the Spanish model. The hospital is embedded in a political and historical context, and this does come into the analysis of the practices, but it is nevertheless its particularity, and specificity of practices of donation processes, which is under study here. I subscribe to Mol's (2002) consideration that when the focus is on processes and modes of coexistence, then one hospital might contain them all. The final discussion chapter will develop how such analytical attentiveness to situated specificities and contingencies of donation processes enables this research project to offer some key insights that contribute to current problematisation of organ shortage that looks into ways of increasing low donation rates.

This present ethnographic study does not adhere straightforwardly to Silverman's (2006) textbook definition of ethnography as the study of people in their natural settings, in order to know and understand their activities and the social meanings that underpin

those. Similarly, it digresses from Geertz's (1973) interpretative anthropology take on the use of 'thick description' to unveil the actors' constructions and meanings about their actions. As has been articulated in the preceding chapters, the purpose of this ethnography is to map the practices of donation as a process of assemblage. Different actors, meanings, knowledge and perspectives become decentered so as to take a broader, and hence less anthropocentric, approach to the clinical practices under study. After all, this is not a work of cultural anthropology. However, it is interesting to note that STS as a discipline has drawn prominent lessons from this field. Mainly, that cultural practices – scientific practices being another version of those – involve materialities and that objects are also invested in meanings (Mol and Berg 1998), which is the position that sustains Latour's prerogative for an anthropology of science (1996). Similarly, it is possible to trace back the partial connections of Mol's work on multiple ontologies with the ethnographic work of Strathern (1991). The latter is a prominent cultural anthropologist whose influential work on Melanesian social life has contributed greatly on the development of notions of multiple ontologies, mutual inclusion and topological interrelations between self and other, part and wholes, the local and the general (1991).

The fieldwork methods deployed to studying decentered processes in practice do not need to differ substantially from those that underpin cultural or social ethnographies. Rather, the change resides in that they will be deployed to answer a question posed differently, from 'what is the object of study according to the actors' perspectives' to 'how is it done in practice'. The emphasis is not on uncovering a taxonomical list of different interpretations or actors' conceptualisations, but to follow how different versions of the object are enacted and coexist in motion, with all the interferences and clashes these processes can entail. Tracing the partial connections amongst shifting boundaries of differentiation requires an inquisitive gaze to be exercised on site. As Mol and Law put it, "sensitivity to multiplicity suggests a number of questions about similarity and difference, about the embeddedness of orders in language and materiality" (2002, 11). Overall, it becomes a task of following actions, unravelling processes in motion, as Bruun Jensen (2012) has largely captured in his claim that STS is 'the following science of following science'. The assertion is based on his use of Deleuze and Guattari's philosophy to define anthropology as a 'following science' with an itinerant and nomadic character in pursuit of "following a flow in a vectorial field across which singularities are scattered like so many 'accidents' (problems)" (1987, 372 in Jensen 2012, 3), which Bruun Jensen sees as the predicament of ethnography. Additionally, the author, contends that both the conceptual and the empirical domain cannot be separated neither in STS ethnographies – identified

as over-reliant on the conceptual - nor in anthropological work – over-reliant on the empirical – and that instead, it is a matter of identifying lateral movements and overlapping trajectories between empirical settings and conceptual resources (2014). Such task requires, needless to say, inventively employing research methods that can respond to dealing with situated enactments, multiplicities and complexities as processes on perpetual motion. Law (2004) has suggested crafting what he calls ‘methods assemblage’ to enable social science to stay with the ‘mess’, or to become sensitive to the non-singular, non-coherent and non-out-there reality. The aim is to move away from representational knowledge of reality and instead to mobilise research methods to act as ‘reality-detectors’ and ‘reality-amplifiers’ (Law 2004). Following Law’s call to develop other toolkits, Lury and Wakeford’s edited collection (2014) presents a perpetual inventory of inventive methods to study the enactment of the social. In parallel with Law, the authors assert that the inventiveness does not come ingrained within the method per se, but rather it is developed by the researcher’s use of it reflexively with a clear engagement to produce relevant research. The focus on mobile temporalities and material-semiotic objects of study is crucially concerned with the interdependence of what Bruun Jensen (2014) calls the empirical and the conceptual. Thus it is noted that “inventive methods grasp the excess of specificity that is always present in the actual by making relation to elsewhere as they make themselves...if they are able to grasp the here and now in terms of somewhere else” (Lury and Wakeford 2014, 12-13). A method will be inventive if it brings such disconnected things and concepts together, in a topological and fluid way, the entanglements between the problem and its context and definitions, both academic and non-academic, specific and general, in the pursuit to make it visible and to intervene (Lury and Wakeford 2014).

A shared characteristic of Mol’s empirical philosophy and Latour’s laboratory ethnographies is the focus on action rather than actors’ perspectives. The description of the processes at stake slowly traces the scale of the phenomena under study, and as Bruun Jensen writes “what is central is to depict how materiality shapes ontology in practice” (2012, 15). Bruun Jensen (2012) contrasts the tenets of STS empirical philosophy, action-centered, with those of cultural anthropology, in particular with the work of Strathern with indigenous peoples’ ontologies, actors’ conceptualisations-centered. Strathern contends that Mol’s bracketing of actors’ descriptions of their own actions produces significant analytical consequences and exclusions given its implication that “acts are not affected by how they are described...because blending the empirical and the conceptual, the inside and the outside, is what occurs in description” (in Bruun Jensen 2012, 18). In the

next section I will indicate my own take on such debate, right now, it is sufficient to say that finding ways of decentering the human in anthropology and STS is by no means easy but neither is it impossible, and as Wiener (2015) suggests in her move toward a 'nonanthropocentric pluriversal anthropology', the generative interface of both disciplines can be an appropriate site from which to shift boundaries and challenge 'taken-for-granted-habits and reflexes' (in de la Cadena, Lien et al. 2015).

Garforth (2012) is another author that takes stock of the STS ethnographic style that privileges action over actors. In particular, she situates the bone of contention in the study of scientific knowledge making practices as she identifies the shortcomings of Latour's early laboratory studies (1987). Mainly, she argues that STS overreliance on observational methods and tropes of witnessing, exclude that which remains invisible to the ethnographer's gaze. To Garforth these are the scientists' cognitive processes and solitary work. Latour's laboratory studies are said to borrow their authority from the prerogative of 'being there' or having been a direct witness of the scientific practices. Garforth (2012) indicates that Geertz's (1988) original notion of 'being there' was never deployed as mere witnessing but rather as a textual construction. Moreover, that the rhetoric of witnessing and revelation in Latour's work reifies the figure of a detached and external observer to the action under study. Thus, she argues, "that the lab study genre has tended to rely on the rhetorical authority of witnessing and revelation, rather than exploring the discursively and materially situated gaze and 'partial vision' (Haraway 1991, 1997) of the ethnographer as part of a reflexive methodology" (Garforth 2012, 12). With the purpose to make in/visibilities matter and to acknowledge the limitations of the 'ethnographic gaze', another element is also called forth, that is, the interactional relationship between researchers and participants. Garforth draws on Beaulieu's (2010) distinction between 'co-location' and 'co-presence'. The former corresponds to the detached witnessing of being there, whereas the latter foregrounds the negotiated and dynamic nature of interpersonal processes better described as 'being near and being with'.

Another aspect that can be said to define most STS ethnographies is that they take place 'at home', as opposed to traditional anthropological works on distant, sometimes remote, locations. Lien and Ween (in de la Cadena, Lien et al. 2015) illuminate the challenges of doing anthropology at home, in their case studying salmon practices in Norway, and how to deal with knowledge that does not appear special or esoteric but rather far too familiar to the researchers. Their suggestion is to persistently question taken-for-granted realities with strategies such as 'queering the familiar', because as they write "no matter how

familiar they might appear, our topic or units of study can never be really known beforehand. They are generated through fieldwork, step by step, at home as well as abroad. Hence they are emergent in ongoing field practices” (Lien and Ween 2015, 459 in de la Cadena, Lien et al. 2015). In the next section, I will relate my fieldwork experiences with aforementioned discussions around doing STS ethnographic work ‘at home’, on prioritising action over actors’ personal views and on the performativity of methods. I will also discuss the situated figure of the researcher sorting through theoretical and methodological choices and working around contingencies and limitations.

#### **4.2.1 – Doing fieldwork: Being where? Following what?**

Fieldwork took place in the Hospital Clinic of Barcelona, which is a large university hospital located in the centre of the city. The next section on research ethics will explain about the choice of disclosing the hospital’s name. As it was introduced before, the site was chosen for its high rates of deceased donation and transplantation. A short fieldwork stay - three weeks of observations and interviews with the TC team - was the preliminary work conducted for a first MSc in social research in 2010. The pilot findings were the base of the research proposal that later on developed as an MSc and PhD in STS. During the second masters I went back to the hospital, a week in 2011, to conduct further observations of TCs’ work in the hospital. The purpose of the stay was also to present the pilot work to the TC team and to propose a long-term ethnographic study as part of the PhD research. In the section about research ethics, further details will be provided on issues about access, authorisation and different consent procedures that were necessary to secure the opportunity to conduct ethnographic work in the hospital. It was agreed with TCs and the university hospital that I would spend six months shadowing the work of the TC team. After that, I was given a period of three months for interviews which also included several days a week access to the hospital.

Long-term fieldwork started after a two-year period of contact and yearly visits to the TC team in the hospital. Thus, by the time I began doing fieldwork, TCs already considered me an ‘old visitor’, and likewise I thought of them as my long-standing hosts in the hospital. It is a university hospital and the TC team have an ongoing array of visitors, mainly medical students on placement, or international students who wish to learn about efficient systems of organ procurement. Thus, my presence in the hospital was akin to that of another student eager to learn about organ donation practices. I became an addition to the TC team not an intrusion like in Garforth’s (2012) problematisation of co-

location in laboratory ethnographies. The TC team were very accommodating hosts from the start of our relationship. I was given a few white coats, keys to the different offices and meeting room, and I was even allowed to occupy a desk in the main TC office, along with the five senior members of the team.

The everyday work of TCs involves multiple face-to-face interactions with other healthcare and non-healthcare hospital practitioners, as well as many phone conversations with various other professionals from outside the hospital. As I entered the different hospital units, mostly ICUs and A&E with one or more TCs, I was introduced as a longstanding student visitor. I would when possible, add I was a social researcher from the University of Edinburgh, but mostly I was perceived as another transitory member of the TC team, another student doing a placement. I looked like one after all; I was wearing a white coat, eagerly taking notes, and had the perplexed look of someone new to hospitals that deal with patients in critical conditions. In contrast to Lien and Ween (in de la Cadena, Lien et al. 2015) I did not have to make any efforts to 'queer the familiar' while doing ethnography at home. Catalonia is indeed my country of origin, I might not live there now, and I have spent the past fifteen years living abroad, but nevertheless I speak both Catalan and Spanish and hence I was accepted as an 'insider' in the hospital setting. However, doing fieldwork in my own country did not equate to dealing with familiar situations aside from the fact that the languages spoken there were my own. The hospital setting and the TCs' work with deceased patients on an everyday basis is a disquieting place to call home. I would say that my process could be seen as the opposite of Lien and Ween (2015); my efforts were directed at 'domesticating the queer', or in other words, getting better at enduring the discomfort. The discomposure that I was subjected to was to do with everyday death at the hospital, there were many cases everyday but they did not become ordinary because of that. The realisation and constant confirmation that our bodies are vulnerable and that our lives are fragile is forever enforced in the hospital, especially when following the work of TCs. It is a lesson that even if it is hammered home on a daily basis, it never seems to lose a trace of its troubling primary effect. Or at least that was my experience whilst doing fieldwork. This was a lesson that hit me hard and loud as I came to know about people that died crushed by a palm tree, hit by a stalactite, a flowerpot or eating poisonous mushrooms. The wreck that follows some fatal collisions that involve, in any permutation, pedestrians, cyclists, motorbikes, cars, trucks, buses, trains. Some people die suddenly after a heart attack or a brain stroke, others have long disease trajectories and even some die at a very old age. But there are also those that cannot wait to die and kill themselves, self-defenestration, intoxication, hanging were all

effective methods. Some are murdered too. Others die iatrogenic deaths and never make it out of the hospital. Everyday death is part of everyday life in the hospital.

I cannot say I domesticated the general discomfort it produced on me; rather enduring it became part of this project, a necessary step in a long trajectory with some tricky passages. Its effects also translated into the type of observations that were included and excluded whilst doing fieldwork. On the whole I was given unrestricted access to all TCs' activities, but some I chose not to observe as they were altogether excluded from my research design, such as the living donation programme in the hospital. Others became excluded as I hit my own limitations. Detecting potential donors amongst A&E admissions is part of TCs' daily routines, and so I was there to observe. I didn't choose to faint on witnessing some cases with severe injuries and emergency medical interventions, but I did and this affected prospective fieldwork observations and decision-making processes. It was agreed with the TC team that they would inform me when the incoming patient was suffering from polytrauma injuries; on those occasions I wouldn't go along with TCs to A&E.

My researcher's role conducting observations of the TCs' daily tasks shifted from complete participation, group meetings where I was asked to contribute, to complete observer, during medical interventions or family interviews. As Junker (2003) noted, such role reversal is part of the ethnographic study and further shaped the type of information gathered. It was paramount at all times to reflect on my intervention on the sites of observation, thus, once I had observed multiple donation interviews with families of eligible donors I decided to stop attending and instead be informed by TCs of the families' response to the consent request. The reason was twofold, primarily because even though it is a very common situation in a university hospital for a healthcare professional to be accompanied by a student/observer, the particular situation of the donation interview made it very difficult to be a passive observer. Further details will be given on the issue of covert research in the following section on research ethics. And secondly, as it was agreed with the hospital that I would not collect any data about hospital patients and relatives, and the responses of families were not part of my research design, I considered it was unnecessary for me to be there, as a direct observer when TCs approached families to discuss donation. On the other hand, issues that emerged during my own observations or discussions with TCs about donation conversations were incorporated in the interview topic guide and further discussed with TCs during individual research interviews. Thus, I would agree with Trow's response to Becker and Geer's assertion that observational methods are superior to interviews in regards to capturing accuracy of events, in that

interviews give access to non-observable events and particular issues that escape direct observation (in Seale 2003). Similarly, I would join Garforth's (2012) problematisation of the use of Geertz's trope of 'being there' for STS ethnographies. I was not doing a laboratory ethnography, neither did I encounter the invisibilities that Garforth referred to as solitary cognitive work of scientists. Nevertheless, it became a matter of serious consideration to address questions on what becomes visible or invisible to a situated researcher in the hospital with a very specific interest. For my particular pursuit, to follow the donation process along its stages proved to be an enterprise not amenable to direct observation, nor a process that regularly developed chronologically along different identified stages. Different donation processes would be taking place simultaneously within the hospital; they involved many practitioners, and many sites, inside and outside the hospital. The task of the TCs is to coordinate the whole process of deceased donation from the hospital. The process of donation is not a singular object that can be observed as it unfolds; rather it is a complex and overlapping process of assemblage that takes place on different sites along simultaneous temporalities. It is indeed a topological process that connects remote factors and actors. I did not have to make any efforts to tune into the 'mess' that Law (2004) refers to, when studying donation processes reality does become a non-coherent, multiple, and complex, generative flux. Overall, during fieldwork I strived to gather information on donation processes as assemblage with a clear focus that my primary objective was to map the TCs' responsibilities along the process. Thus, it was not a case of observing the totality of the actions, as most of TCs' responsibilities relate to actions that take place elsewhere, in a laboratory, an ICU, another hospital or inside the eligible donors' bodies. Mapping responsibilities is different to following scientists, as Latour (1987) did in his early work, and also to following practices or actions like Mol's (2002) praxiography of atherosclerosis in the body multiple.

With regards to the discussion about prioritising the study of actions to the actors' descriptions and interpretations, my fieldwork experience was that I never got the choice. Even though a focus on action was inscribed in my research design and my theoretico-methodological stance, being there, in the hospital, and more importantly being with the TC team, meant that I was constantly exposed to their verbalisations about their work. It was beyond my choice to exclude actor's accounts, talking was part of their daily working lives, and further to that I was also included in most conversations that went on amongst the TC members in the hospital. Being there did not involve being a detached observer, simple co-location, but rather it entailed what Beaulieu (2010) refers to as co-presence, being near and being with as interactional processes. My fieldwork experience was also

largely interspersed by processes of being talked to and talking back as well, there was no outside from which to observe, only an inside that I was also part of as a situated and relational being amongst others.

### Observation of TCs' Daily Practices

TCs gather and work a large part of the day in their office, and as I noted previously, I enjoyed the privilege of being allocated a desk in the senior TCs' office. Unlike in Garforth's (2012) accounts, TCs rarely conduct solitary, silent work, on the contrary, time spent at the office was mostly talking time. It was never a case of separating talk from practice, their conversations were mostly about their job, and they included specificities, particularities and details of their responsibilities in assembling donation processes. I made copious use of field notes during these conversations, as well as when following TCs around the hospital. I implemented a system of notations, following Lofland's (2003) suggestion, to differentiate entries about detailed observations and descriptions, to verbatim transcriptions of dialogue, less precise paraphrasing or vague recall. Writing field notes at my desk allowed me some stabilising periods amidst the excess of information that constantly enveloped me during fieldwork. I experienced my researcher's role as subjected to processes of diffractive absorption of any information available on the process of donation, with all its ensuing indigestions and partial digestions. I was acutely aware of the excess of specificity within the actual that Lury and Wakeford (2014) refer to, and its entanglement with the many 'elsewheres'. Or in other words, there was no separation between the conceptual and the empirical during fieldwork, both domains, like Bruun Jensen (2012) states were interdependent and simultaneously present both in my annotated field notes and the interactions in the hospital. It would happen that in conversation with TCs we would be referring to an article published in a medical ethics journal, or a new policy implemented in another country, or I myself would bring in issues into our discussions, such as details about UK practices and policies in regards to donation, or ethnographic readings on donation in sites like Turkey or Japan. Additionally, the many visitors that entered the TC office also brought in other worlds, which also intervened in TCs' everyday practices; such as members of the central office OCATT, the director of emergency medical services, forensic, funerary, and legal practitioners, as well as a variety of medical students and professionals from the national and international domain. The TC office was also a topological site where many disconnected elsewheres, heres and nows unravelled and

further amalgamated contributing to my fieldwork experience and subsequent thesis writing.

In the office I also got access to the TCs' computer software and the many forms that comprise any particular donation file. A careful study of large numbers of these folders gave me an insight into what an assembled donation process or donor file looked like, what it involved and above all on the TCs' particular responsibilities coordinating the many intervening factors and actors. The TCs' work in filling in the forms was solitary and invisible, as in Garforth's (2012) ethnographic experience, nevertheless access to the completed files and folders in the office made their work and the many intricacies visible to me and prompted further questions and specific observations.

I fluctuated between observations of the TCs' unruly everyday work and readings of nicely packaged educational materials, handbooks, medical textbooks and articles that the TC team and others have written. I attended many university lectures for medical students given by the TCs themselves, and got access to the curriculum and materials of the postgraduate masters in organ donation offered by the university. I attended specialised workshops with TCs, and joined in international events that took place in the hospital that gathered practitioners from other countries who wanted to learn about effective systems of organ procurement.

Over the six-month period my diffractive absorption of information covered some stages of the process better than others. As it was noted earlier, some actions were excluded from observations: the evaluation of critical patients in A&E, and family interviews (after an initial period of observations). I intended to gain access to other areas of observation at a later stage of fieldwork, as these required securing access by other medical professionals in the hospital. This was mainly the stage of organ extraction, which usually takes place during the night, and involves many hours and the work of many different medical teams coordinated by a TC. However, by the time I enquired about the possibility I was told that it was no longer a choice I had, given that I was pregnant and as such not allowed inside the operating theatre. It became another exclusion from observations that I incorporated into the following stage of individual interviews with TCs. Another limitation I had to tinker with and resolve to gather information about from other means than by being there and seeing it. Nevertheless, being pregnant also afforded me some opportunities that further enhanced my researcher's reflexivity on site and off site and that contributed to the development of the project. Mostly, this was the process of becoming a patient in

another hospital as the pregnancy became considered high risk. It involved a constant monitoring of my then developing son and me; this meant several monthly appointments for various medical tests and at least a monthly scan. Time spent in the hospital as a patient – waiting hours are long so it was always a matter of half a day – brought to the fore the shifting distribution of restrictions and availabilities that intervene in being enacted as a patient in a Catalan public hospital. It enabled me to reflect on the differences and similarities between being an individualised patient in a consulting room and a hospitalised patient in ICU or A&E. It helped me to focus on the intervention of materialities, such as various medical technologies and my growing medical file. I was also made aware of the semiotic relevance of spatialities, in that individualised patients have the benefit of closed doors, while hospitalised critical patients are distributed within circular spaces to be observed at all times. The hospital I attended was at that time trying to introduce natural birth protocols, and to reduce the level of medicalization of birthing practices. I was a first-hand participant to the many tensions this incorporation produced, about the contingencies that set limits to such enterprise and the shifting shapes of the availabilities of choice. My experience as a pregnant patient there was greatly imported to the Hospital Clinic while doing fieldwork. It sharpened my focus into the process of donation as the making of the choice, and the necessary trajectories of closures that enable some openings of choice, with all the shifts and distributions of responsibilities along the different intervening actors throughout the stages. To sum up I would say that being a patient in another hospital was also a way of being there, in an ethnographic sense, as the experience prompted many reflections that shaped the development of the research's project to map the overlap and separation between healthcare and procurement, between patients and donors.

#### **4.2.2 – Interviewing the Transplant Coordinators**

The TC team were the sole research participants of this study, even though during fieldwork I interacted and gathered information on the work and responsibilities of many other hospital practitioners that contribute to the donation process. I had initially planned to interview some of them but after a few months of observations I had gathered enough knowledge about their jobs and responsibilities for donation practices, thus individual interviews were considered unnecessary.

It was during fieldwork and regular revision of field notes that I worked on emerging exploratory paths that shaped the consecutive stage of interviews. The research questions

became less diluted as I progressively analysed the data gathered and worked on the design of the interview topic guide. Following Charmaz's (2006) methodological advice, this study greatly benefited from a stance that saw data generation and analysis as two simultaneous and interrelated parts of the same generative process. Moreover, such iterative processes of data collection and analysis became crucial in the ongoing refinement of the project's scope, as it moved towards, what Hammersley and Atkinson (2007) have called, the 'funnel structure' of ethnographic methodology

I arranged individual interviews with all the members of the TC team. They were ten in total, five senior TCs, three of them doctors and two nurses, four junior TCs, all nurses, and the team director that was an ICU doctor (see Appendix 6 for List of Research Participants). I discussed with them beforehand that the interviews would serve the purpose of extending, supplementing and discussing issues that had become relevant during observations of their practices. The type of questions and research objectives were also included in the informed consent forms I distributed before each interview took place (see Appendix 7 for Informed Consent Form), more will be said about the latter in the next section. In short, the interview guide was structured along the different stages of the process of donation, detection, evaluation, consent request, maintenance and extraction, and it also included a section on the TC professional profile (see Appendix 8 for Interview Topic Guide I).

I made use of Mason's (2002) suggestions for designing qualitative interviews (there was a common topic guide and a grid of questions), but so as not to affect the conversational flow, I also allowed for any interviewee to alter the order, and expound on specific issues that sometimes were not originally included. During interviews TCs were reminded that I was interested in their situated practices, with an emphasis on 'relevant specifics'. Also drawing on Mason (2002), the interviews were designed and implemented as a way to delve deeper into the contextualisation and practicalities involved in their job as TCs, unlike other qualitative interviews that might put an emphasis on personal opinions, abstractions and phenomenological insights from individuals. The process was akin to what Mol (2008), whose work subscribes to a long-standing tradition of feminist methodologies, refers to as enlisting the collaboration of medical professionals as 'co-researchers', to extend ethnographic observations, rather than turning them into the objects of the study.

All interviews took place at the meeting room that is part of the TCs' offices. The duration was from two to three hours. It was not unusual that while conducting the interview the TC would get a call about a potential donor and had to leave the room. On most occasions, the interview was resumed on the same day when the TC became available, except once that the interview had to be re-arranged for the following day. All interviews were digitally recorded, TCs had agreed beforehand to my use of a recorder so that interviews could be transcribed later on. Information about the research process and use of materials was also included in the informed consent form that each participant signed prior to the interview session.

During fieldwork I had discussed with various TCs many of the issues broached during interviews, nevertheless the time constraints and other contingencies of our everyday interactions didn't allow for extended conversations. Thus the opportunity to conduct individual interviews with dedicated time for my questions was very much relished by me, and thoroughly enjoyed by TCs as they commented afterwards. Above all, our one-to-one conversation was underpinned by a shared engagement with the topic of organ donation practices. I was the social researcher asking questions to the medical professionals but I was neither a stranger nor were they informers about unknown actions to me. The previous months spent in the hospital doing fieldwork, and three years of interactions with the TC team, shaped the encounter away from a standard sociological qualitative interview with separated roles for insider and outsider that is premised mostly on a one-off event. Hence, my experience was more akin to that associated with ethnographic interviews, as in Roulston's (2010) definition, when the researcher has got a thorough knowledge of the context that the interviewees are embedded in, along with sites, events, people and objects.

Upon completion of interviews I attended and presented at a conference on ethical, legal and psychosocial aspects of transplantation in Rotterdam<sup>16</sup>. It is an international event that gathers both social scientists and medical practitioners of all kinds around thematic discussions on both organ donation and transplantation. Many issues that had become salient during fieldwork and that had entered my discussions with TCs were performed there from a variety of different angles; different European countries hold different legislation, clinical practices and policy frameworks on organ procurement. But above all, what I experienced as most alarming, but not that unexpected, was the contentious tone of most discussions. Indeed, bioethical debates that question the legitimacy of death

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<sup>16</sup> ELPAT Rotterdam 2013, part of ESOT (European Society for Organ Transplantation)

diagnosis, at the moment is circulatory criteria and not neurological ones that are at stake, can be a highly political and explosive topic to deal with at a conference. Nevertheless, the oppositional taking of stances I observed during the conference and the consequent division between social scientists and medical scientists was somehow deeply disturbing and quite far removed from my experience discussing the same topics with the TCs during fieldwork. Thus, I decided to arrange a second round of interviews to address some of the issues that had been part of our frequent talks but not discussed at length in the previous interview on the process of donation in the hospital.

The new topic guide covered public health regulations in Spain and Catalonia, public education on organ donation, the financial crisis' effects on healthcare practices, the sphere of transplantation, circulatory death diagnosis' specifics, and issues around donation after circulatory death without donors' or families' consent (see Appendix 8 for Interview Topic Guide II). The cue I provided prior to each interview was a reminder that my interest lay in getting a better understanding of the situated practices and inherent contingencies and frictions. In a sense the interviews became a way of enacting interdisciplinary encounters around organ donation differently; an open dialogue upon which many different working knowledges were admitted and entangled. Some of my questions transposed the political debates at the conference, also present in medical ethics journals, to the hospital site and prompted TCs to reflect on their practices and responsibilities. The inquiry was also concerned with finding ways of mobilising the accounts coming out from TCs and donation practices to inform and intervene in the spheres where the political discussions were taking place. The interviews were recorded, but I was aware that most of the interview would not become in a straightforward sense collected data. Unlike Back (2014), in his comment on the overreliance on recorded interviews within the social sciences, I do not think that recording a dialogue makes it into data, nor that it doesn't exist as such otherwise. The recorder, on those occasions, became a symbol of my longstanding engagement with TCs, their procurement practices and the project's purpose to contribute to the aforementioned debates with research that strived for political relevance.

### **4.3 – Doing Ethical Research and Research Ethics**

The research proposal produced at the end of the first-year of the PhD, the board paper, was submitted for ethical clearance to the University of Edinburgh Research Ethics Committee. The ethical review form level 2 was accepted and the research project

received the institutional consent to proceed to the fieldwork stage (see Appendix 4 for Ethical Review Form Level 2).

Once I arrived at the hospital I discussed with TCs about the available procedures to submit the project to ethical review within the hospital. Initially, the TC team did not consider such procedure necessary; their approval of my project was thought to suffice. The project proposal had been presented to them, as explained before, the previous year and the team unanimously agreed to their participation and to my long-term fieldwork stay at the hospital. Nevertheless, upon arrival at the hospital the TC team was under a new directive and it was then decided that ethical clearance from the hospital should also be sought. The available route to do so, as suggested by the TC team, was an application to the academic department of the university hospital. The procedure was for the use of visiting researchers undertaking research projects within the hospital for a brief period of time. In the form I explained about the social research objectives and purposes (see Appendix 5 for Hospital Clinic's Approval of Research Placement). It became a matter of paramount importance to clarify that my purpose was not to collect any data on hospital patients or relatives, and that instead my data collection activities were concerned solely with the TC team activities. It was also noted that even though the anonymity of the hospital could not be fully guaranteed, given its international reputation for deceased donation practices, it would still be an endeavour of the project. I will further comment on that later on in this section.

Parallel to the process of being granted ethical clearance to conduct fieldwork in the hospital, I arranged a meeting with the totality of the TC team to give them a presentation and brief summary of the project's purpose and objectives. However, I would say that the disclosure of the research objectives was a gradual process that took place during the hospital stay in ongoing conversations with the TCs on site. As Aldred (2008) suggests, earning ethical integrity for a project is not a matter of a one-off contract, such as a signed informed consent form, but a process of close collaboration and regular discussion about the research's progression with the participants.

The disclosure procedure of my social researcher's role at the hospital to other hospital practitioners was also an ongoing enterprise. Following TCs around the hospital involves coming into contact with a myriad of other professionals, TCs would most times introduce me as visiting student. I would when possible, given that those were work encounters, explain about my researcher identity and project overview. On the whole disclosure of

research aims was effected at different levels at different times to different professionals I interacted with. I agree with Spicker (2011) in that disclosure is best seen as a spectrum of activity rather than a dichotomous concept. Nevertheless, there were many other situations in which I was present as part of the team and was not introduced personally but rather simply taken to be part of the TC ensemble. It was not my choice but rather just the way things work in a university hospital with many students doing placements and research stays with different hospital practitioners. The practitioners' encounters involved urgent work that had to be done and there simply was no time to disclose about my research then. My experience could be captured in Aldred's (2008) critical stance that the current research ethics code is based on an individualised model of researcher-researched dyad, and thus it does not always cover aspects regarding organisational dynamics that emerge when conducting research within institutional settings and their representatives. However, it is important to note that the research project only intended to map the practices involved in the donation process through the responsibilities of TCs, hence information on other practitioners was included but they were not considered direct participants of the study as such.

One of the ethical considerations that had already been raised in preparation for fieldwork, and flagged at the ethical clearance form for the university of Edinburgh, was my covert observation of donation interviews with families at the hospital. On those occasions the TCs would not introduce themselves as such to families of potential donors, instead the topic of organ donation was broached later on in conversation. I was not introduced either but rather stood next to the TC as silent observer, sometimes along other visiting students or trainee TCs. As it has already been explained, the objective of the observations was not to collect data on the families and donors but on the conduct of TCs when approaching families to request consent to donation. Thus, I would argue that it was not a case of covert research, as it did not involve direct participants of the study. Nevertheless, as introduced beforehand, during fieldwork I became aware that my presence during interviews was unnecessary and hence it would be better avoided. TCs never expressed any objection to me being there, however, I felt it added an extra element to the already emotionally charged situation of dealing with grieving relatives, which interfered both with the work of the TC and the experience of families that were not told about the reason for my presence there. On top of that, it was also a situation in which it was extremely difficult to remain a silent observer, because sometimes I took part in the comforting of families that were under an intense shock after the news of their relatives' death. It was not a matter of my researcher's choice but rather a natural reaction when for

example my intervention was elicited directly by some relatives, I held hands, I provided tissues, fetched water, helped walk down the corridor, or simply cried with them when I could not help it. Doing fieldwork and being there involved being a researcher and taking decisions but sometimes there are limitations to those decisions, as in former instances, some situations escaped the scope of the research and they entailed, in Beaulieu's (2010) terms, both co-location and co-presence, being there and being with as a person not a detached researcher. After nearly two months of attending several interviews, I decided that it would be better not to interfere during the donation interview as I already had a clear idea of the TCs' actions and responsibilities towards families of eligible donors. It was an ad-hoc decision taken during fieldwork and an example of doing ethics in practice, or what Guillemin and Guillam (2004) call 'ethically important moments'. It had not been anticipated by procedural ethics forms, and there was not a theoretical framework to draw on to confront the difficulty, rather the guidance came from exercising researcher's reflexivity in a way that encompassed the ethical dimension of doing research. Similarly, it exemplifies Mason's (2002) notion of reflexive practice that addresses the interpersonal dimension of research conduct on site, as I submitted my role and interaction with participants to the same scrutiny as data generation and analysis activities.

Informed consent forms were given to each TC prior to individual interviews. They contained details of the investigation, a brief outline of the questions and information on the use of digital recordings for transcriptions. As well as a clause about the anonymity of the hospital and TCs in the research files. During the interview stage I discussed the matter further with TCs, both individually and as a group. The issue at stake was that even though I would strive to grant anonymity to the hospital, this was expected to be more an endeavour than a promise, as Wiles et al. noted (2008), because the international reputation of the hospital could make it potentially identifiable. The outcome of our discussions was to resolve to lift the anonymity clause and instead I was enabled to disclose the name of the hospital and the first names of the TCs. The team were also informed that given that the project was funded by the ESRC it was highly possible that the raw data would have to be made available for their open data repositories. There was no objection on that inclusion either. However, given that the updated ESRC data policies consider the sharing of raw data for secondary analysis optional, I plan on not submitting interview transcripts given that they cannot be anonymised.

The signed informed consent forms also ensured that all efforts would be made to keep data strictly confidential. All research data was stored in my computer protected by

personal password, copies of the research folder were stored and updated in an encrypted USB device. I transcribed most of the interviews, except five from the second round that were done by a trusted friend during my maternity leave. In the process all files were exchanged using encrypted software and upon completion of transcriptions my friend deleted his copies of the files.

The TCs were offered a copy of their interview transcript and they were all duly informed that extracts from these might be used in final thesis report, and further publications emerging from it. It has been agreed with TCs that upon submission of the thesis, I will visit them and provide a presentation to summarise the thesis, as well as providing a brief summary in Catalan and a copy of the thesis to each of them.

#### **4.4 - Mapping the Data: Untidy Analysis**

As has already been introduced, this research project proceeded from the position that data collection/generation and analysis are iterative and simultaneous parts of the same generative process (Charmaz 2006). Field notes taken were constantly revised and incorporated into ongoing emerging analysis of the growing corpus of data gathered during ethnographic fieldwork. Upon completion of fieldwork, the totality of the data was submitted to further analytical processes. That is handwritten field notes, research diary entries, interview transcripts, documents from the hospital and others related to policies and legislation. I used the qualitative data analysis software NVivo 9 as a platform to store computerised raw data and to work on interview transcripts codification. This software offers suitable tools to code the data in order to work on the process of conceptualisation and the identification of discrete categories and themes that run through the data (Charmaz 2006). However, as explained beforehand, this was never this project's analytical path, as much as working through the data implied processes of reduction and narrowing down to some central themes. Thus, the use of the software did not correspond straightforwardly to its associated grounded-theory inspired approach. The analysis was very much concerned with distilling multiple repertoires and their entanglements and situated complexities, processes of mutual inclusion and exclusion. Hence, a less fragmentary approach to data analysis was required to go beyond coding the data into separate categories. I support Atkinson and Coffey's (in Bryman 2008) criticism of the use of this software that leads to fragmentation of the data, and a consequent decontextualisation and disruption of the narrative flow. NVivo was a great resource during the initial processes of familiarisation with the entirety of the interview transcripts, and at that stage I created a list of codes that broadly covered the different stages of the

process of donation and the TC profile. However I would say that once the process of analysis moved on to consider more focalised organisations of the data, that is, once I decided the structure and content of each empirical chapter following the different stages of the process of donation, then the use of NVivo was paired with the composition of a text as a word document. These texts agglutinated extracts from interviews in their original language (Catalan and Spanish)<sup>17</sup>, coding information, and any associated thinking processes that each interview fragment (comprising one or more paragraphs) prompted at the time. Each text covered the stages of the process that were to be analysed for each empirical chapter, on average they were around fifty pages each. The generative analytical procedure was expansive, unbound and indeed messy. The objective was to think with and through the data whilst foregrounding at all times my particular theoretical interests, such as issues about materiality, agency and partial connections. Prior to writing each empirical chapter, I would revise the whole text – some parts had been colour-coded to differentiate fragments more related to theory, links with literature review, policy, or methodology – but mostly it was an untidy all-inclusive rendering of my free-flow thinking processes and emerging analytical paths to be further pursued once writing the draft of each chapter. The latter was accomplished through a close scrutiny of the raw data in NVivo, according to codes, paired with the aforementioned word document and associated multiple lists, mostly handwritten and untidy, of the main topics and themes that were to be reflected within each chapter.

#### **4.5 – Distilling a Story: Tidying Up Accounts**

The aforementioned process of mapping the data, analysis and drafting empirical chapters was executed as a primary stage within the larger process of crafting the end product of the research project, the PhD thesis. Once I had the empirical chapters, which corresponded to the mapping stage, I would say I moved on to the distilling stage, wherein the main objective was to bring multiple accounts together and make them cohere into a somehow coherent singularity. It entailed a great deal of shedding and letting go of many potentialities that had been present but that were left out so that the emerging thesis as a whole could become thinner and sharper. The decision-making processes drew on finding ways to give shape and depth to the No heroics, please proposal, and its five different versions, so that its main themes could be resurfaced in all the chapters. I also engaged in reflexive processes that considered the performativity of both my method and

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<sup>17</sup> The data was kept in their original language, Catalan and Spanish. Only the selected quotes for the thesis were translated into English. Notes on translation issues will be identified when relevant within chapters.

the account I was making public, or at least readable for the intended audience of the thesis. As Law (2004) puts it, the hands of the story-teller are never clean, thus, the responsibility I espoused, as author of an academic text, resonated with Law's words in that "in its different versions it operates to make (certain) political arrangements more probable, stronger, real, whilst eroding others and making them less real" (2004, 149). Ultimately, the creative process has been put to use in order to crystallise the thesis, a full-length academic text that is not a book. Unlike a book, it has to conform to the academic requisites of a PhD thesis to be evaluated. It is the work of a novice and it has to be capable of rendering the inscribed intellectual associations visible for examination, whilst performing a certain degree of expertise in and through the STS lens and the field of organ donation studies.



# Chapter 5 – Detecting and Evaluating Eligible Donors

## 5.1 – Introduction

This empirical chapter will cover the initial stages of any donation process: potential donor detection and evaluation of eligibility. These represent the primary condition of possibility for a process of donation to become assembled in the Hospital Clinic. The sections will offer a mapping of the practices that take place in the hospital in regards to donor detection and evaluation by following the daily work of TCs. The focus will be on their various responsibilities as organ and tissue donation specialists within the hospital. The analytical exercise will be articulating simultaneously the first three of the *No heroics, please* propositions. That is 1) to approach deceased donation as an embedded practice within the hospital, 2) to decenter donors and families and 3) to decenter TCs through showing their professional interdependences inside and outside the hospital. The empirical accounts will illustrate that in practice, donation is both procurement and healthcare. The emphasis is both on the integration of donation activities and on the instances when procurement collides with healthcare. Procurement and healthcare are mutually inclusive and exclusive. Scrutinising the work of TCs in the hospital will highlight the partial connections and interdependencies as they emerge in practice. As noted beforehand, the stress on the notion of responsibilities is intended to foreground donation as a situated medical practice. This work is thus aligned with previous medical ethnographies on donation (Hogle 1999, Lock 2002, Sharp 2006, Jensen 2011), and previous work on health professionals' experiences with deceased donation practices (Hadders and Alnaes 2013, Hoeyer and Jensen 2011, 2012, Paul, Avezaat et al. 2014, Hoeyer, Jensen et al. 2015, Cooper and Kierans 2015). It shares with the aforementioned works the intention to show the practicalities and intricacies that organ procurement entails, hence, asserting that it is a process that depends on various sociomaterial arrangements rather than purely being a product of individual choice (Healy 2006, Manzano and Pawson 2014). In the following accounts I will exemplify the *No heroics, please II* premise that consent is decentered, in that even though it is an essential part of assembling any donation process, it is neither the start nor the only factor that intervenes. It is the work of TCs in the hospital that makes possible the choice of donation that some families of eligible donors

will be given. Nevertheless, in these accounts TCs will also become decentered (*No heroics, please III*), they coordinate the whole process but their work would not be possible without the collaboration of other practitioners and an enabling legislation, public health regulation and hospital protocols. The scope and limitations of the TCs' responsibilities will be further delineated by attending to examples of processes of donation that became disassembled at different points during the initial stages of detection and evaluation.

Mapping the practices of donor detection and evaluation will show the different ways in which donors are enacted in practice, exploring when and how are they enacted as patients. Here the donor/patient figure will be the axis of the analysis, and the research also considers when donors are not enacted as patients. The latter instances will be associated with the formerly presented objective to map the areas of friction between procurement and healthcare. The donor/patient figure is deployed so as to give an account of donation as an integrated healthcare practice, normalised within the hospital but with inherent tensions. Hence, this work is not about the difficulties that the transition from patient to donor causes to practitioners and families in the hospital. Donors are also patients in the Hospital Clinic. It is important to note that TCs' responsibilities are decoupled from the death diagnosis of the patient, their job starts after someone dies in the hospital. TCs are not responsible for individual patient care, which is the responsibility of ICU nurses.

The donor/patient figure, with its overlaps and separations, will be articulated along a specific trajectory as encountered in the practices under study, that is, from detected potential donors to evaluated, and if not ruled-out, eligible donors. The stress will be on the TCs' responsibilities to ensure the viability of the donation; the practices directed at minimising the risks of disease transfer to the future transplant recipients. The activities, order and interdependencies with other hospital practitioners will vary depending on which type of donation process TCs are dealing with, namely, donors after brain death diagnosis (DBD), donors after cardiac death diagnosis (DCD) and tissue donors. The terminology (see Appendix 2 for Glossary) and the differences between these diagnoses will be explained in the following sections on detection and evaluation, as well as expanded in prospective chapters on the stages of donor maintenance, organ extraction and the consent request with families of eligible donors.

## 5.2 – Donor Detection

This section will introduce empirical accounts to start mapping the practices of the TC team in the hospital. This will be done, as previously explained, by following the TCs' responsibilities in their daily practices, and particularly with regards to the initial stage of any donation process, potential donor detection. The guiding research questions are 1) *When does a donation process start?* 2) *What are the responsibilities of the TC team?* 3) *What part do other hospital practitioners play in regards to detection?* 4) *How does the legal and policy framework condition the TCs' donation-oriented practices that are in turn embedded in the given hospital as part of healthcare activities?*

The answers to these questions will inevitably hinge upon the three different types of donation processes that take place in the hospital Clinic of Barcelona. It includes both organ and tissue donors. And it encompasses two different death diagnosis, brain death criteria and circulatory death criteria diagnoses. The death diagnosis is not the responsibility of TCs but some details about the two distinct procedures will be given in the following sections that will cover, in this order, the different donor detection practices for tissue donors, donors after brain death diagnosis (DBD) and donors after circulatory death diagnosis (DCD). With reference to DCD, it must be clarified that it only refers to the category of 'uncontrolled DCD', that is, type II according to the Maastricht classification criteria<sup>18</sup>.

Every category of donor is detected by different mechanisms and each involves a particular set of activities and interdependences amongst TCs and other practitioners in and outside the hospital. The detection of tissue donors amounts to seventy per cent of all donation cases carried out in the hospital; on average nearly seven cases every day are detected and followed up. Thus, considering that tissue donor detection is a great part of the TC team daily activities, this section starts by reviewing how these donors are detected in the hospital.

### 5.2.1 – Detecting Potential Tissue Donors

Most tissue donation processes start with a phone call from a hospital unit. They call the TC office to request a death certificate form; a patient has died and the doctor that has carried out the death diagnosis needs to sign the official death certificate document. It is

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<sup>18</sup> See Appendix 2 for Glossary.

always a quick call from a nurse: ‘we had an Exitus<sup>19</sup>, will you please bring us a death certificate’. Nurses know that when asking for the certificate they must specify the location of the hospital unit as well as providing the name, surname, and age of the deceased patient. The first thing TCs do after answering the call is to log into the hospital’s database to check the given patient’s file. If s/he is less than 89 years old then s/he becomes a detected potential tissue donor and the process of donor evaluation starts; details to follow in the second half of this chapter. After an initial evaluation, a TC will then go to the hospital unit to tender the requested document. TCs have not always had the responsibility for providing death certificates in the hospital. It was an idea proposed by a medical student doing his placement in the TC unit a few years ago. The aim was to increase the number of detected tissue donors. The hospital board accepted the proposal and transferred the competency from the in-hospital funerary services to the TC team. It was a move that quickly translated into a substantial increase in tissue donor detection. It is what TCs call an *automated detection mechanism*. It works but it has drawbacks, thus, it is the TCs’ responsibility to ensure that there are alternative mechanisms available to detect all potential tissue donors amongst deceased hospital patients.

Sandra<sup>20</sup>, a senior nurse-TC, considers the death certificate a great method but points at the instances in which it fails, such as when the case falls under forensic authority or when an autopsy is necessary, given that a death certificate is then not needed, the nurses don’t call the TC team. It is in the process of detection, she tells me in an interview, that the collaboration of other healthcare professionals (HCPs) is most crucial. Thus, even though an automated detection mechanism works most of the times, to her, it still has the shortcoming of being a way of forcing nurses to contact TCs for non-donation purposes; namely, their need for a death certificate document to carry on with their responsibilities in the hospital unit. It is a shared perception amongst the members of the TC team that such sense of obligation is not what will help them to enlist the active collaboration of the relevant HCPs. Therefore it is their responsibility to inform hospital practitioners about donation practices; what they usually refer to as the ‘promotion of donation’ in the hospital. All TCs agree in stating that it is a simple relation, if all HCPs are informed that any deceased patient, not older than 89 years old, can potentially become a tissue donor, then when faced with any such case they will be aware that donation is a possibility and contact the TCs. Mostly, the information provided covers donor eligibility criteria and the transplantation uses of donated tissue like cornea, skin, bone and heart valves. And more

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<sup>19</sup> Exitus is the medical term in Latin for death, it is commonly used at the Hospital Clinic to refer to circulatory death cases

<sup>20</sup> See Appendix 6 for List of Research Participants.

broadly the message is to highlight the task of the TC team in the hospital and the importance of other HCPs collaboration to detect potential donors. It is an on-going task in such a large hospital with high staff turnover.

The change in detection rates that followed the so-called promotion of donation amongst hospital porters, is a testament to the importance of enlisting the collaboration of key hospital practitioners. Angel, a senior doctor-TC, recalls the initiative and results during an interview:

We control all the deaths in the hospital for the tissue donation programme, so since any hospital unit is a potential generator of deceased patients and any deceased patient can become a tissue donor, what we really need is fast and efficient detection mechanisms so that we can evaluate any case as soon as possible, to see, to try to get him<sup>21</sup> to become a donor. For a long time we weren't aware of most of the deceased cases in the hospital, we used to detect only 10% of the cases, but from the year 2000 approximately, we tried to collaborate with the porters in the morgue to detect the dead, because they are responsible for transferring the dead patients to the morgue, and we went from detecting 10% or 11% up to 70%, the second year we were already detecting around 95% and 99%, therefore it can be said that in two years we went from 10% to detecting all the cases (Angel).

This quote illustrates that it is the TCs' responsibility to detect all cases of deceased patients in the hospital so as to consider their donor potentiality; nevertheless, it is a task that relies heavily on the participation of other hospital practitioners. In the case of porters particularly, their collaboration has greatly enhanced TCs' detection capabilities. Porters don't have to call TCs, unlike nurses in need of a death certificate, but they have now incorporated it as part of their job. They know that any dead patient under 89 years can become a tissue donor, and as TCs put it, they bear in mind that after a patient dies there is still another possibility; the option of tissue donation. However, porters usually call the TC team when the dead body is being taken to the morgue and usually at that time the relatives of the deceased person have already left the hospital. TCs' detection strategy needs to be comprehensive but also fast. This is why the death certificate mechanism, albeit a compulsory measure for other HCPs, is of great importance to their practice. It allows them to detect any potential tissue donor when the relatives are still in the hospital so they can be approached to request their consent to donation.

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<sup>21</sup> Gendered language from original language interviews.

The detection of tissue donors is mostly carried out by nurse-TCs<sup>22</sup>. Ferran and Sandra are the senior nurse-TCs with the longest experience. They emphasise that it is all a matter of establishing good communication with nurses and other key practitioners such as social workers in the accident and emergency unit (A&E), porters and funerary services staff. In short, to remind them that donation is part of the hospital's healthcare activities, and that it would simply not be possible without their help.

Most of the times TCs are greeted cordially in every unit they go to, but sometimes they find some reticence from HCPs. The latter might not call them when someone dies or they might refuse to provide a patient's information to them. It might be the case of new staff that do not know about the TC figure and donation processes in the hospital. Ferran, in these cases, likes to explain to them the reasons why he is not 'a death certificate distributor', and that he is there as a TC. To him the idea to convey is that it is not good that families of deceased patients go away without having had the option to donate. Yet another source of reticence or lack of collaboration, as identified by TCs, is associated with particular misinformation about the TC's job and interests:

Generally, reticence is due to the history of this service that still weighs heavily on us, when the TC service started, the staff that were part of it, uh, they used to get a bonus for their collaboration, so still today a lot of people think this way, they think we get paid per donor, and we need to clarify that whether they call me or not, or whether the family consent or not, I will get paid the same at the end of the month (Sandra).

The hospital Clinic was the first site where a TC professional and a coordinated system of donation and transplantation were implemented in 1984 (Valls 2009). It was led by medical professionals from the hospital, and even though the collaboration of many was necessary, only a selected group of practitioners were being compensated with what was then called 'transplantation bonuses'. To Ferran this explains the fact that some nurses aged fifty or older might refuse to collaborate with them, as he puts it, they remember that at the start nurses were the ones doing the hard work and they never received any money or acknowledgement for their task. Hence, all TCs when confronted with such reticence, duly inform them about current practices, and vehemently remark that they are no different from other hospital professionals; their responsibilities are also embedded within the hospital's healthcare program and the TC team represents another unit of the hospital.

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<sup>22</sup> See Appendix 6 for List of Research Participants.

### 5.2.2 – Detecting Potential Brain Death Diagnosis Donors

Everyday around mid-morning, one of the TCs, usually a doctor-TC, visits the seven intensive care units (ICUs) in the hospital. They call it the daily round and the objective is to detect potential brain-dead donors. Unlike in tissue donors' detection, TCs play an active role in the detection of potential DBD. Early detection is imperative because potential cases are identified amongst patients with sustained severe brain injury in the hospital. Any patient with a Glasgow coma score<sup>23</sup> between three and seven is considered a potential brain-dead donor. The TCs' responsibility then is to assess the probability that the patient's condition will deteriorate to a brain-dead situation. This is done in conjunction with the HCPs, mostly ICU doctors and neurosurgeons, in the unit where the patient is located.

TCs' relationship with ICU staff is direct, constant and mostly positive. During daily rounds, TCs are received in a friendly manner in all ICUs; their visit is expected and welcomed. Senior doctor-TCs have worked in the hospital for around twenty years and the heads of most ICUs have known them for all that time. Sometimes the round is a succession of sociable encounters and enjoyed as a chance to catch up amongst old colleagues. Other times, the exchange can be very brief and can even be conducted without words. On one occasion during fieldwork, following Angel during the round, we found the unit's director in her office, busy on the phone, and a quick gesture from Angel pointing to his head was enough for her to understand the question 'any potential brain-dead patients here today?' she just signalled no with her hand, smiled and waved goodbye to us. Angel then explained to me that daily rounds are crucial for the TC team but that they need to proceed with great care, 'we don't want to annoy people that are very busy with their jobs, we try to do this daily but without becoming a bore to them'.

The round's last stop is at the A&E unit. Angel, during an interview, gives details about the importance of the Emergency Room (ER) to detecting potential brain-dead patients:

It is important for detection especially the ER in A&E because there we find the patients that have just been admitted with severe brain injuries, in this room there is a book to register all admissions, so we go there everyday and we check the

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<sup>23</sup> The Glasgow Coma Scale provides a practical method for assessment of impairment of conscious level in response to defined stimuli (<http://www.glasgowcomascale.org/>).

book and we see if there are any severe brain injuries, if that brain injury has gone to surgery, if a CAT scan has been done, sent back to another hospital or transferred to a ICU in this hospital, so we see the destination of the patient by checking the book and then we follow up each case with the daily round (Angel).

The admissions book is a handwritten register of all new arrivals at the hospital. The information it contains is very detailed: type of injury, treatment and destination of the patient. TCs can thus detect potential brain-dead patients before they have been officially admitted into an ICU, at a time when a specific patient record has not yet been created. It can happen that TCs already know the type of brain injury, neurological prognosis and ICU destination of a patient who is still in the ER waiting to be transferred or for beds or surgery slots to become available.

Once the critically ill patient has been transferred to the relevant ICU, s/he has already undergone a neurosurgical operation and been intubated to be put on a ventilator<sup>24</sup>. TCs follow up each case that is deemed likely to end up in brain-dead criteria. That is, when the neurological prognosis is very poor, and the specific type of brain injury is associated with high probability to, as the medical terminology puts it, evolve to brain death. Follow up of such patients is done during daily rounds, discussing the state of the patient with the treating neurosurgeon and nursing staff in the ICU. Additionally, TCs check the electronic patient medical records in the hospital database on a daily basis to ensure that they are up to date with detected cases and any developments such as further tests or emergency interventions.

Aside from physically checking the admissions book in A&E, there is another mechanism to detect any potential-brain dead patient entering the hospital. All TCs carry a hospital beeper that alerts them of any new arrival with severe injury. It is called the cardiac arrest alert. It is a code activated by A&E staff to request the immediate presence of multiple teams in the ER to assist a patient who has suffered a cardiorespiratory arrest. That is, anaesthesiologists, internists, the resuscitation team and emergency surgery team for urgent patient intervention and the TC team for donor detection purposes. TCs, after receiving each arrest alert, go to A&E to check what type of injury the patient has and to assess the probability s/he could become a potential brain-dead donor. Usually, once in A&E, they are informed about the state of the patient and the ICU destination if known already. However, there is a type of critical patient that TCs recently started dealing with that demands a completely different approach:

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<sup>24</sup> See Appendix 2 for Glossary, DBD.

Lately, a type of patients that are becoming more and more frequent are those that have no vital prognosis because of the type of pathology, then it is decided that there will be no further intervention because there is no benefit for the patient possible, and then we can approach the family to discuss the possibility of donation, because if they accept that the patient will become a donor, then what we ask them is permission to intubate and the necessary time for the patient to evolve to brain-death, so those patients we need to detect in A&E upon arrival because otherwise they would not get to any ICU (David).

Medical practices around the care of critical patients have changed significantly in the past few years in the context of Spanish legislation. In 2012 new legislation was passed to allow for measures of limitation and withdrawal of life-support treatment when it was considered futile for the patient. The change has implied a shift in the decision-making process. Whereas in the past every patient with a severe brain injury would be subject to intervention and intubated regardless of the prognosis, nowadays, the patient's family are given the choice to continue with futile treatment or not. The TC team have noticed a great reduction in numbers of potential brain-dead donors since change of legislation, and as they explain, they have had to adapt to a new situation with different protocols for action. Namely, and unlike with ICU potential donors, TCs approach the patient's family after the medical team has informed them about the futility of any treatment, that is, before the death diagnosis. Such early intervention, as we read in David's quote, is to allow them to request permission to intubate and transfer to ICU with the only purpose being donation, or as TCs put it, so that later on donation can be a possibility.

### **5.2.3 – Detecting Potential Circulatory Death Diagnosis Donors**

The third type of donor, following a typology based on death diagnosis, is that of donors after circulatory death determination (DCD)<sup>25</sup>. It is a highly complex procedure that involves the coordination of several professionals both in and outside the hospital. This section will offer a longitudinal description of the process, the activities, sites and practitioners involved. DCD characteristics imply that detection evaluation and maintenance tasks are carried out at the same time. The majority of the cases are patients who have suffered a cardiac arrest outside the hospital and are brought in an ambulance by the emergency medical services (EMS). Upon arrival to the emergency area, EMS professionals have already applied advanced resuscitative measures to resume circulatory

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<sup>25</sup> See Appendix 2 for Glossary, DCD.

and pulmonary functions for a minimum of 30 minutes<sup>26</sup> with no success, both manually and during transfer with external cardiac massage device. During their intervention EMS practitioners consider if the patient could become a potential DCD according to current inclusion criteria and if so they activate the code 303 of donor detection. This code sends an alert to the EMS central office to inform them that they are transferring a potential DCD to the hospital Clinic. EMS central office then call the Hospital Clinic's emergency unit, the OCATT<sup>27</sup> office, and the TC team to notify them about the imminent arrival of a potential DCD. Once contacted, TCs have an interval of time, it can range from ten to thirty minutes, to go to A&E, prepare the emergency room for the incoming potential donor and alert other HCPs about the impending case. If it is a junior TC on duty that day in the hospital, who is taking all the calls for any potential cases, s/he then has to contact the senior TC on-call that day to come to the hospital to start DCD preparations as soon as possible. In the emergency room, TCs prepare all the material necessary for the organ preservation intervention that will take place swiftly after death has been declared.

By the time the potential DCD is brought in by the ambulance, A&E nurses have activated the intra-hospital arrest alert which, as previously described, is the normal procedure for any case of incoming patient with acute cardiorespiratory arrest. The arrest alert summons the relevant teams for urgent patient intervention and also the TC team. In those instances, TCs are already in the ER when they receive the arrest alert because they have been formerly notified by EMS central office about incoming code 303 potential donor. Nevertheless, it is really important to them to make sure that alternative mechanisms of detection are in place just in case one was to fail. On one occasion, the EMS failed to alert them and the TC on duty was contacted once the potential donor was already in the hospital by the arrest alert. Preparation procedures had to be rushed but organ preservation was still initiated just below the time limits for DCD. After the incident, the TC team issued a formal complaint about the EMS's lack of professional rigour, explaining the complications it entailed for their responsibilities. These were mainly related to the risk of, as they put it, losing the donor if early activation procedures were not executed fully.

When emergency staff have the personal details of the patient, name and age, those are communicated to the central office so that TCs can initiate early evaluation procedures.

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<sup>26</sup> 30 minutes is the timeframe according to international standards on strategies for cardiopulmonary resuscitation (CPR).

<sup>27</sup> OCATT is the Catalan Transplant Organization, the equivalent of the ONT, it regulates donation and transplantation activities in Catalonia.

TCs are to check as early as possible if the patient does indeed comply with current DCD criteria. To do that they access the hospital's medical records database. If the patient's file is not found there, they then access the national Catalan Health Service shared history database that hosts the entirety of the patients' medical files of the country.

In A&E it is an anaesthesiologist or internist who discusses with EMS staff all the available information about the case, cardiac arrest circumstances and time frame, CPR evolution and medical history. Based on that, the doctor decides whether to discontinue CPR and carry out the death diagnosis using circulatory criteria. EMS staff then remove the external cardiac massage device, and stop all drug administration via peripheral or central venous lines. Death diagnosis takes place in the general A&E unit, by the main medical professional. The standard is absence of signs of cardiorespiratory activity for at least five minutes. It is what is called the 'non-touch' period whereby no actions can be performed on patients until they are officially declared death. This time is crucial for TCs, and by then there are at least two TCs on the scene; one has to attend the death diagnosis and obtain as much information as possible from EMS staff, especially in regards to time frames. TCs establish with the doctor in charge of death diagnosis the official times of the cardiac arrest, the initiation and length of CPR, and the time of the death declaration. All of these elements have to conform to current criteria of DCD eligibility. Additionally, emergency professionals can provide information about the accompanying relatives or friends, if any, such as type of relationship, emotional state, whether they seem aware that there is no recovery possible for the patient or if they are awaiting the arrival of other more immediate family members. At the same time, the other TC is finishing the preparation of the emergency room materials and organising collaborating professionals to initiate the organ preservation procedures. These consist of a surgical procedure, cannulation, which will be carried out by a team of surgeons and assisted by an A&E nurse and a nurse assistant. A cannula needs to be inserted in the femoral vein<sup>28</sup> so that abdominal organs can be perfused with the potential donor's own blood. This will be done with the use of an extracorporeal membrane oxygenation (ECMO)<sup>29</sup> machine that will circulate the blood and maintain a constant body temperature. Chapter 6 on donor maintenance will further expand on this procedure.

Upon death declaration, the responsible medical professional signs the death certificate and proceeds to communicate the bad news to the family members there present. In

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<sup>28</sup> Femoral vein is the large vein in the groin that carries blood back to the heart from the lower extremities (<http://www.medicinenet.com/script/main/art.asp?articlekey=10783>)

<sup>29</sup> See Appendix 2 for Glossary. DCD.

chapter 7 I will cover the TCs' approach to the family to request consent for organ extraction following death communication. However, at that moment, the only authorisation that is needed is the forensic authorities' consent to proceed with organ preservation. This is done, following current legal precepts<sup>30</sup>, by sending a fax<sup>31</sup> to the coroner with the deceased patient's personal details and time of death along with the request, signed by the main TC, to initiate preservation intervention. The forensic authorisation follows a presumed consent logic, in that if the coroner fails to respond to the fax in 15 minutes to object about proposed activities, TCs can presume that consent for organ preservation has been granted and initiate abdominal area recirculation. Later on in this chapter, more details will be given on the forensic consent to organ preservation and the implications for the process of assembling donations and TCs' responsibilities. At present, the analysis will move on to discuss how the pivotal stage of potential donors' detection, along with the different types of mechanisms in place to do so, illustrates the first of the *No heroics, please* propositions. The latter suggests that deceased donation is a situated medical practice, and that in the hospital studied it is an institutionalised practice, the responsibility of the TC team, and that it is thoroughly embedded, and thus dependent on, the given hospital configuration, which in its turn is inserted in an enabling regulatory landscape.

#### 5.2.4 – On Detection Mechanisms

The previous empirical accounts have shown that detecting potential donors depends largely on the collaboration of some key figures in the hospital; that is, those who will initially be aware of a patient's death and alert the TC team about it. These include, ICU nurses and doctors, A&E social workers, porters, funerary and EMS staff. The initial alert is the moment when a given donation process starts; from that moment onwards TCs will carry out all necessary tasks in order to assess the eligibility of the potential donor. All TCs stress that a good relationship with these practitioners is essential to their everyday practice of potential donors' detection. Thus, great care is taken to enlist and maintain a good collaborative relationship with all of them. Camino, a senior doctor-TC who has worked in the hospital Clinic for over twenty years, puts it this way:

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<sup>30</sup> Presumed consent Spanish legislation from 1979 and 1999 amendment to allow for organ preservation intervention to start prior to family's consent to organ donation ([http://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2000-79](http://www.boe.es/diario_boe/txt.php?id=BOE-A-2000-79)).

<sup>31</sup> Fax machines have become almost obsolete in this hospital, nevertheless the TC office have to have one for this specific use only.

You simply cannot carry out any program of donation and transplantation if the HCPs in the hospital are not properly informed about it, because this is essential, they are the ones that will help you, when there is a death, when there is a tissue donor, talking in general here, when there is a potential donor, because they are the key people that can either make your job possible or on the contrary put insurmountable impediments to your job (Camino).

This quote reinforces the main message conveyed so far: TCs do not work alone. Their responsibility towards donor detection unfolds in a series of actions that are thoroughly embedded and enabled by existing hospital practices. It is their interrelationship with other practitioners in the hospital that, as they argue, makes their job possible. The promotion of donation that TCs carry out around the hospital follows a different purpose to organ donation public campaigns. TCs are not asking other practitioners to become registered donors and to endorse the idea of donation. Rather, their objective is to inform them that donation is also a hospital activity; another end of life choice for some deceased patients, and that for this option to become a possibility, their collaboration is essential. Participation can be enlisted by talking to the particular practitioners, as is the case of the working relationship with the team of morgue porters, or with the A&E social workers and funerary services staff. However, while good relations matter, detecting potential donors does not rest solely on the recruitment of collaborators through informative sessions. This is a complex sociomaterial arrangement that needs a lot of work and the intervention of many people, things and also politics. The former elements can be encapsulated in the terminology used by TCs, that is, donor detection mechanisms. An example could be the nurses' call to the TC office to request a death certificate after a patient has died. The phone call does not hinge on the nurses' relation with TCs or on how well informed they are of donation practices. That call is mandatory to the nurses' job, a necessity of their practice and thus not a choice taken depending on their individual stance on donation. It was discussed beforehand that the death certificate mechanism was suggested by a medical student; a way to solve the problem of undetected tissue donors that TCs were experiencing, as well as a way to detect donors earlier on so as to be able to locate the family before leaving the hospital. The process for that idea to turn into a mechanism extended beyond the TC team since the support of the hospital board was needed for its execution. Similarly, the beeper arrest alert, that allows TCs to detect both potential DBD and DCD at an early stage, is also an existing mechanism within the hospital but that was later on extended to incorporate donation purposes. The hospital board, once more, was the authority that passed orders that TCs will also be automatically contacted in any cardiorespiratory emergency and added to the beeper system. The practitioners in A&E who are activating the arrest alert, a red button on the wall, do it to

get the help of the resuscitative team, anaesthesiologist and internist to deal with a particular patient's emergency. It is a responsibility of their healthcare practice and again not a choice they have based on whether they think donation could be a possibility at that moment. Those were automated detection mechanisms, but there are other mechanisms that also fall outside the sphere of individual practitioners' support of donation in the hospital. For instance, the admissions book, a valuable instrument for TCs to detect any potential DBD even before hospitalisation so they can intervene in the decision-making process about possible intubation. Or the patients' record database to check on detected potential donors' medical history. Access to the database is not open to all HCPs in the hospital, different practitioners enjoy different levels of access, but TCs were granted unrestricted access to the totality of the database by the hospital board. Thus and considering the aforementioned detection mechanisms, it is also the hospital's task, not the TC team's alone, to make possible the detection and follow up of all potential donors. Nevertheless, the integration of donation as a routinized hospital practice is also entrenched within a broader political setting. This can be conveyed by the fact that TCs enjoy unrestricted access to the entirety of the Catalan Health Service patient's records database, which was made possible after the Catalan government directly authorised them to do so. This was part of a larger public health policy project, the multidisciplinary programme of donation after circulatory death. The latter, under the name of CatAsistol, brought together the collaboration of EMS, OCATT and TCs in the hospital Clinic to detect potential DCDs. A brief look at the history and contingencies of DCD donation can add to the discussion about the enabling conditions for TCs' donation practices.

The legal basis for the creation of such a programme is to be found in Spanish presumed consent legislation. The original 1979 law was amended in 1999 to legitimise organ preservation intervention prior to relatives' consent to donation. Shortly after that, in 2000, the TC team established the collaboration of the EMS so that all non-recovered cardiac arrest patients in the metropolitan area would be transferred to the hospital Clinic to be assessed as potential donors after circulatory death diagnosis. Later on, in 2004, the Catalan transplant organisation, OCATT, took over with the development of a strategic health plan programme for DCD with the participation of Barcelona's EMS and different transplant hospitals, as well as Fire and Police departments. The project CatAsistol was officially implemented in 2006 as a public health protocol. It designated the hospital Clinic as the reference hospital to receive all potential DCDs. It initially covered the city area with 1.7 million inhabitants but it later on expanded to encompass surrounding cities and to include 2.3 million inhabitants. The former historical incursion adds more weight

to the proposition that TCs could not work alone, and it emphasises that the collaboration of other individual practitioners in the hospital is necessary but not sufficient to make donor detection practices possible. Thus, and summing up, I maintain that donation is a situated medical practice that requires complex sociomaterial arrangements as enabling conditions of possibility. The list of participants includes key people like TCs, and practitioners in the hospital, but also things like admission books, beepers and computer databases, as well as hospital protocols and regulations, OCATT donation programmes, Catalan public health policies and Spanish presumed consent legislation.

Donor detection is the pivot stage of any donation process in the hospital, as TCs put it: without donor detection there is simply no donation. The TC team responsibility is to detect the entirety of potential donors in the hospital everyday, here Marc, a nurse TC, explains their practice:

What we want is to detect 100% of potentials because detection is basically trying not to miss any at all, but of course as we were saying, all hospital systems have caveats and there is leakage but in principle and following all our protocols non-detection rates should be zero (Marc).

Marc's choice of terminology resonates with the main argument that TCs' donation practices are inscribed within broader healthcare hospital practices. He talks about hospital systems and protocols to articulate the TCs' approach to total potential donor detection. More on that will follow on the next section about donor evaluation. Ultimately, detecting all potential donors is necessary given that it is later on in the process of evaluation that it will be established whether a potential donor becomes eligible or on the contrary is ruled out as a donor altogether.

### **5.3 – Donor Evaluation**

The empirical accounts will now move on to cover the stage of donor evaluation, and the guiding questions will be the following: 1) *What do donor evaluation processes involve?* 2) *What are the responsibilities of the TC team?* 3) *What part do other hospital practitioners play in these evaluative processes?* 4) *How does the evaluation of a donor's eligibility intervene in the particular trajectory from detected potential donor/patient to eligible donor/patient in the hospital?* It should first be clarified that there is a significant overlap between both detection and evaluation processes. As discussed in the previous section on donor detection, the overlap will shift and vary depending on which type of donor TCs are dealing with. Such issues

will be addressed in forthcoming sections accordingly but it should be noted that overall the section does not follow the threefold structure of different types of donors. When it comes to donor evaluation, the axis of difference that structures TCs' practices is to be found in the four types of evaluations that need to be performed in order to ascertain a given potential donor's eligibility. Namely, the scrutiny of the patient's medical history, the clinical tests carried out with the patient's blood, a consideration of the deceased person's social history and a physical examination of the dead body. Different kinds of evaluation practices will mobilise various modes of knowing, interrelated and interdependent ways of identifying disease that are brought together by TCs to bear upon the decision of a detected potential donor's eligibility for transplantation purposes.

### **5.3.1 – Patients' Medical File Evaluation**

Once a potential donor has been detected, the first information TCs need to get is the patient's name and surnames to check the medical record file details. As described in previous sections, TCs are given this information promptly by practitioners that identified the potential donor. In the case of both tissue donors and DBD, since they are mostly in-hospital patients, TCs check their existing complete medical files available in the hospital's database immediately after detection. In DCD cases, EMS staff provides personal details of incoming potential donors or later on the social worker in A&E. If the given patient doesn't have a medical file open in the hospital then TCs proceed to access the national health records database to retrieve any available health records.

The primary criterion they check initially is age; if the patient is 89 years old or older then s/he is immediately ruled out as potential donor. If younger, the deceased patient could be considered a potential cornea donor and a thorough evaluation procedure would be activated. Evaluation responds to the need to identify any reasons that could rule the potential donor as non-eligible, those are commonly referred to as contraindications to donation. Here Angel, a senior doctor-TC, explains the evaluative process and the objective:

The first thing we need to do once the donor is detected is to assess whether he is a valid donor or not, and if he is a valid donor then what he can be a donor of, we do an initial evaluation of the patient's medical history to see if he has or has had some disease that could represent an absolute contraindication for donation such as Hepatitis C or B for tissue donation, HIV or history of cancer, especially

haematological neoplasm<sup>32</sup> or if he has a solid neoplasm<sup>33</sup>, then he might not be able to donate organs or some types of tissue but he could donate corneas because it is vascular tissue, that is to say that there are a set of medical criteria in the history that can make us rule out the donor altogether from the start (Angel).

As the quote illustrates, it is a process to identify, as TCs put it, any given cause for non-donation or contraindication, in the medical history of the patient. Thus, the objective is to rule out the altogether not eligible donors from the detected potential donors according to a different set of medical criteria for each tissue type and organs. There are two types of contraindications, as in any other medical usage of the term, absolute contraindication and relative contraindication. However, the objective of the initial evaluation is to identify absence of any absolute contraindication, namely older than 89 years, HIV, Hepatitis C, Hepatitis B, uncontrolled active sepsis<sup>34</sup> and haematological neoplasm<sup>35</sup>. When the scrutiny of the medical files shows absence of absolute contraindications and there is potential for at least one type of tissue donation, TCs then leave the office to go to the unit where the patient has just died. It is important at this stage to talk to the HCPs who treated the patient to obtain as much information as possible about the exact cause of death and the evolution of the disease during hospitalisation. It is usually the nurses who were in charge of the patient that are looked for, but there is also another information resource that is always readily available by the deceased patient's bed, the patient's folder. In there TCs can find everything they need to know at that stage, such as presence of infection and if so what type of antibiotic treatment was administered, and the results of any daily tests carried out up until the patient's death. Nevertheless, they always discuss all details with the nurses and they especially enquire about otherwise unavailable information about the deceased patient's family, whether they are in the unit and what they look like so they can approach them for the consent request later on. In DCD cases, if the name of the deceased patient is provided by the EMS call, the evaluation of the medical history, inside and outside the hospital, commences straight away. Nonetheless, the emergency personnel are aware of the DCD medical eligibility criteria, that is the absolute contraindications in regards to age, younger than 15 or older than 65 years old, and HIV, Hepatitis C or B, active cancer or active infection/sepsis. Therefore, when they decide to activate a code 303 and send an alert of a potential donor to their central office it is after having checked the absence of any contraindication to donation known to them at that moment.

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<sup>32</sup> Haematological neoplasm or blood cancer.

<sup>33</sup> Cancer localized in any organ or tissue area.

<sup>34</sup> Sepsis refers to a bacterial infection in the bloodstream and/or tissue areas (<http://www.sepsis.org/sepsis/definition/>).

<sup>35</sup> See footnote 18.

Detection of potential brain-dead donors is via the identification of a critical patient with severe brain injury either upon arrival to hospital in A&E or once hospitalised in an ICU. In these cases, evaluation of donors' eligibility takes place before the patients' death. It is important to do it as soon as possible for various reasons as Camino here explains:

What you need to do, even before you speak to the family, to avoid unnecessary efforts in terms of healthcare, let's imagine a patient that arrives with a severe brain pathology and that he has been intubated and is in an ICU, and you know that the probabilities to naturally evolve to brain death are high but that could take two, three days, and there is no more surgery possible, there is no medical prognosis, there are no other options and the patient is there intubated, well then what are you doing there when you have already detected the donor! Well of course you have to evaluate medically because imagine that he is 77 years old and that he has an antecedent of colon cancer from 30 years ago, so with this evaluation you already rule him out and you explain to the HCPs, for us it is a contraindication (Camino).

Thus, early detection and evaluation matters to TCs' donation practice, especially in DBD that as we have seen earlier might involve asking the family for permission to intubate the patient in the first place so that later on donation can become an option.

The pattern of ruling out non-eligible donors also responds to economic reasons. TCs always remark that their job is mostly done with the computer to firstly confirm the absence of absolute contraindications before proceeding to do a more thorough clinical evaluation of the then potential donor. They note that checking the database is free whereas tests for the clinical evaluation represent a considerable financial cost for the hospital and thus can only be carried out if all previous steps to rule out non-eligible donors have been taken.

### **5.3.2 – Clinical Evaluation**

Once the TC team have detected a potential donor and confirmed the absence of absolute contraindications in the medical history files they move on to what they refer as the clinical evaluation of the potential donor. For that they need a series of blood samples that will be extracted in order to detect any signs of disease, which, even if unknown and/or undocumented in the medical history, if present in the body would rule the patient out as potential donor. The main tests needed for both organ and tissue evaluation purposes are

serologic<sup>36</sup> tests to screen for any signs of infectious disease, viruses such as hepatitis B or C, HIV or bacterial infections like syphilis. The techniques used in the hospital are innovative fourth generation<sup>37</sup> ELISA tests that measure both presence of antigen and antibodies to disease and infection types. They represent a great advantage for TCs' evaluation tasks as now they can screen for past infections, such as Hepatitis B, but also check if patients developed any antibodies that would make them currently immune to the disease and therefore not ruled out as potential donors.

In the case of organ donation evaluation, the number of blood samples needed is greater than in tissue donation because there are further tests requested. These are undertaken mainly to provide information about immunological and HLA<sup>38</sup> profiling, blood type, biochemical tests, CBC<sup>39</sup> and coagulation index. Additionally, urine samples are also required to screen for any active bacterial infections that if detected could be treated in the potential donor and subsequently in the organ recipient transplant patient.

The person in charge of blood extraction will vary according to the typology of donors:

When it is a case of DBD we ask the treating HCPs for an authorisation to take the blood samples, then it is usually a nurse that does it in the ICU, when it is a DCD we do it ourselves because when the person arrives at A&E and from the moment he is declared dead then he becomes a donor, so then we are in charge of taking all samples, and the same when it is a tissue donor because it is also a deceased patient at the time we detect him and we find the body with no intravenous access, all has been removed already, so we have to prick and extract the samples ourselves (David).

In DBD, given that the detected potential donor is in most cases still a living patient in the hospital, the TC role is to get authorisation to obtain the blood samples that will then be extracted by ICU nursing staff responsible for the care of that particular patient. Most ICU practitioners are collaborative and provide the samples promptly, however, it is not unusual to encounter some apprehension and end up being told 'Now it is not the time!' That was the case experienced by Xavi, a junior nurse-TC with a senior nurse in the ICU where he also works as a part-time nurse. He recalled the event and explained that the

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<sup>36</sup> Serologic tests are any diagnostic test based on detection of antibodies or antigens in the blood (<http://medical-dictionary.thefreedictionary.com/serologic+test>).

<sup>37</sup> ELISA stands for Enzyme Linked Immuno Sorbent Assay, a technique used in laboratories to measure the amounts of an antigen, or of an antibody in a biological fluid (<http://www.medicinenet.com/script/main/art.asp?articlekey=9100>).

<sup>38</sup> HLA or Human leukocyte antigen is the major human histocompatibility system. It is done to determine the degree of tissue compatibility between donor and recipient (<http://www.medicinenet.com/script/main/art.asp?articlekey=3771>).

<sup>39</sup> Complete Blood Count.

nurse was very busy and could not attend to his demand at the time. However, he added that when the nurses understand that he is there as a TC and have known him for many years, they trust him enough to say 'you go ahead and do it yourself'. The moment to take the blood samples can be crucial for evaluation purposes, as the TCs' objective is to rule out all non-viable donations as early as possible, but also the urgency responds to the necessity to obtain valid blood samples before any transfusion to the patient. Thus, it is imperative to detect the potential DBD upon arrival to the hospital A&E or in ICU prior to any major surgical intervention that would inevitably entail a blood transfusion and thus make the blood samples too diluted and invalidate the tests results.

The situation varies significantly when dealing with cardiac-dead donors, as David's quote illustrates. The potential donor is 'nobody's patient' because the unrecovered arrest patient is taken to hospital by EMS staff for the sole purpose of donation. Thus TCs become directly responsible for the donor/patient once death diagnosis has been signed and forensic authorisation for organ preservation obtained. This different distribution of responsibilities engenders another configuration of practices. Especially in regards to TCs and nurses in A&E interdependencies:

DCD is the only link with A&E and up until now it used to be regarded negatively, it is now starting to be something positive, let's just say that before when there was an arrested heart<sup>40</sup>, the emergency room nurse would just leave, I mean she would just leave the patient there with all the needles and all and she would just go away! She would say 'this is not a patient, this is a dead person, this is not my job' and she would just leave! So, whose fault is this? I think it is because we were not regarded as another unit in the hospital (Marc).

Marc is a nurse-TC who has over ten years of experience in A&E. He recalled his experiences both as a TC and as ER nurse who, unlike the nurse in the example, always took an active and collaborative stance towards TCs and DCD activities. He explains that the problem was that A&E nurses didn't feel that DCD was part of their job nor that donation practices were part of the hospital's services. The change he refers to is the recent incorporation of DCD protocols in the A&E department to integrate donation practices within the hospital's healthcare practices. As a result of this protocol, there are now two appointed practitioners to assist TCs, an ER nurse and a nursing assistant who will be present during cannulation and who will also clean up the room and leave it ready for the next case, be it a recoverable patient or a potential donor. TCs largely remark that

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<sup>40</sup> DCD or donors after cardiac death diagnosis are commonly referred to as 'arrested hearts' in the hospital and in official clinical practice and policy documents in Catalan, Spanish and French languages.

the changes in protocols have so far had a very positive effect on their job. Above all this is because they have helped to establish that DCD tasks are also A&E staff's responsibility and not TCs alone. However, they caution that further work needs doing to make all relevant hospital practitioners feel part of and assume their responsibility in various donation-related practices. Marc thinks that A&E staff's reaction is understandable because TCs go to different hospital units and give a lot of extra work to practitioners who are already struggling with increased workload. Over the past five years the hospital has implemented several staff reduction plans in order to better cope with the financial crisis that is deeply affecting public health services in Catalonia. Hence, he adds, it is essential to establish that donation is also HCPs' responsibility, and to clarify punctually when needed, that TCs' work is just another healthcare service and by no means based on financial bonuses, as was discussed in regards to some hospital staff members' reticence to collaborate in detecting potential donors.

Lastly, in tissue donation, and also drawing from David's quote, the potential tissue donor is detected after death diagnosis; thus, by then s/he is no longer anyone's patient, but rather a deceased body under the responsibility of morgue porters. This entails none of the aforementioned problems, neither stepping into other HCPs' responsibilities towards a living patient, nor having to clarify that a DCD is also a hospital patient albeit dead. Blood extraction takes place in the morgue where the dead body is being kept. Here, TCs simply greet the porter at the morgue, they are a small team that have been working together for several years and they have a very close and friendly relationship with the TC team. Note that enlisting the morgue porters' collaboration was key for TCs' donor detection activities. The porter in charge simply indicates in which cupboard the given dead patient is located so that the TC will be able to proceed with blood extraction. The timing of the extraction also matters with tissue donors. A thorough medical file evaluation with no contraindications will by then have entailed a prompt approach to the deceased patient's family to discuss the option of tissue donation. Notice, that as discussed previously, TCs need to locate the family straightaway after an initially positive medical file evaluation, so as not miss them while still in the hospital and be able to talk to them personally rather than on the phone. Thus, it is only for those cases in which family consent to donation has been granted, that TCs proceed to carry out a further clinical evaluation of the donor's blood. The timing of the task also responds to other pressures that intervene at that stage; that is, the decreasing validity of the blood test in the hours following the death of the patient. TCs need to extract the blood as early as possible so that the samples and test results will still be valid and representative of the given patient's

health. If too many hours have elapsed after the patient's death, the blood is considered too degraded and thus the results of serologic tests would be deemed unreliable. The direct consequence of this would be to rule out the donor altogether due to insufficient information to confirm necessary absence of disease, a situation that represents a contraindication to donation in itself. More details on this will follow in prospective sections. Once blood samples have been extracted they are sent to the analysis lab in the hospital; usually hospital porters are in charge of both taking the samples and bringing the results back to the TC office. There are two types of results obtained, an initial screening ready in just two hours, and a more thorough report in 12 hours. An initial negative result that confirms absence of disease is sufficient for TCs proceeding with cornea extraction, the only type of tissue donation that TCs carry out by themselves. Note that chapter 6 will provide details about the organ extraction stage and TCs' associated responsibilities.

### **5.3.3 – Social History Evaluation**

A third type of evaluation is also needed in order to ascertain the potential donor's eligibility. That is to say, to rule out any contraindications that would otherwise pose a risk of infection for the future recipient/s of the donated organs and/or tissue. It is seen as a necessary complement to the aforementioned medical file and clinical tests evaluation procedures. The information is gathered by TCs during the donation interview with the potential donor's family; this will be the subject matter of chapter 7. Once consent to donation has been granted, TCs then inform the family members that a series of questions on the medical and social history of the deceased person need to be discussed so they can rule out any, as they put it, biological risks that could affect transplant recipients. Initially they gather any additional medical information that might not have been logged in the patient's medical record file and that can be relevant to the decision on the donation's viability. In the case of tissue donors, note that age criteria is up to 89 years old, it might be that the person contracted tuberculosis sixty years ago, with no health repercussions thereafter, and it was not recorded in the rather recent electronic patient files. Or it could be the case that it is not considered important for the disease the patient was being treated for, such as corrective eye surgery or stomach reduction. Similarly, there are other interventions such as hip replacement that might not figure in the patient's file because it was done in a private clinic hence not part of the national public health record. Furthermore, a complete list of medications taken prior to death is not always available on the medical file and relatives can thus provide a valuable complement to the currently

available information TCs consider to assert the donor's eligibility. The information that relatives might provide can also cover signs of undiagnosed disease, such as Alzheimer's or Parkinson's<sup>41</sup> in advanced age. TCs would ask about the person's lifestyle, level of independence, mobility: 'Did she still live alone?' 'Did she need any help going to places?' 'Was she quite forgetful in the past years or with propensity to disorientation?' The answers to such questions can be very revealing for TCs about the general health condition of the now deceased person and about any noticeable signs of specific neurological diseases.

Lastly, TCs would go through the social history questionnaire to rule out any risk that the donor could be a carrier of some infectious disease. This consists of a list of eleven closed-answer questions that cover: tattoos, piercings and acupuncture; sexual relations with different heterosexual and/or homosexual partners; prostitution; sexual relations with persons with a history of HIV, hepatitis B or C; time in prison; drug injection; treatment for syphilis or gonorrhoea; travel to endemic zones like Japan, Caribbean, Africa and Polynesia in the past 12 months, and finally whether the person had lived in the UK more than six months in between 1980 and 1996<sup>42</sup>. Usually, relatives' answers are very fast and all negative so it can take less than a minute to complete the whole questionnaire. Other times, some TCs would prefer to hand over the folder and pen to the closest relative who has the necessary information to answer, so as not to turn it into a group discussion. Or they might consider that a close friend in the hospital will be a better informant than the mother of the deceased person and thus complete the questionnaire jointly away from the rest of the group. On one occasion, Xavi finalised the donation interview omitting the social history questions; it was a German catholic priest whose sister had decided to authorise donation of his corneas. On response to my immediate inquiry about such omission he simply stated that 'it was absolutely unnecessary'. Still, that was not Angel's, a senior doctor-TC, view when the issue came up later on back in the office. He explained to me that negative answers to all the questions are compulsory so as to be able to validate the donation, even though he was aware that in other Catalan hospitals this was not a necessity neither was it discussed with the donor's relatives. During interviews, Camino emphasised that the social history questionnaire's reliability can never be taken for granted, relatives might answer negatively when in fact it was the opposite. However, what matters to them is that in the event of a given positive answer then they need to

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<sup>41</sup> Alzheimer's and Parkinson's contraindicate as neurological diseases of unknown etiology

<sup>42</sup> The latter refers to the risk of BSE

consider it thoroughly and carry out further clinical tests if possible or rule out the donation altogether due to biological risk being a relative contraindication.

An illustrative case witnessed during fieldwork helps to convey the importance of the social history evaluation as a necessary complement to the medical and clinical evaluation procedures. This was a DCD case, a man who had suffered a heart attack while having a Reiki massage. EMS staff arrived promptly at the massage centre and initiated advanced CPR straightaway on site and while transferring him to hospital. Resuscitation was unsuccessful and he arrived at the hospital A&E as a code 303. The DCD process was activated, and given that there were no age or medical history contraindications, the cannulation and recirculation of the thoracic area for organ preservation went ahead. The relatives were contacted and arrived swiftly at the hospital, TCs were able to conduct the donation request shortly after and consent to organ and tissue donation was granted straight away. The answers to the social history questionnaire were all negative but TCs still proceeded with caution with extra clinical tests to rule out any absolute and relative contraindications in regards to biological risk. The dispute was over the legitimacy of the massage centre; TCs believed that a Chinese massage parlour in a rough area of the city was most probably associated with prostitution activities rather than genuine alternative healing practices. The team agreed not to proceed with organ and tissue extraction due to unconfirmed absence of infectious disease. At the same time, the issues about the unexplained cause and location of the man's death meant that it had become a judicial case and further forensic investigations were going to be carried out. A few days later, one of the morgue porters went to the TC office, the corpse had been under custody in the morgue up until closure of the judicial investigation, he told them how the story ended: "You are all a bunch of dirty-minded people! The Chinese woman was truly a certified Reiki practitioner and the holistic health centre a very reputable establishment in the area!". The TCs then told me that it was not the first time they had wrongly ruled out a donor for cautionary reasons but that they could only go ahead with extraction if absence of all contraindications had been previously confirmed. Ultimately, they are responsible for procuring organs for transplants and this entails several actions to ensure the safety of the organ and tissue recipients.

### 5.3.4 – Physical Exploration Evaluation

TCs have one last type of evaluation to carry out before being able to ascertain that there are no contraindications to a particular activated donation process; that is an exhaustive exploration of the potential donor/body. It takes place at different times of the process depending on the typology of donors, methods of detection and location in the hospital. In tissue donors it is done when the TC goes to the morgue to extract the blood samples, meaning when medical file evaluation and social history evaluation have showed no contraindications to donation, and after the deceased's family have already given their consent to tissue donation. It allows them to gather further medical information that might not be documented in medical files or not reported by family members:

Another thing that we do is a thorough physical exploration of the donor body, just like in DCD we do it upon arrival to check the general appearance of the patient, in tissue donation it can usually happen that it is not until we examine the dead body that we become aware of gaps in the medical history, and even if you ask the family, as we do, if he had any other disease aside from the ones recorded in his medical history, and they tell you that there isn't anything else, because the family are still in shock and they don't feel like talking, and then you go downstairs [the morgue] and you do the physical exploration of the body and you see that he was amputated or that he had a surgery scar that denotes a hip replacement, and this was not in any medical record file (Xavi).

TCs need to check all areas of the dead body to confirm absence of signs of any disease that could present a contraindication to donation. In the morgue, as noted before, the TC has already taken the dead body out for inspection and blood extraction. The physical exploration needs to cover a series of items from a checklist form. Some of them relate to biological risk such as tattoos, piercings and drug injection marks. Donated skin will later on be extracted from the back area so they need to turn the dead body round to check all areas. They started doing this after an incident of an eligible tissue donor that was sent to surgery and swiftly after, the extraction team called the TCs to inform them that the back area was fully tattooed; hence, the extraction did not proceed. TCs then explained to me that the problem was that patients in a hospital, especially those in ICU connected to a ventilator, are always lying down and no one checks the back area or turns them around. Thus, they started doing it for every case and it was added to the evaluation checklist.

Signs that could indicate any type of tumour growth are also evaluated by feeling the abdominal and thoracic area; and a breast examination is carried out on all women

donors. Likewise, the neck area is felt to check any signs of inflamed glands or lymph nodes that could indicate infection or cancer. Any freckles are given particular attention as they could indicate undiagnosed melanoma or skin cancer. On the occasions that visible or palpable potential signs of cancer are found then TCs either rule out the donation altogether or authorise extraction but with further clinical evaluation needed.

The genital area is also examined to check for signs of fungal infections, vaginal or penile candidiasis, genital warts or condylome associated with syphilis or other viruses. TCs remark that even if the family had given negative answers to all the social history questions, they could never have known everything about the sexual history of the person, so it is essential that they check thoroughly the dead body for any signs of disease that could be transferred to recipients. On one occasion, after both medical file and social history had been evaluated and family granted consent to donation, it was found during physical exploration that the donor/body presented evidence of severe anal fissure. The unanimous decision was to rule out the donor because of an indication of sexually transmitted infection and possibility of syphilis or herpes.

The physical exploration of organ donors, DBD and DCD, follows the same procedure as for tissue donors. Yet, there are other features that also need to be noted; namely, the measurements of the body, weight, height and BMI<sup>43</sup>, as well as the specific measurements for the abdominal and thoracic area. The figures must be logged in the physical exploration checklist so that donated organs will be allocated to a suitable transplant recipient/s with similar bodily proportions. On the other hand, there are other details that TCs are observant of but that are not listed in the body exploration form. For instance, a DCD is brought into the hospital and physical exploration is done swiftly after death diagnosis and simultaneously to initiation of organ preservation interventions. Note that sometimes the dead person might not even be properly identified and thus access to medical history files would not yet have been possible. Equally the TCs will have had no contact with the family to enquire about the potential donor's social history. Thus, it is seen as imperative in these cases, to do a thorough physical evaluation as soon as possible. In such cases, special attention is given to the general physical appearance of the deceased person. If TCs' first impression is that the potential donor/body shows clear signs of lack of hygiene, such as long and dirty nails, or poor health like extreme obesity, then they would rule out the donation and discontinue any already initiated activities such as cannulation for organ preservation.

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<sup>43</sup> BMI: body mass index.

#### **5.4. –Evaluating the Donor/Patient within the Process of Assembling Donations**

The previous sections have considered the fourfold process of evaluation that is necessary in order to determine the eligibility of a detected potential donor. It has been shown that, differently from donor detection mechanisms, during the evaluative procedure it is TCs' sole responsibility and judgement that will, as they put it, validate a given donation. Nevertheless, and drawing from previous illustrations of practices, there are a host of other hospital practitioners involved in carrying out various tasks in regards to evaluation. These include ICU nurses, who will provide blood samples from a potential donor or authorise the TCs do it themselves. Hospital porters, mostly morgue porters, who are in charge of taking blood samples to the in-hospital biochemical laboratory and take the results back to the TCs' office. Overall, it can be argued that TCs' reliance on other hospital professionals in relation to donor evaluation processes is of a much lesser degree and importance than those related to donor detection activities. The technicians carry out all tests that are brought into the laboratory regardless of their provenance or finality; a living patient's blood sample tube is no different than those coming from dead donors. Practitioners in the lab do not need to be enlisted or reminded about their relevance for donation practices to be carried out in the hospital. Likewise, the hospital porter's job is based on delivering items around the hospital with their trolleys, be it a blood sample, a document, a donated organ or a piece of extracted bone. To them TCs' requests are like any other hospital professional's request. Nevertheless, those are also instances that further shape the preliminary proposition that donation practices are thoroughly inscribed and thus made possible by the broader setting of hospital healthcare activities. However, the analysis of different processes of evaluation also brings to our attention a novel set of issues related to TCs' interrelatedness with other HCPs. Specifically, tensions that arise in the practice over issues to do with the distribution of responsibilities over the donor/patient. In cases of DBD evaluation, TCs might encounter some resistance from ICU staff to provide blood samples from one of their patients that TCs are considering as a potential donor. Similarly, albeit in the opposite direction, in DCD a problem might arise because A&E nurses refuse to deal with a deceased donor/patient because their job is to care for living patients. Over the past few years the hospital has implemented specific protocols to alleviate the aforementioned tensions and enable the TCs' responsibility of detecting and evaluating all potential donors. Here, the analytical figure of the donor/patient is deployed so as to emphasise that both in donation practices and in DCD and DBD hospital protocols, the message enforced is that some patients are also donors

and hence that donors are also patients. In short, that donation practices are also part of the hospital's healthcare programme. Nevertheless, the progressive institutionalisation of organ and tissue procurement within the hospital's setting and the embeddedness of the donor/patient figure is not always a seamless integration. Sometimes the differences between donors and patients are brought to the fore, and procurement-oriented practices stand in opposition to individual patient-care oriented practices.

The empirical accounts have shown that one of the frictions might be in regards to whose responsibility it is to deal with donors/patients within the hospital. Procurement in the hospital Clinic is another healthcare practice, albeit with a series of tensions that emerge throughout the shifting overlap and separation of the donor/patient configuration.

Moreover, the intervention of another set of patients also shapes the practices of the TC team, that is, their responsibility to ensure the safety of the transplant recipients.

Ultimately, the evaluative tasks respond to the necessity to ascertain absence of disease or infection that could be transmitted from donor to recipient. It will be shown in chapter 6, on donor maintenance and organ extraction, that evaluation procedures to guarantee donation's viability continue up until, and even after, organ transplant or tissue banking.

TCs remark that their initial evaluation, prior to extraction, even though it determines whether the donation process will be further assembled, is only an evaluation of probabilities of viability. It is not up until extraction that TCs in conjunction with transplant teams will assert the given viability of particular organs to be transplanted to particular recipients. The next section will focus on how TCs' evaluative practices shape the trajectory from detected potential donor to eligible donor, and later on the analysis will move on to consider how TCs' donor eligibility decision is contingent to and intervenes within the larger process of assembling donations in the hospital.

#### **5.4.1 – On the Trajectory from Detected Potential Donor to Eligible Donor**

It is the TCs' responsibility to determine initially who becomes an eligible donor and who becomes ruled out. The decision might take place at different stages of the process given that each type of donation, DBD, DCD or tissue donation, comes with a different set of affordances and constraints in regards to TCs' actions and timing. Chapter 6 will present details about TCs' evaluative practices during donor maintenance and extraction stages, then their examination moves on to consider the viability of particular organs in regards to their functionality. However, at the stage of early donor evaluation that concerns us here, different medical knowledges are mobilised by TCs with the purpose to identify any

signs of transferable disease. If evidence of the latter is found then the donation process is not assembled any further, the next section will provide further details and exemplifications of various disassembled donation processes.

It has already been stressed that TCs' donor eligibility decision responds to their responsibility for the safety of transplant recipients. Hence, it is paramount to them to ascertain the lack of evidence of particular contraindicated diseases by any means available. That is, by bringing together results from different modes of knowing disease – medical history, clinical tests, social history and physical exploration – as they become gradually assembled and incorporated within the donation process trajectory. There is no hierarchical ordering of such knowledges, rather they become available at different times and within the given constraints of each particular type of donation. For example, in tissue donation given that families need to be approached shortly after death communication (more on that will follow in chapter 7) the physical body exploration does not take place until after their consent to tissue extraction has been granted. Sometimes it might be that visible hip replacement surgery scars would represent a contraindication to bone donation, or similarly tattoos for skin donation. Ultimately, the decision can only be taken once all interdependent evaluations have been carried out and absence of contraindications has been confirmed by all of them. As observed previously, crosschecking is essential because different evaluations can complement each other. It might be that there was no recorded medical history of Alzheimer's but in talking with the donor/patient's family TCs might be told that she was very senile and could not be left alone anymore. Signs of embodied disease would be enough to rule out the tissue donation because of undiagnosed but advanced neurological disease. Indication of infectious disease, such as sexually transmitted diseases, are given special attention, as in the example that even though all evaluations confirmed absence of contraindications, TCs still decided to consider the potential donor non-eligible due to their suspicion that death occurred within a prostitution setting and hence it entailed a high risk of infectious disease for the transplant recipients. In short and summing up, it is the TCs' sole responsibility to determine the donor's eligibility at that initial evaluative stage. Their decision is crucial to determine the continuation of the donation process; nevertheless, it is only a stage in a larger trajectory of assembling donations in the hospital. Ferran, a senior TC, refers to the viability decision in regards to the whole assembling process:

The objective of our evaluation of viability is viability in itself, that is to say, if we have a donor or we don't have a donor, we are, we are trained and we are capable

of deciding whether that corpse, in conjunction with the family, medical and clinical evidence, can come to help other people through donation (Ferran).

The stress here is on the interdependencies necessary to make the choice of donation a possibility for some, eligible donors, and not to others, ruled out potential donors. Later on the analysis will encompass the timing and the weight of the eligible donor family's decision upon donation, by now, the main message conveyed is that both the stage of donor detection and evaluation are essential conditions of possibility for the choice of donation to be offered to some families of deceased patients in the hospital. Thus, when attending to deceased donation as a situated practice, donor family consent becomes decentered; it is neither that which starts a donation process, nor the only intervening factor. And the same goes for the TCs' donor eligibility decision; it is a necessary albeit not sufficient condition that participates in the given donation practices. The next section will present some illustrative cases of activated donation processes, that is, when TCs had decided a donor was eligible, but that became disassembled afterwards in response to various circumstances and constraints.

## **5.5. – On Disassembled Donation Processes**

The empirical accounts presented here will give further shape and depth to the thesis' *No heroics, please* II and III propositions to both decenter the donor/consent and the TCs' decision-making processes. Overall the aim is to move the analysis to a broader plane, that of processes of assembling donations in the hospital, which in turn incorporate, albeit in a decentered way, the intervention of both the TCs' responsibilities and the donors' families' consent to authorise the donation process to continue to organ extraction. The premise is that various sources of consent are distributed throughout any donation process – namely, medical confirmation of absence of contraindications, family consent to extraction and forensic consent to different parts of the procedure – each and all of them are equally necessary and none of them is sufficient unto itself. Thus, any donation process must gradually assemble all different sources of consent in order to continue up until extraction and further to the transplantation surgery.

As I have already shown, some cases become disassembled due to the TCs' decision to rule out the donation. A donor will be non-eligible if they decide that the transplant could transfer some disease to the recipients. Yet there are many other instances in which a donation process falls through and is not assembled any further for other reasons aside

from medical responsibilities towards transplant recipients' safety. As in a case encountered during fieldwork about a cardiac-dead donation process; a victim of a motorbike accident was rushed to the hospital, EMS staff had identified a potential donor and activated code 303 after confirming CPR was unsuccessful. Upon arrival, the doctor in A&E carried out death diagnosis by circulatory criteria and proceeded to sign the death certificate form. Formerly, EMS staff had looked for his wallet and found his identity card<sup>44</sup>; the detected donor/patient had been identified. TCs were preparing the emergency room for cannulation. The initial medical file evaluation, hosted in another hospital database, hadn't shown any contraindications. TCs had an eligible donor and a flurry of orders was being given to all collaborating professionals. The police were also involved and present in the hospital, as usual for any case of traffic accident. On such cases police officers have a code to unlock any mobile phone and access the listed contacts so as to call the victim's family. An officer got through to the victim's mother and on hearing it was the police with news about her son she exclaimed 'Have you found his stolen motorbike then? I will pass you on to him he is here with me'. Promptly the police officer notified TCs that the donor was not who they thought he was. By then, cannulation was complete and donor maintenance recirculation in progress. The TCs decided to wait for the police to find out the real identity of the donor so the right relatives could be contacted and take a decision about donation. However, an hour later a patient was brought to A&E with acute cardiac arrest. The emergency room was needed for a young patient with high chances of survival; in the hospital everybody knows that a living patient is more important than a deceased donor/patient. The TCs and nurses quickly dismantled the recirculation machine, removed the cannula and prepared the dead body to be transferred to the morgue. The donation process so far assembled was thus disassembled.

Wrong identity or unknown identity is also a contraindication to donation. Firstly, without a name TCs cannot access any patient's medical records, and no donation can proceed without a medical history evaluation. Secondly, TCs cannot proceed with any case without a valid death certificate. The document they had was under the name of a living person looking for his stolen motorbike. So the donation was disassembled and the eligible donor became an unidentified corpse in the morgue.

The next example also concerns a cardiac-dead donation but the reasons for disassembling it are of a different kind. TCs had activated a DCD process, the potential donor was found eligible and thus cannulation and organ preservation manoeuvres were

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<sup>44</sup> Spanish Identity Card is usually carried at all times

carried out. As noted before, cardiac death donation requires the authorisation of the coroner, or lack of objection thereof, to initiate donor maintenance procedures. TCs had previously sent a fax to the coroners' office and received no reply in 15 minutes; so donation preparations went ahead and further evaluations were taking place simultaneously to conducting the consent request with the donor's family that accepted to the TCs' request. Later on, a coroner called the TC office and indignantly demanded an immediate clarification about the fax she had received. Sandra, a senior TC, was on the phone answering evenly all the questions while the other members of the team gathered around her to overhear the conversation with curiosity and disbelief. Once she hung up, she sighed and said "Guys, we have a new coroner in town and she knows nothing about donation legislation!" The coroner had requested a document in which the TCs explained, in detail, the reasons for 'wanting to take the organs of the dead patient'. The general response was laughter in the face of what seemed to them such an absurdity. They quickly drew up a document that cited the current legislation on donation and succinctly explicated that the purpose of organ extraction was 'naturally for transplantation'. The coroner's reply took a few hours. TCs were calling frantically other judiciary authorities but it was all to no avail; it was that particular coroner's job that day to authorise the donation. It should be clarified that in addition to the initial coroner's consent to donor maintenance, which can be inferred from lack of response to TCs' fax, there is a later expressed consent to authorise organ extraction that TCs must receive as a signed official document. In the end the arranged organ extraction couldn't take place and the donation was disassembled because the coroner's signed consent authorisation was not obtained on time. All cases of DCD, given that they are mostly sudden and unexplained deaths, must be initially reviewed by forensic authorities, thus the purpose of the initial fax to the coroner's office. When the coroner or judge decides that the cause of death needs further investigation, then the case automatically becomes a judicial one, and therefore not eligible for donation. Sometimes, TCs might be given partial consent to donation; that is they might be allowed to open and extract organs from the abdominal area but the thoracic region must be left untouched. The reason is that a forensic postmortem will take place after organ extraction to clarify the cause of cardiorespiratory arrest. However, mostly when a case becomes judicial the already initiated donor maintenance procedures are discontinued and the donation is disassembled altogether.

There is yet another type of consent needed to assemble a donation successfully; the family consent. It has already been discussed that the donation interview with the donor's relatives serves a twofold purpose for TCs: firstly, to request consent to donation and

secondly, to obtain further information on donors/patients' medical and social history. The latter could bring evidence of some contraindications or biological risk that would ensue a disassembled donation for medical reasons. The consent request will be the subject matter of Chapter 7. It might well be that TCs' request for donation is swiftly met by a resolute negative from the donor's relatives, in which case nothing else could be done and the process would simply be halted due to family refusal.

Additionally, there are other instances in which the family consent cannot be ascertained for different reasons. An illustrative case follows: TCs had detected a potential brain-dead donor, a patient with a severe brain injury that was in a coma. ICU neurologists' initial results seemed to indicate that the situation of brain death was imminent. During the daily round, the nurse in charge alerted the TC that no family members had yet been located; the patient was an inmate of a mental health institution. Eventually, a sister was located, and in phone conversation with an ICU nurse she plainly stated she had no intention of going to the hospital or to discuss anything else on the phone. The TCs had reviewed the medical file and initial clinical tests results indicated absence of any medical contraindication. To them the patient was an eligible donor, but without the required family consent the donation had to be disassembled. Chapter 8 will further discuss the importance that such accounts of donation practices have for current organ shortage problematisation in the UK, namely, on the proposal to shift to presumed consent legislation in Scotland so as to increase national donation rates.

The aforementioned examples of the proposed analytical theme of distributed consent within processes of assembling donations in the hospital, contribute towards a delineation of the contours of the TCs' professional profile, that is to identify the scope and demands of their responsibilities, but also the limitations inherent to their position as procurement specialists within the hospital setting.

The final section of this chapter will further build upon mapping TCs' practices as embedded in the hospital and hence responding to a framework of protocols and healthcare regulations. The focus will be on the issue of donation rates and how the practices of donor detection and evaluation respond to the TCs' and the hospital's organ and tissue procurement programme.

## 5.6 – On Donor Detection, Evaluation and Donation Rates

Every three months the OCATT sends all Catalan hospitals with an organ donation and transplantation programme the provisional statistics of the year so far. They cover all the figures related to numbers of detected potential donors across the three types of deceased donors, tissue donors, donors after brain death and donors after circulatory death. The general figures for Catalonia are provided and then broken down into participating hospitals. Angel is usually the most enthusiastic to receive such information; he scrutinises every detail and systematically compares current statistics to previous ones. On one occasion during fieldwork I sat with him and he talked me through the whole document with especial attention to the so-called potentiality tables. The tables presented the figure for all potential cases that ended up being ‘utilised donors’ for transplantation; TCs adhere to the latest standardised terminology for deceased donation following Dominguez-Gil, B., et al.’s (2011) prescriptions. The formula goes like this: all detected cases minus medical contraindications, minus judiciary negatives and minus family negatives equals the number of resulting organ and tissue donors. Lately, Angel explained, donation rates in the Hospital Clinic have plummeted compared to other years. Consequently, other large hospitals in Barcelona present higher donation rates than usual. He concluded that brain-dead donors are now distributed differently across hospitals. A fragment of the conversation, transcribed verbatim on the same day, can contribute to initiate a discussion on donation rates:

S: Yes but anyway how do you know it is the same number of donors for this year to claim it is a case of redistribution?

A: Well yes, we should look into this properly as there are plenty of factors involved but the thing is that here we always had the highest donation rates in Catalonia and the number was pretty stable year after year, the reason was because we always had ICU beds available for patients with severe brain injuries that would eventually become brain-dead donors. Other hospitals would simply refuse to take in such patients with no prognosis, even though they had the means to treat them, whereas here we always had beds ready and so they all ended up here, but now other hospitals with advanced ICUs have discovered the trick and now they also have beds to admit such patients.

A quick glimpse at Catalan statistics for the year 2013<sup>45</sup>, the period when fieldwork was conducted, shows that the hospital Clinic held the highest donation rates both for DBD and DCD but that the other four large hospitals in Barcelona were rapidly increasing their

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<sup>45</sup> See Appendix 3 for OCATT’s statistics and the Hospital Clinic.

donation rates. In conversation with Angel, I was instructed that additionally to the redistribution of donors across hospitals, brain death donation rates have nevertheless been decreasing rapidly over the past few years. The factors involved are all outside the TCs' domain of action; it is not a case of undetected donors, as discussed in initial section; they already have several detection mechanisms in place to cover the totality of potential DBD in the hospital. It is about the fact that fewer people are dying in the right circumstances to be conducive to a brain death diagnosis. The reasons are diverse but the ones that TCs in general include in the list are: a progressive significant reduction of traffic accidents due to better safety and prevention campaigns; more efficient, early and aggressive neurological treatment for cerebrovascular disease and brain trauma means that more patients recover after severe brain injury, and some of those that die are ruled out as donors because of medical contraindications that are a direct consequence of the aggressive nature of the late treatment received; some public health programmes implemented recently have helped to reduce considerably the number of stroke victims; the recent enactment of Spanish law to legitimate withdrawal of life-support, as discussed before, gives the patient's family the choice to discontinue futile treatment before brain death; and usually last but not least, they mention the effects the current national financial crisis is having on donation rates. They argue that decreased employment rates also mean fewer workplace accidents, fewer people driving to work and fewer traffic accidents. Moreover and within the medical domain, significant cuts in public health budget, as a consequence of the austerity measures, mean that fewer surgeries are performed and so fewer people die in the hospital. TCs deal with significantly fewer potential donors to detect; that is, donation processes that will neither be assembled nor disassembled but that will remain unassembled and thus not listed in the statistics. This is a matter of heated debate in the TC office, and most frequently it sparks just after receiving OCATT's latest statistics. In the list of Catalan hospitals and their donation rates, the Hospital Clinic occupies by far the first position. Next to every hospital's results there is an arrow, green indicates that the hospital has increased donation rates and red that rates have decreased. The colour of the arrow matters to them but just as an indication of their so-called semester results. OCATT reviews are informative about rates but it is a nation-wide organism with no evaluative powers towards TCs' level of activities. In contrast, the reviews of donation rates carried out periodically by the hospital board, do have repercussions on TCs' jobs.

The hospital runs an auditing regime applied to all units of the hospital. Activity levels are periodically reviewed and any divergence from set targets for the year is addressed. For

TCs this means that if donation rates, of any of the three types of donors, are lower than expected, they will be summoned to discuss their results with the auditing team and there will be a further inspection of the documents provided reporting on cases of non-donation or what I here call disassembled donations. The particular document that is subject to further scrutiny by the hospital board is the form commonly called 'the contra' file amongst TCs; it refers to the contraindications to donation that must be identified to justify all disassembled cases of detected donors. Different contraindications have already been reviewed, namely medical contraindication, judiciary negative and family refusal. On one occasion when the 'contras' were being audited, Sandra commented that it is understandable that the hospital looks into the recent decrease in donation but that the problem is that they do not take into account those factors that influence rates but that are outside of TCs' control, such as the ones previously listed. Camino, following the conversation, explained for my benefit that there is never any problem as long as they can justify all the negative cases. However, she added that it makes her feel very uncomfortable when put on the spot because it is as if TCs are only providing 'lame excuses' for something that they didn't make work out. Thus, she complained the auditing system plainly neglects the fact that TCs' actions are limited when confronted with situations like reduced mortality rates, non-eligible donors, family refusal to donate or judiciary appropriation of cases. During an interview, we extended on the topic of donation rates:

We get what we get [donation rates] and if we are below target we are simply put in red but this doesn't mean we don't do our job properly but rather that the objectives are wrong and need to be adjusted! It all comes down to being able to justify that we have a work plan and follow all protocols and that we control all deceased cases in the hospital and follow up all potentials (Camino).

The attitude expressed in the quote is representative of the whole of the TC team, in that donation rates matter to them too, but there is only so much they can do and they are already doing it. A testament of their commitment to their task is the implementation of their strategic donor detection and evaluation mechanisms to enable them to detect the totality of eligible donors available in the hospital.

Besides, TCs clarify that the hospital board is perfectly aware that carrying out donation processes is a very complex task that necessitates the collaboration of a great variety of professionals and other factors within the hospital; and thus that donation rates never rest solely on TCs' responsibilities. Additionally, they explain that the hospital, as part of

Catalan public health services, is under strict corporation management rationales of efficiency and cost-effective practices. This too, is a consequence of the recent financial crisis that has translated into hefty cuts in public health funding. The resulting situation is one of decreased number of staff, reduced wages and a suffocating climate of justification of all activities and expenses to a rigid auditing system within the hospital.

In 2011 the hospital elected an external figure to the TC team to serve as general director and address the then current trend of lowering donation rates. Both during fieldwork and in a personal interview, Ramon<sup>46</sup>, the director, discussed the creation and responsibilities of his role within the hospital and towards the TC team. He explained that he was elected because he was the head of the surgical ICU and thus he was already linked to a 'donor generation area'; meaning that his extended experience as an ICU anaesthesiologist indicated that he had managed numerous cases of DBDs in his unit. He described his role as follows:

I was made responsible for personnel selection and organising all internal circuits to optimise everything so there were more donors because we were going through a donation crisis and that was partly because there was a general disengagement of people working in the hospital towards the TSF<sup>47</sup>. They saw them as somewhat alien, not part of the hospital, and that they bothered rather than helped, so they saw donation as something not part of their healthcare process, I mean, your job is up to here and anything else is just a bother, so we decided to integrate donation within healthcare processes in the hospital so that it was more...so that it was healthcare (Ramon).

The quote brings forward that some of the problems that were identified as impediments to increasing donation rates was the non-collaborative attitude of HCPs towards donation practices. The director's job thus focused on achieving a better integration of procurement activities within current hospital healthcare practices. Ramon stresses that this was the area in which they could intervene, unlike in other areas such as those mentioned earlier that have resulted in a drastic reduction of potential donors. The line of action taken for the given integration of donation translated into the creation and implementation of several hospital protocols that stipulated that donation tasks were also a responsibility of hospital practitioners; in particular, ICU staff for DBD and A&E for DCD. As noted earlier, such protocols aimed to reinforce the message that some patients are also donors and hence that donors are also patients, or that organ and tissue procurement can also be

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<sup>46</sup> See Appendix 6 List of Research Participants

<sup>47</sup> TSF: Transplant Services Foundation was the company that managed the tissue bank and dealt with TCs contracts up until it was absorbed by the hospital Clinic in 2011

considered part of the hospital's healthcare practices. Ramon stressed that the shift conveyed that generating donors was also a hospital-wide objective; to him increasing donation rates is about identifying which areas have donation potentiality, that is where potential donors could be detected, and inculcating to the practitioners in the unit that obtaining donors is also one of their objectives. Thus, a thorough review and audit of all cases of potential donors, those that ended up in donation and those that didn't, is seen as a prime necessity for the current hospital's strategy to address the reduction in donation rates.

This thesis' *No heroics, please I* suggestion is here unravelled in regards to the issue of donation rates. The aforementioned discussions with TCs and the director illustrate the core proposition to consider donation practices as an integrated part of healthcare activities within the hospital Clinic. TCs' responsibilities towards detecting and evaluating eligible donors are embedded and enabled by the hospital's protocols and regulations, as well as being dependent on wider national public health policy and legislation. The proposition also implies that procurement doesn't stand in opposition to healthcare but rather depends on it; donation is both procurement and healthcare. It follows that donors are also hospital patients, although the donor/patient overlap and separation shifts across types of practices and practitioners involved. Mostly throughout the stages of detection and evaluation, donors are enacted as any other hospital patients, although sometimes frictions emerge and donors are not like other patients, especially when it comes to defining which practitioners are responsible for donation-related tasks.

The analytical invitation advanced by *No heroics, please II*, to decenter consent and instead look into processes of assembling donations, is articulated and illustrated in this chapter by mapping the TCs' responsibilities to detect and evaluate eligible donors. Overall and to sum up, it can be said that both the TC team and the hospital board's objectives converge in their shared efforts to implement an efficient donation programme. Ultimately, TCs' responsibilities are directed towards detecting all potential cases of donors amongst deceased patients in the hospital and to determine which cases will not be ruled out and thus become provisionally eligible for donation. The efficiency rationality that TCs endorse is not about generating more donors – as we have seen assembling a donation successfully is a highly complex process with several interdependencies across and outside the hospital – but rather about using up better the currently available albeit diminished hospital's mortality rate; the deceased patients detected as potential donors daily by TCs. Finally, in this chapter the proposed *No heroics, please III*, to decenter the

figure of the TC, has been illustrated by a delineation of both the scope of TCs responsibilities, as well as the inherent limitations of their task in regards to organ and tissue procurement for transplants. TCs are indeed responsible for coordinating the whole process of assembling a donation in the hospital, nevertheless, they could not work alone, their practices are enabled and embedded in a wider hospital and national setting defined by specific institutionalised protocols and public health regulations in regards to deceased donation.

The final discussion in chapter 8 will further mobilise the aforementioned *No heroics I, II, III* propositions so as to analyse the current problematisation about low organ donation rates in the UK, and particularly to examine critically the proposed way to increase national donation rates by shifting to a presumed consent legislation in Scotland. It is argued that the question of how to increase donation rates cannot be reduced to the issue of consent only. As these ethnographic accounts from a hospital with high donation rates have shown, the consent of a donor's family is neither the start nor the only factor that intervenes in any given process of assembling a donation. A close scrutiny of TCs' responsibilities for initial detection of potential donors, and subsequent evaluation of their eligibility, has shown that the primary conditions for a donation process to become gradually assembled incorporate various sources of consent. That is, consent is distributed along the different stages of a donation process, and in each of them there are several contingencies that intervene and that can potentially lead to a disassembled donation. The following chapter 6 will continue the analysis by providing details on the TCs' responsibilities during donor maintenance and organ extraction; their tasks in regards to procuring viable organs and tissue for transplants are also interdependent with the collaboration of other healthcare practitioners. The shifting configuration of the donor/patient will be further articulated along with the inclusion of the donor/body figure; the latter will also be encompassed in the analysis as an intervening actor within the processes of assembling donations in the hospital.



# Chapter 6 – Maintaining Donors and Extracting Organs

## 6.1 – Introduction

This empirical chapter will continue to map the TC team's responsibilities as the process of assembling a donation moves on to the stage of donor maintenance and finally organ extraction. The *No heroics, please* theme will be revisited when appropriate, and referred back to the relevant propositions. Nevertheless, this chapter will focus mostly on the donor/body figure and hence it will aim to give shape and depth to the *No heroics, please IV* proposition in particular. The guiding questions that will scaffold the analysis will be 1) *How are donors qua bodies being done in the practices of assembling donation processes?* 2) *How is the donor/body enacted and acting in these given medical practices?* 3) *How are organs inside and outside the donor/body active and responsive entities embedded within these situated donation practices?* As elucidated in chapter 3, by exploring such questions the analysis aims to overcome some omissions that former social studies of organ donation have recurrently reified. In short, and following previous discussion about the reviewed medical ethnographic works (Fox and Swazey 1974, 1992, Hogle 1999, Lock 2002, Sharp 2006), it is argued here that their accounts of donors have been framed within a Cartesian divide that separates acting sentient subjects from passive material objects, thus relegating bodies to mere matter or mute externality. This is principally, or so I propose, because their analysis has encompassed a critique of the commodification of the body within these organ procurement practices, deemed as technocratic, utilitarian and dehumanising. Hence, it is the aforementioned authors' critical approach to the reductionist transition from subject to object, that is from person to thing or more specifically from patient to donor or from whole to parts, that has reduced the donor/body figure to an objectified entity devoid of capacity to respond and to intervene in the practices from which it emerges. Accounts of both donors and donation practices have revolved around the brain death ethical quandary, on the legitimacy of the diagnosis and on the ambiguities and transgression to the foundational life and death dualism that donors have posed both to families and medical professionals involved. The living cadaver figure, present in Fox & Swazey's (1974, 1992) Hogle (1995, 1999), Sharp (2006) and Lock's (2002) ethnographies, is mobilised to denounce the objectification and commodification of the body in donation and

transplantation practices. The argument I advance here can be illustrated with various grounding conceptualisations in the aforementioned works, such as the fragmentation of the person/body into 'an ensemble of interchangeable spare parts' (Fox & Swazey 1992), donors as dehumanised cyborgs or 'docile bodies' as 'incubators of organs' (Hogle 1995), brain-dead bodies subject to commodification (Lock 2002, 2003, 2004) or 'medicalised cyborgs' as 'depersonalised passive objects' or 'repositories of reusable parts' (Sharp 2006). However, this empirical investigation diverges from these authors' critical stance and addresses the complexities of routinized donation practices (*No heroics, please I*) that both encompass brain-dead and cardiac-dead donors, all considered equally and irreversibly dead in TCs' practices. It is important to highlight that this investigation is grounded on Lock's (2002) elucidation of death as a relational process and not an event, and that it includes, in Lock's parlance, both the biological body, the person, and the social setting in which it takes place. Nevertheless, and given that TCs are not responsible for the death diagnosis, this research excludes any questions about the practice and effects of differential death diagnoses. It is not part of this analysis to question whether donors are more or less alive/dead and whether the donor/body's activity can be identified as observable signs of life or after-death residual activity.

Ultimately such questions, that have largely permeated and characterise former medical ethnographies on organ donation, presuppose a clear boundary between life and death, thus rendered as an event and not a gradually unfolding process. Moreover, they are premised on an atomised notion of the body exclusively defined along humanist conceptualisations of individuality and personhood. As explained in chapter 3, this thesis moves away from such individualising notions that further epitomise the subject/object hierarchical binary, as it bounds agency within anthropomorphic terms and defines it as a property of autonomous subjects whilst denying it to entities that are defined as objects. To do that, I will make use of material semiotics tools so that the analysis can open up to the active intervention of both bodies and organs in the medical practices under investigation. In particular I will be drawing on Mol and Law's (2004, 2008) incitement to study the enacted/acting body in situated practices. In their empirical studies, actors are both enacted and acting, yet they do so as embedded actors within particular configurations of practices. Accordingly, the analysis put forwards here, initially turns to the practices and TCs' accounts about their responsibilities in regards to donor maintenance.

It is crucial to note that this research is not about disentangling actors from distributed joint action, i.e. what the body does as a singular entity, but rather it is about decentering the singular donor/body and instead focusing on entangled processes that encompass the unstable donor/body, the technoscientific configuration of maintenance technologies and the multiple corporeal death processes that unfold in the three different types of donors/bodies encountered in the hospital Clinic. In doing that, the analysis mobilises Haraway's (2008) notion of responsibility or the capacity to respond, it is suggested that this enables a more detailed unravelling of the relational and nonanthropomorphic processes that take place and that concern the donor/body; a responsive entity entangled and bounded by differential maintenance configurations. Response-ability is, following Haraway, crafted within multidirectional relationships, hence, it accounts for both the TCs' responsibilities for intervention, and donors/bodies' response-abilities and participation in the practices under study. Moreover, thinking with responsibilities helps to circumvent symmetrical attributions of agency as in Latour's call to extend agency to nonhuman actants (2005), and it foregrounds the way in which each entity will participate asymmetrically to the conjoint unravelling processes – here TCs or maintained donors/bodies. The donor/body responds to maintenance interventions and correspondingly enables or precludes different responses by TCs, it is the shifting distribution of affordances and limitations of response-ability that are under scrutiny here.

It should also be clarified, that even though the analysis focuses on mapping the TCs' responsibilities, it does so by acknowledging the key collaboration of other hospital practitioners that make such donation practices possible (*No heroics, please III*). Nevertheless, it is through an exclusive focus on the TCs' responsibilities that this investigation foregrounds the overlap between donation as both a procurement and a healthcare-based activity (*No heroics, please I*). In that their attempts, as it will be later shown, to keep the donor/body as a more or less stable assemblage of functions, respond to their objective of procuring viable and thus functioning organs for transplant recipients/patients.

The second half of the chapter will cover the organ extraction phase; the transfer and preparation of the donor/body for the surgical intervention will also foreground the donor/patient figure, as will be duly indicated. And later on, during the process of bodily reconstruction, the donor/corpse figure will be briefly introduced, although it will not be properly unfolded until the discussion in chapter 7 about the consent request with

families of eligible donors. The focus will remain, as in the first half of the chapter, on the donor/body figure and in particular on the participation of organs in the practices under examination. Organs, just like donors/bodies, are responsive entities that emerge bounded by the technoscientific practices of donation in the hospital. Thus, the question of organs' intervention will be addressed by focusing on entangled processes and joint action, for organs, like bodies or any other entity, are always acting-with, responding and enabling response (*No heroics, please IV*). I will once more indicate the exclusion that this research takes stock of, essentially the omission that former social studies of organ donation and transplantation effected. In that by portraying organs through different actors' meanings alongside antagonistic renderings of acting subjects and passive objects their analysis left out the intervention of organs altogether. Needless to say, the latter was never their matter of concern, rather their works wished to unveil the discrepancy of discourses that construed donated organs as either objectified within medical rhetoric – 'replaceable parts' as 'depersonalised objects' or 'alienable commodities' – and subjectified through meanings attributed by donor families and recipients (Fox and Swazey 1974, 1992, Hogle 1995, 1999, Lock 2002, 2004, Sharp 2006). Likewise, previously reviewed social studies that defined organs as either gifts or commodities were also premised on the hierarchical subject/object binary (Joralemon 1995, Siminoff and Chillag 1999, Scheper-Hughes 2001, Healy 2006). The limitation of such a social constructionist approach is that it relegates organs to brute matter, singular and extrinsic blank canvases on which to impress the different actors' subjectified or objectified meanings. Thus in order to circumvent this constraint altogether, this research proceeds from an in-depth analysis of organs as intervening and emerging from the specific medical practices of donation for transplantation.

## **6.2 – Donor Maintenance**

Donor maintenance activities, similar to donor detection procedures, are divided into the three different categories of donors, that is, donors after brain death diagnosis, donors after cardiac death diagnosis and tissue donors. The latter are declared dead following cardiac death criteria, but given that organs will not be procured then there is no need for any maintenance intervention, aside from donor/body refrigeration at the morgue. Nevertheless, they are included here as they offer valuable information in regards to the responsive donor/body and corporeal death process that will be examined in the theoretical discussion on section 6.3.

The different donors/bodies that will be narrated in the following sections are already considered eligible donors/patients, meaning that TCs' early evaluation right after initial detection, has not shown any contraindication to donation, and thus they are considered viable donors so far. As explained beforehand, families' consent to organ and/or tissue extraction is ascertained at different points of the process of assembling a donation, and those differ for the three kinds of donors. Whilst maintenance intervention for brain-dead donors starts after families have consented to donation, in the cases of cardiac-dead donors organ preservation manoeuvres are initiated right after death diagnosis, and hence prior to deceased patient's families being approached to discuss donation. This will be discussed at length in chapter 7 on the donation request.

The main questions that will be addressed are: 1) *What are the responsibilities of the TC team during the stage of donor maintenance?* 2) *And how does the donor/body intervene in the processes of assembling donations or in cases of disassembled donations?*

The theme of the donor/patient overlap and separation will be dealt with accordingly for each type of donor. However, given that this chapter focuses mostly on elucidating the donor/body figure, the following stories from the hospital will foreground enactments of the unstable donor/body as a responsive organism to be kept circulated.

## **6.2.1 – Maintaining Donors after Brain Death Diagnosis**

### The Donor/patient in DBD maintenance practices

In the different ICUs in the hospital there are always multiple copies of an information leaflet addressed to healthcare practitioners about brain death diagnosis and donor maintenance. One side covers the process of death diagnosis following neurological criteria and the other one specifies the treatment guidelines for donor maintenance. The instruction highlighted is that 'once brain death diagnosis has been confirmed the TC team ought to be notified'. However, as has been shown in the previous chapter, TCs are already aware of the potential brain-dead donor/patient prior to the death diagnosis. In fact, a TC needs to be present during confirmation of death diagnosis tests along with the required three neurologists<sup>48</sup>. The leaflet renders a separation between patient and donor that does not map onto the practice, yet the objective is to separate the differential

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<sup>48</sup> Spanish legislation on brain death diagnosis' specific requirements ([https://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2012-15715](https://www.boe.es/diario_boe/txt.php?id=BOE-A-2012-15715)).

treatment applied to a critical patient from that applied to a donor. In short, and following the leaflet's terminology, after death diagnosis the treatment changes drastically; it shifts from measures to minimise neurological damage, to measures to preserve the viability of organs and tissue. In the Hospital Clinic, DBD maintenance is the responsibility of the treating team in the ICU. The same doctor and nurses that carried out all healthcare interventions on that particular patient become responsible for monitoring the donor/body. More will be said on the sort of measures it entails later on, firstly the task at hand is to delineate the distribution of responsibilities in donor maintenance as this can further contribute to the analysis of the donor/patient figure. Camino explains about the stage of donor maintenance and the role of the TC:

In terms of donor maintenance and follow up we are in a great position here because our hospital has had great clinical experience maintaining donors properly, and donor maintenance requires exactly to look after him just like any other patient...basically it is a set of simple protocols and it is here established that it is the job of healthcare practitioners' in ICU, as TCs we can only give advice on specific treatment measures...but really our task at that time is to coordinate the whole process of extraction (Camino).

The supervision of donor maintenance in the hospital Clinic is carried out by doctor-TCs, that is Camino, Angel and David. Nurse-TCs might have the necessary knowledge, especially senior TCs like Ferran and Sandra, but they don't have the medical profession credentials to advise ICU practitioners on what type of medication or intervention should be provided for a particular donor/patient. Ferran remarks that his job then is basically to monitor the vital parameters but without making it very obvious to the ICU personnel because, as he explains, even if these patients are dead they are still responsibility of particular ICU doctors and nurses. Thus, TCs need to supervise donor maintenance activities but without intruding unnecessarily into other professionals' domains. Angel, like Camino, recognises the experience and expertise of ICU staff in donor maintenance and limits the TC role to that of an advisor when needed. To him the message to convey to ICU staff is that:

Now we are not treating a patient anymore but maintaining a dead person and what we are actually doing is maintaining the organs and tissue as well as possible up until extraction, so the focus of the treatment inevitably shifts because so far you have been taking certain measures to avoid neurological damage and now this doesn't matter anymore, treatment for donors might even involve opposite measures, so the protocols are different but the ICUs we deal with already know that and they do it quite well (Angel).

This distribution of responsibilities amongst ICU staff and TCs is unique to this hospital. Ramon, the director of the team and ICU doctor, explains that in other large Catalan hospitals it is usually ICU practitioners who are also part-time TCs. Angel remarks that the fact that the TC team are dedicated exclusively to donation makes them an external unit to those ICUs where donors are located. Thus, he says, it has been more difficult for them to become accepted at ICUs or to be listened to in regards to donor treatment guidelines. The main cause of friction here is that, as he puts it, ‘these donors are not our patients’. At least not until they leave the ICU unit; by the time donors are transferred to the operating theatre they become TCs’ responsibility exclusively. While eligible donors are ICU patients TCs’ suggestions might be met with certain reluctance. An example could be those instances when there is an infection detected and TCs advise the treating staff to administer an antibiotic to the donor so that the infection is not transferred to the transplant recipient. Ramon, as an ICU doctor, has been in this situation several times, he highlights that donors in his pulmonary unit are not only treated like any other patient but also with greater care and close monitoring because if any problems arise they will negatively affect a potentially large group of patients, the transplant recipients. However, some TCs like Xavi complain that some ICU practitioners fail to do so because their attitude is, as he puts it, “he is already dead, I am a nurse, I know how to care for a patient but if he is dead I don’t care<sup>49</sup> anymore”. Xavi, an ICU nurse himself, is the only one in the TC team that suggests that TCs should carry out all donor maintenance activities themselves because they are the ones that know about what is at stake at that stage. In general the team express that some ICU personnel are better than others in terms of donor maintenance but they all agree that it is their job to do so and it is not a matter of individual attitudes towards donation but rather a thoroughly scripted and detailed protocol they all have to follow. Once more the practices and distribution of responsibilities over procurement-oriented tasks reflect the premise that donation is a thoroughly embedded and integrated part of the hospital’s healthcare programme (*No heroics, please I*). This in turn also contributes to the routinisation of the donor/patient figure, which as formerly presented accounts illustrate, it is not always enacted as a seamless integration of donors as patients but it can also entail disputes over patients that are not yet regarded as donors.

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<sup>49</sup> Translation note: the verb to care in Catalan is used to refer to attending a patient, it does not denote absence of concern as in English usage ‘I don’t care about something’.

## TCs' Responsibilities for Donor/body Maintenance

Brain-dead donors in ICUs are intubated and switched on to a ventilator; their respiratory and cardiovascular functions are being maintained artificially. ICU nurses check that the monitored parameters are within a normal range, but it is the TCs who are ultimately responsible for dealing with any contingencies that might arise and that can threaten to disassemble an initiated donation process at any time. During donor maintenance their utmost concern is, as they put it, to avoid losing the donor. Here Ferran describes the situation of brain-dead donors/patients and TCs' objective:

Donor maintenance and follow up means basically not to lose the patient because when the brain fails certain processes of the body start failing too, blood pressure might drop and when there is not enough pressure then the kidney will be not be perfused sufficiently for example, this is why we die because the brain stops giving orders, the hard disk drive is not working, the heart is not beating well, the pressure drops, all the hormones in the body start to scramble and there comes a moment that nothing works anymore, what they call multiple organ failure and what we want is to avoid this multiple organ failure because some of these organs are the ones we want to use up (Ferran).

It follows from Ferran's quote that it is what the brain stops doing that marks the trials of maintaining a donor/body. The vital parameters that are being monitored both by ICU personnel and TCs relate to different bodily functions that are being artificially maintained with various technoscientific means. These include correct oxygenation through ventilator, regular heartbeat, arterial pressure, diuresis, haemoglobin levels and body temperature. TCs explain that in order to have properly irrigated organs the whole donor/body needs to be kept circulated and stable. Ramon, the director, says that it is basically continuing with the same treatment applied to the patient; the same general measures as for any other patient on a ventilator in intensive care. The monitoring process is described as dynamic, one must check constantly and be ready to intervene to adjust values if needed, and very systemic, meaning that it is the donor/body as a whole that is being monitored and maintained. David sums it up quite well when I ask him if the maintenance measures are directed towards the donor as a whole or to the individual organs specifically: "If you want to have organs you first have to have a donor so it is always both donor and organs at the same time". During the donor maintenance stage, TCs arrange and coordinate several evaluative procedures that will measure the functionality levels of individual organs, and further ascertain absence of transferable disease that could put the future transplant recipients/patients at risk.

## TCs' Responsibilities for Individual Organs' Viability Evaluation

In order to determine the individual organs' viability, an array of tests will be performed on the donor/body. Some of these tests involve imaging technologies and are carried out by the medical specialists of each organ or relevant technicians. TCs remark that such tests are done only when they have an eligible donor and after the family has consented to donation; the reason given is to avoid incurring any unnecessary expense on public health resources before having an eligible donor. TCs need to summon each relevant specialist to the ICU to conduct the tests and discuss the results together. The tests are a thoracic X-Ray, abdominal scan, electrocardiogram, echocardiogram, and in some cases they also arrange a Brain CT scan<sup>50</sup>. It might be that the donor/patient had a tumour that s/he was unaware of or that was still undiagnosed, thus, TCs use imaging technologies like scans and X-Rays to further ascertain that the donor/body and specific organs do not present any contraindications to donation, in this case any visible cancer growths in the abdominal and thoracic area. On one occasion the abdominal scan revealed a considerable tumour in the liver and as a result the donation process was disassembled; the organs were non-viable for transplantation as they entailed a high risk of disease transfer to the future recipients/patients.

Both the electrocardiogram and echocardiogram will provide measures to check the heart's functionality levels, and provide a general measure of the heartbeat regularity that contributes to the maintenance of the donor/body as a whole. Further clinical tests are also arranged, such as culture growths both for donors' blood and urine to determine the absence of disease to avoid any transmission to transplant recipients. The next section on organ extraction will provide further details about the gradual process of evaluating organs' eligibility. As noted previously, it is not until after extraction that the final decision about particular organs' viability is taken by the extracting surgeons. At this stage, TCs need to use all available means to identify any case of non-eligible donors or particular organs that would be ruled out. Camino explains in an interview:

Well we don't decide only organ by organ because the organism as a non-static body demands a continuous evaluation and I could say well this liver is good even though the clinical tests are not great but he is young and even if he drinks a bit he

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<sup>50</sup> Brain CT scan: computed tomography scan of the head that uses special x-ray equipment (<http://www.radiologyinfo.org/en/info.cfm?pg=headct>).

hasn't been drinking for that many years and the scan came out well, so it is always a continuous analysis and any evaluation will always comprise a medical evaluation, a social history evaluation with the family during the donation interview and then you have the third part of the evaluation based on the results of the complementary tests we arrange according to our medical perception, these are the three basic pillars, if you put them together and they fit then you have a donor or a donor of specific organs (Camino).

Camino's quote resonates with the research objective to analyse the TCs' practices of assembling donation processes, and it highlights that even when evaluative tests are directed at individual organs they are still interdependent with prior evaluations that considered the donor/patient's medical history, clinical tests and social history. The next sections will open up the analysis to the figure introduced in Camino's account, 'the organism as a non-static body', on the different affordances and constraints that poses to TCs' organ procurement practices and the many ways in which a donation process can become disassembled.

### The Unstable Donor/body: Labile Organism and Disassembled Donation Processes

The donor/body might remain stable on a ventilator for up to twelve hours with a great variability across cases, type of death and donor characteristics. TCs need enough time so as to be able to evaluate all organs and organise extraction but they are always aware that any complication could speed up the process or halt it altogether. In short, the more time that passes after death, the more complications the donor/body can present and the more interventions to correct and adjust will be necessary to avoid losing the donor. Camino explains in an interview the difficulties of maintaining brain-dead donors:

Once we reach brain death situation what happens is that there is a break out of several substances because really the organism, even if it's artificially maintained with drugs and everything, experiences certain changes like release of some hormones that lead to a situation of high instability and response lability, these alterations make the previously living organism extremely labile, it doesn't respond to medication or anything you do to it and this is when the heart might stop and everything stops and the whole donor is lost (Camino).

The organism, as per Camino's quote, is indeed active after brain death diagnosis. The unstable donor/body is enacted and acting as a responsive labile organism. Lability is the medical term used in the hospital, meaning susceptible to change or easily altered. During

interviews I inquired about the basis of this lability, most TCs indicated the release of substances in the body after death, such as in Camino's former reference to hormones, and in Ferran's previous quote that also mentions that the 'hormones in the body start to scramble'. I was told that after fatal brain injury there is a release of multiple stress hormones but that these are not the sole cause for the donor/body's instability. Rather, it is the combination of such hormonal changes, the vasoactive medication administered before and after death diagnosis, and the many other oxidative substances that are released during death processes. Additionally, the cause of death and age of the donor also intervene in accentuating the so-called organism lability; for example a brain injury produced by a gunshot in a seventy year-old donor would entail more complications than a contained brain haemorrhage in a younger donor. Such corporeal death process are a matter of great concern to TCs, it is their responsibility during donor maintenance, in conjunction with ICU staff, to deal with any complications that, as noted beforehand, can entail a lost donor and a disassembled donation. Dealing with the unstable donor/body is an unpredictable and complex task that TCs face, Camino refers to it as 'the wild mechanism that biology has in death', similarly in the next quote Angel brings up the labile organism figure and talks about chaos:

The brain death situation is a situation of lack of control in the sense that the brain has stopped working and there is no control of brain functions so then the rest of the organism keeps working with the support of the ventilator and medication that we apply but other functions like temperature control or antidiuretic hormone are disabled so as time goes by it is more difficult to keep all the systems of the organism under control, there is a lability, well in short there is a lack of control so what we need to do besides trying to maintain each organ correctly is to apply a systemic treatment to control this chaos up until extraction because the brain is not working anymore (Angel)

It is the TCs' responsibility to keep the organs in good condition prior to extraction surgery, and as Angel here explains in accordance with David's previous explanation, keeping the donor/body stable is a prime necessity in order to ensure that the organs will be continually perfused with blood and kept in optimum functioning conditions. This entails a prompt response to any changes in the parameters that are being monitored whilst donors/bodies are connected to a ventilator. There is a great number of actions that are called upon so as to correct, adjust and normalise when possible the donor/body as a more or less stable assemblage of interrelated functions.

During fieldwork I learned of the many different ways that an eligible brain-dead donor could be lost during the maintenance stage, and consequentially of the risks it entailed in

regards to donation process that would then become disassembled. The first sign usually came when suddenly after a very brief phone call, the different members of the TC team in the office that day would run out in different directions whilst on the phone with several other practitioners. Some would be talking to the ICU nurse who had alerted them that the donor/body was destabilising, others would be informing OCATT about the potential risks of losing the donor anytime, and others would be trying to get hold of organ extractor teams to speed up extraction before it became too late and organs were irreversibly damaged. The first case I witnessed started with a phone call from a nurse 'the donor's pressure is hitting rock-bottom!' The three TCs on duty then started frantically making phone calls whilst leaving the office, Camino was the last one to leave and she still had time to help me out with my confusion:

S: What is going on?

C: We might be losing the donor so it is time to run

S: Yes but what is actually happening?

C: His blood pressure is dropping dangerously and he might stop anytime, did you think that a dead donor can be switched on to a ventilator and forget about him because the machine is doing all the work? No way! Death is very complex to deal with and the body very unstable, I must run.

On that occasion, TCs and ICU professionals managed to stabilise the donor/body in time, high doses of dopamine and adrenaline were needed to correct the blood pressure values and return them to normal parameters. This section will now move on to present a few cases of disassembled donations, to show the scope and limitations of TCs' actions when dealing with the active intervention of donors/bodies as responsive entities within the particular donation practices in the hospital. The cases will illustrate how different bodily functions that are being artificially maintained might become altered and thus place some obstacles to the process of assembling donations.

Brain-dead donors' hearts are still beating autonomously, but it is what is called residual activity; various vasoactive drugs are continuously needed to maintain the regular pumping motion. However, the brain-dead body's absorption capacity is gradually lost, thus there comes a time that all of these medications cease to be effective because they are not absorbed and circulated to the target areas. TCs explain that this is why the medication they use is in liquid form when possible, because it is easier to absorb in brain death situations. Sometimes, any intervention might be ineffective and then the donor/body, as TCs put it, will *do* an arrhythmia, the medical term for irregular heartbeat, which will entail a drastic drop of arterial blood pressure. The risk this poses is that the

organs will then cease to be perfused; without a constant supply of oxygenated blood organs quickly become ischemic and hence not viable for transplantation. Once this happens the initiated donation process becomes disassembled, donor maintenance is discontinued and TCs have to inform both OCATT and several extractor teams that the process has been cancelled because they have lost the donor. Later on, TCs will be filling the necessary forms to report on the causes of non-donation for the particular case, they will be ticking the box of 'irreversible asystole'<sup>51</sup> in the section 'problems during donor maintenance'.

Other bodily functions that are being maintained can also fail with disastrous consequences for donation practices. The kidneys are no longer in charge of diuresis, if liquid retention was not kept under control, the donor/body would inevitably lose all fluids and gradually become dehydrated. This would result in high sodium levels in the blood, which would entail discarding the liver, or it might end with, as TCs put it, the donor/body *doing* a hyperosmolar coma<sup>52</sup>. The latter leads to a completely disassembled donation as all the organs would then become non-viable for transplantation.

Another function that the kidneys have ceased to perform is to regulate the body's haemodynamic situation, thus, it is the job of TCs and ICU staff to monitor that both the blood volume and circulation across the organs is within normal parameters. Sometimes maladjustments can be corrected with adequate blood transfusions, as long as the procedure takes place swiftly after detecting the failure. This is not always possible. ICUs are short of staff and TCs might be too far to get there on time, or that unit might have run out of the specific blood type needed for that donor/body. In those cases, in the form that needs to be completed after every case of disassembled donation, TCs would be ticking the box of 'haemodynamic maintenance impossible' as cause of non-donation.

Once the brain ceases to function, the body temperature regulation is also lost, ICU staff and TCs are responsible for ensuring that the donor/body's temperature remains stable. A simple gesture like making sure that the bed blankets are well tucked under does significantly contribute to the general maintenance of the donor/body. The dead body might have lost the capacity to regulate the temperature but it has not lost the capacity to adjust body temperature to room temperature values. Thus, if a donor/body were left

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<sup>51</sup> Irreversible asystole: heart arrest.

<sup>52</sup> Hyperosmolar hyperglycaemic state (HHS) is a complication of diabetes in which high blood sugars cause severe dehydration and high risk of complications such as coma and death in living patients ([https://www.diabetes.org.uk/Guide-to-diabetes/Complications/Hyperosmolar\\_Hyperglycaemic\\_State\\_HHS/](https://www.diabetes.org.uk/Guide-to-diabetes/Complications/Hyperosmolar_Hyperglycaemic_State_HHS/))

uncovered, as can happen after a test like an X-ray or a scan, and the temperature in the unit is quite low, the body would rapidly adjust and hence cool down. The inexorable resulting situation would be an imminent cardiac arrhythmia, lowered blood pressure and most likely a case of a lost donor. TCs are very aware of the complications that follow once the donor/body's temperature becomes maladjusted as any other bodily functions become even more instable and not amenable to any medical interventions.

Sterile conditions are a must all through donor maintenance procedures as the donor/body is still prone to suffer infections. If the probe for diuresis was to come out accidentally, and was not duly cleaned prior to reinsertion, a local infection would ensue. Some infections can be kept under control with antibiotics, but as already noted there comes a time when all medication ceases to be absorbed and so the donor/body can respond by, as TCs put it, *doing* a fever. When that happens, TCs are faced once again with the complications associated with donor/body temperature out of control; the rest of the bodily functions turn into an unmanageable chaos, the heart stops and blood circulation is disrupted thus leaving organs under-perfused. The donation process becomes disassembled because organs that have suffered ischemia become non-viable for transplants; they become pathological organs as their functionality has been severely reduced.

The next section turns to the second type of organ donors in the hospital, donors after cardiac death, as it will be explained they introduce a different donor/patient configuration as well as another kind of donor/body under maintenance.

### **6.2.2 – Maintaining Donors after Circulatory Death Diagnosis**

#### The Donor/patient in DCD maintenance

As was explained in previous chapter, the processes of uncontrolled donation after cardiac death<sup>53</sup> that TCs deal with involve a different type of donor/patient than in brain death donation processes, and consequentially the distribution of responsibilities with other hospital practitioners also varies. TCs are no longer outside supervisors as in ICU with brain-dead donors; rather in DCD cases they become directly responsible for most of the organ preservation activities. Donors after cardiac death are thus different from brain-dead donors, firstly prior to death they were not patients in the hospital, and secondly,

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<sup>53</sup> See Appendix 2 for Glossary, uncontrolled DCD procedures.

they do not belong to any specific hospital unit. TCs state that these donors are ‘admitted to their unit’, even though it is not a physical one, and neither is it one specialised in some healthcare treatment for particular patients. Hence, here donor maintenance is not a case of continuing intensive care treatment albeit with the differential objective of preserving the organs. Here donor maintenance is not even called donor maintenance but organ preservation intervention. The organs involved are not the same as in DBD either, hearts and lungs are not considered<sup>54</sup>, only abdominal organs like kidneys, liver and pancreas. Ferran explains the distinctive characteristics of DCDs:

Arrested heart cases are very different because there you already have a cold death but what happens with these cold dead patients is that what you do is to make their hearts beat with a machine, unlike with a tissue donor that is a cold dead person that is just there, still, dead, in arrested heart donors you want the organs, so what do you have to do to make sure those organs will be OK? Well, you want the blood circulating in the middle so how do you this? Simply by making the heart function with a machine but here the time becomes your worst enemy, you work against the clock because you don’t know how this mechanical thing is working, even if you do analysis to check you cannot see what is happening in there, but what you want is to keep the blood circulating through those kidneys and those livers (Ferran).

So donors after cardiac death are not being maintained because they are already, as Ferran puts it, cold dead bodies. They actually become TCs’ donors/patients after death diagnosis, this means that they have been with no measures to maintain cardiac circulation for at least five minutes. As was explained in the former chapter, the external cardiac massage device is removed during death diagnosis and the subsequent five minutes of the ‘non-touch period’. Thus, once death diagnosis has been completed then it is the TCs’ responsibility to initiate organ preservation manoeuvres that are aimed at restarting the previously interrupted circulation of blood through the abdominal area only. The procedure that then takes place involves several steps: Firstly, the donor is placed on a special portable bed that carries all necessary devices for organ preservation, and moved to the secluded emergency room in A&E. The external cardiac massage machine will be restarted and mechanical ventilation ensured. Secondly, the on-duty surgery team, with the assistance of two A&E nurses and the supervision of at least one TC, will perform donor cannulation. A perfusion catheter needs to be inserted in the femoral vein so that it can be connected to an extracorporeal membrane oxygenation

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<sup>54</sup> Lungs are usually considered elsewhere but the Hospital Clinic does not transplant lungs and time of transfer would be too long to accept them.

machine (ECMO<sup>55</sup>), which will then start to recirculate the donor's blood and maintain a constant body temperature. The ECMO machine used in the hospital has been designed for DCD purposes only but it is similar to that used for cardiac surgeries.

### TCs' Exclusive Responsibility to Ensure Organs' Viability

Angel is the director of the DCD programme and he explains to me that their organ preservation system is based on 'normothermic regional perfusion'; that is keeping a stable body temperature of 37 C while recirculating the blood through the abdominal area. He emphasises that it is the TCs' exclusive responsibility to monitor the ECMO machine and to intervene if adjustments become necessary. Therefore, he argues, their actions bear a direct influence on the resulting viability of those organs and the results of the ensuing transplants. To Angel, this is of great importance because, as he adds, the circumstances of cardiac death donation already entail damaged organs, deprived of oxygen and substrates for a long interval, hence it is their task to make sure that preservation interventions don't add any further injury to those organs that would then be considered non-viable for transplantation. However, he stresses that even though the discarded rate of organs is higher in DCD than in DBD, as organs have already suffered severe damage, given that they are younger patients, up to 65 years of age, and if ischemia can be controlled and evaluated with the use of the ECMO, then it is possible to transplant the organs and revert the acute damage with adequate interventions on the recipients/patients. So Angel concludes that DCD organs not only present similar transplantation results to those of DBDs but that they can also afford better transplantation results given that they are procured from younger patients with a shorter disease history and have not been damaged by sustained ICU treatment with vasoactive drugs. The hospital Clinic, in conjunction with OCATT, heavily invests in the development of DCD programmes as offering new promise to increase national donation rates at times of declining numbers of brain-dead donors.

### The Unstable Donor/body and TCs' Responsibility to Recirculate Organs

The ECMO machine, called the pump by TCs, does indeed pump to simulate the function of a beating heart, but it also simulates the lung's function to provide constant oxygenation, as well as maintaining a normal body temperature to ensure that the correctly oxygenated blood is circulating in the abdominal area. Most of the times it works

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<sup>55</sup> ECMO see Appendix 2 for Glossary and DCD procedures

well but never without the intervention of TCs, there are several parameters that need to be monitored and adjusted when necessary to keep the organs constantly perfused. David explains some of the interventions:

In DCD we do a very constant monitoring too, once the pump is connected, for it to function properly I might have to transfuse some blood, or apply some serum, or more heparin<sup>56</sup>, more things because the organism after death is still very unstable and what I want is to extract the abdominal organs so I need to preserve them as best as possible (David).

A donor can be connected to an ECMO machine for organ recirculation for a maximum period of four hours. The functionality of abdominal organs can be indirectly inferred by several evaluative tests, but nevertheless there are many difficulties that might interfere with the objective to maintain a constant circulation across organs under evaluation. The corporeal death processes and the unstable organism formerly introduced in brain death maintenance section is here also a matter of great concern for the TC team. Their actions will respond to the acting donor/body and the many constraints that can pose to their task of procuring viable organs for transplants.

It might happen that something is impeding the blood flow to a particular organ or area, a physical barrier related to the injury or a blood clot that is hindering venous return from the organ to the machine. On those cases, TCs can only guess what is happening in there, sometimes they might be able to correct it. With high doses of heparin, blood clots could be dissolved and blood flow resumed, but mostly the only thing left for them to do is to try to speed up transfer to the operating theatre. Given that the damage to the under-perfused organs cannot be estimated with the ECMO values available, TCs usually opt for taking donors to surgery because it will not be until after extraction that a thorough macroscopic inspection of every organ will assess the extent of the ischemic damage suffered. The next section on organ extraction will provide more details on such evaluation procedures. However, as noted before, this implies a large medical team that needs to be gathered at the arranged time in an available surgery room in the hospital. Therefore, on those instances TCs alone can do very little to avoid an initiated donation process to become disassembled prior to organ extraction. Their next step would then only be to tick the box 'not enough time for the extractor teams to arrive due to donor instability' as a cause of non-donation and proceed to close the given donation case.

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<sup>56</sup> Heparin acts as anti-clotting agent.

Notably, donation after cardiac death enacts a very peculiar configuration of the body-in-donation-practices, and so a different set of contingencies also emerge when dealing with these donors/bodies. DCDs are, like brain-dead donors, artificially maintained after death, but contrary to the former the maintained whole doesn't comprise the entirety of the body, but rather is restricted to the abdominal area only. The whole that is being maintained is assembled differently in DCD; blood circulation is restarted but only so as to perfuse the abdominal organs. Certain measures are taken to ensure that none of the blood will be circulated and thus lost to any other part of the body. As a result, the donor/body after cardiac death presents simultaneously an artificially maintained and thus circulated area, the abdomen, as well as the sum of all other areas that are not being circulated and that are hence suffering severe ischemia. The end of the blood flow is linked, as noted before, with various corporeal death processes associated with a situation of oxygen deprivation and rapid degeneration that follow death determination. Ferran finds the word 'cold death' or 'cold corpse' very suitable to refer to DCDs' and tissue donors' differential characteristics from brain-dead donors:

In DCD it doesn't take long for death to start showing in the rest of the body, rigor mortis sets in very rapidly, their faces quickly turn blue and so do the extremities that quickly become dead cold and rigid, and in general the whole donor gives an impression of a corpse, as opposed to brain-dead donors that retain their warmth and normal colour appearance (Ferran).

It is precisely this coexistence of circulated with non-circulated or ischemic areas of the donor/body that poses certain constraints to TCs' donation practices. Especially in regards to time, DCD cases are extremely demanding, as the donor maintenance interval prior to organ extraction cannot be more than four hours, as opposed to twelve hours with DBDs. Note that in that time TCs, at least two of them, must coordinate cannulation intervention to initiate organ preservation; approach the eligible donor's family to request consent to extraction; monitor the donor/body and ECMO whilst conducting further evaluative tests to determine individual organs' viability; contact several organ and tissue extractor teams to coordinate extraction surgery; and liaise with OCATT office to receive organ allocation and transportation instructions. Furthermore, as Angel explained, organ preservation in cardiac death donation is the sole responsibility of the TC team, and thus their actions are greatly concerned with keeping the abdominal organs circulated and functioning. Such task might be met with many obstacles that can lead to a disassembled donation process; the cardiac-dead donor/body is also a labile organism where several corporeal death processes are taking place. Additional to the hormonal release, as explained with the case of brain-dead donors/bodies, there are other damaging substances that intervene and that

further add to the donor/body instability, which as noted can affect the viability of the organs. David expanded on this during an interview:

D: All has stopped, there is no circulation in the rest of the body, so then all that starts to release substances that are harmful, this is why we need to refrigerate a tissue donor as soon as possible to arrest all these substances released because after one dies, one is dead, it sounds absurd but if I am dead what happens? That the whole organism starts to decompose, circulation has stopped, the cells say 'I have no oxygen, I have no circulation, I have to die' and they start to release after-death substances that enter the blood stream that is no longer circulating but the substances do circulate just because they are coming out from all the cells in the organism

S: And what are these substances then?

D: They are a product of the cell's rupturing process, when the cell starts to decompose, when it dies the mitochondria opens up and internal structures unfold and release substances so the ischemia induces the cell, prior to dying, to produce substances to defend against bad oxygenation and these are called cytokines<sup>57</sup> and are produced to defend or attack so they are pro-inflammatory and they have harmful effects

S: And the ischemia itself then?

D: It is the circulatory arrest of the whole body.

The unbridled corporeal death processes that gradually disassemble the body are met with fewer obstacles in the cardiac-dead donor/body. It is only the abdominal area that is being circulated and hence ischemia is kept at bay only locally, the rest of the non-circulated and hence ischemic body is quickly taken over by decomposing processes. As David mentions, ischemia-triggered cytokinesis can be slowed down if the donor/body is kept refrigerated in the morgue, however, DCD practices are restricted to the emergency room of the hospital Clinic in Barcelona, and the warmth induced by ECMO recirculation also contributes to an acceleration of multiple corporeal death processes.

Consequentially, as Angel stated, the rate of extracted organs from cardiac-dead donors that are discarded is higher than that for brain-dead donors, and so is the number of disassembled donations prior to organ extraction stage. Chapter 7 and chapter 8 will further deal with the TCS' actions in regards to increasing organ donation rates and their attempts to assemble both brain death and cardiac death donation processes. The next section will address the case of tissue donors, even though they are not being maintained – if no organs are to be procured there is no need to maintain the circulatory flow in the

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<sup>57</sup> Cytokines: Small regulatory proteins or glycoproteins that regulate the cells of the immune system (<https://www.boundless.com/physiology/textbooks/boundless-anatomy-and-physiology-textbook/immune-system-21/cytokines-199/types-of-cytokines-participating-in-immune-response-980-8658/>).

donor/body. Tissue donors introduce yet another cast of responsive entities that intervene in the donation processes under study.

### 6.2.3 – Tissue Donors' Maintenance

The tissue donor/patient is the TCs' sole responsibility, there is no overlap with other hospital practitioners, such as with brain-dead donors that are still ICU patients, or with cardiac death donation that takes place in the emergency department. TCs detect tissue donors amongst deceased patients in the hospital, thus by that time they are 'nobody's patient' and access to the eligible donor/body is directly available by simply going to the morgue and pulling the right drawer where the dead body is being kept refrigerated. As explained by David in the former section's last quote, prompt refrigeration is crucial so as to slow down the inexorable corporeal death processes that are rapidly proliferating in the disassembling body. The whole tissue donor/body quickly becomes ischemic after blood circulation stops, and hence many substances, such as hormones and cytokines, are released. Unlike organ donors/bodies that are kept either partially or totally circulated, ischemic tissue donors/bodies entail the appearance of another set of decay-related substances:

There is another thing because in the abdomen, in the intestines we do have bacteria, which is normal just as we do in the skin or inside the mouth, but because my defence mechanism is dying I am less able to defend myself against them, there are no lymphocytes<sup>58</sup> anymore, neither circulating blood for them to travel to the intestines and defend me against the bacterial translocation<sup>59</sup> that is taking place after death, so bacteria start to grow there and produce gases and gradually colonise everything (David).

The bacterial translocation that emerges from the abdominal area and progressively extends to the rest of the ischemic body is a corporeal death process that TCs respond to whilst trying to assemble donations. It poses some constraints in terms of timing and refrigeration of the donor/body so as to avoid harmful effects that would cancel the so-far evaluation of tissue viability. It does also intervene at an earlier stage of the assembling process, as chapter 5's sections on evaluation showed. TCs must make sure that all blood

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<sup>58</sup> Lymphocytes: small white blood cells (leukocyte) that plays a large role in defending the body against disease (<http://www.medicinenet.com/script/main/art.asp?articlekey=4220>).

<sup>59</sup> Bacterial translocation: the movement of bacteria across the intestinal membrane to other areas of the body where they can cause disease (<http://medical-dictionary.thefreedictionary.com/bacterial+translocation>).

samples are extracted as early as possible, otherwise blood will be too, as they put it, corrupted by these harmful substances and the results of serologic tests would not be considered valid enough so as to ascertain the eligibility of the detected potential donor. This too is a cause of non-donation that would entail a disassembled donation at the initial evaluative stage.

The types of tissue mostly procured in the hospital are corneas, bones, skin and cardiovascular tissue. TCs have a maximum of 12 hours to ensure that tissue donors/bodies degradation does not affect the quality of the tissues to be extracted. Thus, it is here argued that these decomposition processes with substances like cytokines and bacteria need to be considered in this analysis, as part of the responsive donor/body-in-practice, because they are actually intervening and constraining TCs' tasks to assemble donation processes.

Interestingly, it is precisely because there is no more blood circulation in the ischemic body that these substances are allowed to circulate widely, or rather to emanate profusely from all parts of the body. Likewise, the end of the blood flow also entails a disabled immune system that can no longer send defence substances to protect the areas that are being, as David puts it, colonised by these decomposition processes that gradually take over the body; a labile organism or a fragile assemblage of functions that becomes rapidly disassembled. The next section opens up a theoretical discussion on the donor/body figure and the corporeal death processes that gradually disassemble it.

### **6.3 –The Disassembling Donor/Body-in-Donation-Practices**

This section will bring together the three types of donors/bodies that emerge from the specific medical practices of organ donation in the hospital Clinic. The analytical purpose is to advance an answer to the primary research question that guides this chapter, that is, how are donors *qua* bodies being done in the practices of assembling donation processes? As explained in chapter 3, and in this chapter's introduction, this empirical investigation draws on STS material semiotics' notions of ontology, agency and materiality in order to account for the intervention of bodies as responsive entities within the practices of donation. The main premise is to rehearse a way of theorising the body outside the constraints of the polarised and hierarchical binary opposition between subjects and objects.

Accounts of hospital practices in this chapter have shown that to further assemble a donation process once eligible donors/bodies are being maintained requires, as TCs put it, not losing the donor. The latter expression can be unpacked so as to answer the guiding question of this section, simply put, that the donor/body-in-donation-practices is enacted and acting as a circulated organ-ism, or at least this is the aim of TCs' intervention, not always successful as the multiple cases of disassembled donations have illustrated.

Ensuring a constant blood flow around the organism includes both the body/whole and the organs/parts, hence the notion of organ-ism is here deployed to highlight the entangled interdependence between organism as whole and organs as constitutive parts. However, the bodily focus is not on organs as parts/objects but rather on entangled action or unfolding processes. Ultimately, the donor/body being done in these medical practices is a fragile assemblage of functions that TCs try to maintain as a more or less stable whole, so that organs will be circulated and thus kept functioning. Some cases reviewed have dealt with maintenance tasks that have tried to control different bodily functions such as temperature regulation; liquid retention; heartbeat and blood volume regulation. All of them are key to ensure a regular circulation of oxygenated blood around the organism, and as previously shown, if not adjusted adequately a disassembled donation process would ensue.

Notably, the whole being done in brain-dead donors/bodies is different from that of cardiac-dead cases, the difference is that the areas that are kept circulated are reduced in the latter to the abdominal area only. The inclusion of cardiac-dead donors/bodies helps to expand the analysis of the donor/body figure as they present circulated and thus functioning areas coexisting with ischemic and thus decomposing areas. Primarily, ischemia or the circulatory arrest of the whole body, as TCs put it, is what they try, with more or less success, to keep at bay so as to enable the assembling donation process to continue up until the next stage of organ extraction. Ischemia triggers the release of multiple harmful substances, such as cytokines and bacteria, that further exacerbate the donor/body's instability and that complicate the TCs' responsibility to ensure viable organs for transplantation. Nevertheless, it is also the case that in brain-dead donors/bodies that are being kept wholly circulated (except for the by then non-functioning brain), corporeal death processes also start taking place and compound to the labile organism whose indeterminate responses TCs have to grapple with. It is the differential unfolding of such corporeal death processes that ultimately disassemble the body as a whole – as in the dis-integrating body, the de-composing body – that loses its formerly accomplished singularity as it becomes progressively colonised by decay-related

substances. Such unbridled processes of cytokinesis and bacterial translocation rapidly take over the ischemic body; the end of blood circulation also disables the defence system. The disassembling donor/body resonates with Haraway's quote: "Any objects or persons can be reasonably thought of in terms of disassembly and reassembly...What counts as a 'unit', a one, is highly problematic, not a permanent given. Individuality is a strategic defence problem" (1991, 212). Similarly, it converges with Mol's proposition that the body is neither singular nor a coherent whole per se, but rather that its wholeness is accomplished in practice, inside and outside the body, and necessitates of a series of specific and interdependent processes to take place for the body to hang together as a more or less stable whole (2002). The donor/body being done in donation practices does indeed depend on a lot of work, mostly done by maintenance technologies, like ventilators and ECMO machines, various vasoactive drugs, blood transfusions, blankets and the constant monitoring of ICU personnel and punctual interventions of TCs to stabilise the by then disassembling and unstable responsive organism. In chapter 8 the addition this empirical investigation represents for social studies of organ donation, challenging as well as complementing them, will be further discussed. Particularly in regards to the differential accounts that emerge from this research objective to theorise donors/bodies outside the subject/object dualism, and focusing instead on decentered corporeal processes and the gradually disassembling circulated organ-ism. The next section on organ extraction will continue to build on the theme of the donor/body as an assemblage of functions, this will be done by continuing to map TCs' responsibilities and focusing on situated enactments of organs under evaluation. Organs gradually emerge as embedded in a practical configuration geared to procuring viable organs for transplant recipients/patients, and hence, this entails a given set of shifting affordances and constraints.

## **6.4 – Organ Extraction**

The stage of organ extraction will be described here, however tissue extraction is omitted, as it is not the responsibility of the TC team, except for cases of cornea only donation. The focus will be on the trajectory of organs, from maintenance and evaluation inside the donor/body to extraction and preservation outside the donor/body. The figure of the donor/patient will be highlighted when relevant, as well as that of the donor/corpse, which will be appropriately unfolded in chapter 7. Nevertheless, this chapter focuses mostly on the donor/body and the different enactments along practices of assembling donations in the hospital. Thus in the following sections the theme of the body and organs

will be scrutinised by addressing the following questions: 1) *What are the TCs' practices and responsibilities at the final stage of a donation process?* 2) *How are organs enacted and acting during the stage of extraction as per their entangled response-abilities?* And finally, and this will be discussed in the last section that will continue the theoretical analysis opened up in previous section 4) *What kind of body is being done with and through such medical practices of organ donation for transplantation?*

#### **6.4.1 –Donor/body Transfer and Organ Extraction Surgery**

As already introduced, during the donor maintenance stage, TCs are also responsible for arranging the complex logistics for an organ extraction surgery to take place in the hospital. The timeframe will vary according to the type of donation process and the case in particular. Mainly, they need to summon a different extractor team for every organ that will be procured: the cardiac surgery team to extract the heart, the hepatologists for the liver and pancreas and the nephrologists for the kidneys. They will be communicating with OCATT about allocation requirements and organ transfer instructions; arranging further tests if necessary and thus calling for the relevant specialists, mostly from pathological anatomy; and above all to keep monitoring and adjusting the donor/body instability so as to avoid a lost donor and a disassembled donation process prior to organ extraction. Also noted beforehand is the fact that by the time that donors are transferred to the operating theatre, TCs become fully responsible for them; donors are no longer any ICU or A&E registered patients but TCs' donors/patients. However TCs, as in most stages of the process of assembling a donation, depend on the participation of other practitioners to carry out their procurement-related tasks. During transfer to the operating theatre, TCs are busy coordinating a host of different surgical teams, but the donor/body needs to be closely monitored and adjusted if necessary to ensure that circulation is kept stable and all organs properly perfused. This is then the responsibility of an anaesthetist; here David explains the reason for it:

It is very important when we go to the OT to have an anaesthetist there, not for pain anaesthetics, but to maintain and adjust donors during transfer because when you move them from beds, sometimes, there can be instability, or when they get to the OT and they open up the abdomen then the general pressure drops and this can lower the arterial pressure, the person is dead so most reflexes are lost, the pressure drop would generate a cardiac response, tachycardia and other stuff, in brain dead situation most systems are blocked so there needs to be someone in charge of the donor (David).

Such donor/body instability could easily entail a lost donor and a disassembled donation; hence the need for a dedicated anaesthetist to correct temperature and pressure changes so as to ensure an evenly circulated organ-ism. The operating theatres are usually kept at low temperatures, and donors are there prepared for the operation with the hospital's surgery vest that only leaves uncovered the area where organs will be extracted. TCs remark that it all takes place 'just like any other surgery with a patient,' here the donor/patient figure also applies. In particular they highlight the importance of ensuring sterile conditions to avoid any infection given there are several professionals involved for every surgical extraction; TCs are responsible for avoiding any unnecessary ischemic damage to the organs as well as to ensuring absence of transferable disease that could affect the future transplant recipients/patients.

Once the surgeons open up the abdomen and the thoracic area, the first thing to do is to check for any signs of disease, such as tumours, in all the now exposed areas. Even when the only organ to be extracted is the liver, the rest of the organs and the abdominal area would also need to be thoroughly scrutinised. It might be that a tumour is found on the pancreas and so the liver would then not be extracted and the donation disassembled. In the hospital this is called 'in vivo evaluation'. Surgeons and TCs are particularly attentive to general appearance and colour of organs, or as they put it the 'macroscopic evaluation of organs'.

A scrutiny of the visible internal area is carried out checking for lymph nodes and tumours, and the entirety of the intestine is palpated by hand; this can take a while given that the length can be up to seven meters. TCs explain that it is necessary because they have to rule out any contraindication to donation that could pose a risk of infection to the recipients/patients.

At this stage, it is the transplant surgeons' decision whether they consider the particular organs viable for transplantation or not. TCs have carried out all the tests and explorations necessary prior to extraction to, as they put it, validate the donor. Nevertheless, it is during the in vivo evaluation that some organs will be deemed not viable for donation. Situations that can then become visible vary, it might be that the kidneys' blood vessels were blocked and so they were not circulated properly and thus present a 'bad macroscopic appearance'. Or they might decide that the liver looks too fatty on plain sight even if the test results and medical history didn't indicate any major problems. Some organs might be deemed non-viable if they appear under-perfused

because of high levels of vascular disease, such as atherosclerosis, and others like the liver because of fatty degenerative processes like steatosis. Transplant surgeons when faced with dubious situations prefer to extract the organ and take the decision after a thorough 'ex vivo evaluation'.

#### **6.4.2 – Evaluating Organs Outside the Donor/body**

'Ex vivo' refers to the time when organs have been extracted and are outside the donor/body being examined by the relevant surgical team, it is also called 'the backstage'. In the OT there is a table for each organ to be cleaned, examined and prepared for transfer if accepted by specialist teams. The TCs are then responsible to place the extracted kidneys inside a perfusion machine:

Kidneys can be connected to a renal perfusion machine that gives you a simulation of its functionality because cold preservation liquid enters the kidney pulsating as if it was blood and it comes out so this gives you certain values to calculate the flux and pressure that goes in and the level of resistance it finds going through the kidney, so this gives you an indication of how well or not the blood will circulate through that organ (Sandra).

The perfusion machine circulates the kidney with a cooling solution that cleans it and allows it to keep functioning outside the donor/body. TCs remark that such preservation technologies represent a great advantage to organ procurement and transplantation practices. Kidneys connected to a perfusion machine are kept in a much better condition than if stored with ice inside a fridge, being constantly circulated and nourished avoids the usual inflammation that follows after extraction. And more importantly, the use of perfusion machines affords them additional time and information in regards to the organ's viability evaluation. TCs are in charge of writing an assessment report on the given kidneys' functionality, according to flux resistance and performance levels as measured by the machine. The 'ex vivo report' is part of the donor file – it includes all previous evaluation results, medical history, clinical tests, social history and macroscopic evaluation – handed to the transplant surgeons that will then discuss the assembled results with TCs and take a decision about the viability of the specific kidney for the allocated transplant recipient/patient. Angel in particular, stresses that the advantage of perfusion machines 'is not about allowing us to transplant more but to transplant better and with more certainty'. There are other perfusion machines already developed, for the liver and the heart, and others like the lung machine that during fieldwork period were

still in experimental development. Sandra, nurse-TCs with previous experience as a transplant surgery nurse, explains to me that perfusion machines need to be designed specifically for every organ as they all have different preservation requirements. For example, the liver machine is circulated with human blood because past experiences have shown that livers do not respond well to cold fluid like kidneys, this entails an additional set of issues:

The liver is of course a blood filter inside our body so it filters out stuff from medication, nutrition and of course the blood that is repeatedly circulated through the liver becomes degraded after two or three rounds so you need to replace it and this represents a cost, not just economic but social as well, because of the amount of donated blood needed, so it is only a project at the moment (Sandra).

In general the TC team expect that the perfusion machines for the different organs will become the routine preservation technology in the next few years. Notably, they comment that assessing the functionality of the organ directly can also allow them to foresee potential circulatory problems that would complicate the transplantation surgery and the recipient/patient's reaction to the implant. For example, if the organ presents a higher resistance level to the incoming liquid it could be anticipated that there will be some localised thrombosis, transplant surgeons would be directly informed and the transplant recipient/patient would be provided with the right medication immediately after implantation surgery.

At the time when fieldwork was conducted, TCs were responsible for operating the renal perfusion machine and to put together a viability report for the transplant surgeons who would ultimately decide whether they transplanted the extracted kidneys or not. David, a doctor TC and also a former nephrologist surgeon, emphasises that the particular professional expertise that the TC team convey to the transplant surgeons is crucial when it comes to informing their decision about either to accept the organ as valid or reject it as pathological. This is because it is the juxtaposition of all the TCs' evaluative activities and results that allow for a more comprehensive donor/organ examination to be taken into account at the last stage when deciding on the viability of a particular organ. Like other TCs, he stresses that their expertise is very valuable and complements the exclusive individual organ focus of the specialised medical practitioner, namely the *ex vivo* macroscopic appearance evaluation of the extracted organ. The transplant surgeons in turn bring into the discussion the specific situation of the, by then allocated, recipient/patient. For example, the hepatologists might have doubts about the appearance

of an extracted liver and discuss it with TCs. They will ask about clinical test results, if they were satisfactory, and whether the donor/patient ever had any manifested problems associated with the liver recorded in medical files, as well as viewing the graphic results of any imaging technologies available. At this time the TCs' focus is on confirmed adequate functionality levels of the given organ, if those are acceptable and if the transplant surgeon thinks that the recipient/patient would cope well with the particular organ then it will be accepted as viable for transplantation.

There are other evaluative tests that can be performed after extraction, in particular to rule out any risks of transferable disease that would affect the organ recipient/patient. It might be that during earlier evaluation tasks TCs decided it was necessary to carry out a biopsy of the given organ, hence, an anatomy pathologist would have also been summoned to the extraction surgery. On one occasion the medical history examination revealed that the donor had been recently diagnosed with a brain tumour but it was not yet known whether it was cancerous or benign. TCs asked the donor's family for permission to take a brain biopsy and rule out any risk of transmitting cancer to the different organ recipients; they unanimously agreed to it and as the results quickly showed that it was indeed a cancerous tumour the extracted organs were discarded.

Any extracted organ that is at that stage deemed non-viable for transplant is labelled as pathologic and it is thus sent to the pathological anatomy research unit within the hospital.

Viable organs like hearts and livers and pancreas that cannot be put in any perfusion machine are inspected and cleaned by transplant surgeons, afterwards TCs are responsible for preparing the organs for the transfer. They put them in double hermetic bags inside a portable fridge; they are in charge of keeping the temperature stable and making sure the ice surrounds all parts of the organ equally at all times. TCs highlight the need for sterility measures at that point as well so as to avoid any, as they put it, contamination of the organ that could affect the recipient. It is also the TCs' job to label each organ container correctly and to attach the necessary donor/organ documentation; David describes the process and the need for it:

The organ cannot go alone, we need to label it and say if it is a right kidney or a left kidney, a heart or a liver, if I need to send donor's blood samples, lymph nodes, blood group copies, clinical history or whatever is needed because it is important to think that when you send an organ the one that receives it doesn't have all the information, so it is my job to convey as much as I can (David).

Some of the organs are then transplanted in the same hospital Clinic but others will be traveling to other Catalan and Spanish hospitals. OCATT decides according to current transplant recipients/patients allocation criteria and informs TCs about the necessary documentation and materials that must accompany the organ being taken to another hospital. The next section will also encompass the intervention of recipients/patients in the process of assembling donations and the TCs' responsibilities, but from the angle of donation criteria and transplant waiting lists' characteristics.

### The Shifting Criteria of Organ Viability and the Transplant Recipients/patients

The characteristics of particular transplant recipients/patients intervene in the transplant surgeons' decision about organ's suitability; however, they also come to influence much earlier stages of the process of assembling donations. In particular they shift the donation eligibility criteria that determine whether potential detected donors become ruled out at initial evaluative stage according to a given set of contraindications for particular organs. TCs meet up with transplant professionals in the hospital periodically; they are informed about the results of organ transplants and together they discuss if any criteria need to be adapted in light of transplant results. Although all Catalan hospitals follow the same donation criteria determined by OCATT and international regulatory frameworks, adaptations often take place after such discussions. Sandra expanded on the topic during an interview:

There are a set of criteria that have been assessed and mark the limit, for example both in organs and tissue there is an age limit above which we don't evaluate the donor, in the case of pancreas we would still evaluate a pancreas from a 40 to 45 year-old donor but not older because of circulatory problems associated beyond that age, there are certain indicators and sometimes it is only after extending criteria and seeing that it doesn't work, that donation criteria are adapted, or in the case of the kidney there is no age limit because it is an organ that normally works well, and the liver also has very extended age limit, 89 year-old livers have been transplanted and work fine, but for example the heart of a 70 year-old person has been working for 70 years already so the age limit is shorter, up to 55 or 60 like lungs (Sandra).

Different organs perform different functions within the body and they present varied functionality levels at different age cut off points. The use of perfusion machines has enabled a more accurate functionality evaluation of organs like kidneys after extraction, hence, the age limit for kidneys acceptance criteria has been extended to a much older age

than before. Additionally, the current situation – referred to as ‘the extended criteria era’ that aims to address the organ shortage and high mortality rates in transplant waiting lists – also responds to other changes in the inclusion criteria of patients deemed eligible for a transplant. Namely, the increased life expectancy and ageing population that has led to the inclusion of much older patients in the transplant waiting lists. It is what TCs, and transplantation professionals in general, call the ‘old for old’ rationality. Similarly, organs from deceased patients who had a previous history of certain diseases such as cancer or HIV or hepatitis B or C are also now accepted. The reason for the change is also so as to procure organs for patients on transplant waiting lists who have HIV or Hepatitis C or B or cancer. These are now considered chronic conditions that can be managed with adequate treatment; therefore, such patients have become eligible for a transplant.

Thus, it can be said that donation criteria have adapted and now follow a logic of what is commonly referred to as ‘like for like’ allocation criteria. On the other hand, TCs clarify that the level of acceptable risk in any decision about donated organs is also determined by the urgency of the patients in the transplant waiting list. In short, if the waiting list is large and with a high mortality rate, such as those including patients waiting for a heart or liver replacement who don’t have any other therapeutic option – unlike patients with kidney failure who can undergo dialysis – then the level of risk accepted becomes higher. The balance, TCs insist, resides in keeping the risk of disease transfer lower than the risk of dying while waiting for a transplants, as well as encompassing the possibility that some conditions could be treated once the recipient/patient has received the donated organ. Treatable conditions include high levels of thrombosis, as noted by Sandra in former quote, or infectious diseases that could be dealt with specific antibiotic treatment. Chapter 8 will further delve into the theme of organ donation rates and relate it to the TCs’ practices and responsibilities towards assembling donation processes in the hospital. Now the analysis moves on to consider the final stage of the process, what is usually referred to in the hospital as the post-donation phase.

#### **6.4.3 – The Post-donation Donor/corpse**

Once the organ extraction intervention is finalised, the same intervening surgery teams become responsible for stitching up the donor/body, and TCs are there to supervise the process whilst coordinating the organ transfer activities. They emphasise that even though the suturing intervention is as careful and sterile as it would be for a living patient, surgeons are aware that it is not a scar that someone will have to live with afterwards.

Thus, the reconstructive surgery intervention brings forward both the figure of the donor/patient and the here introduced figure of the donor/corpse. For the actions of surgeons respond to the future destination of the donor/corpse, that is, the hospital morgue and after the funeral parlour and finally the cemetery or crematorium. The objective is to reproduce the former volume of the body so that if families were to choose an open casket funeral there would be no visible changes after organ extraction. The next chapter on the donation request and information given to families will expound on this issue and the figure of the donor/corpse in general.

This present chapter will not include details about the coordination of tissue extraction, as TCs are no longer responsible for it, the hospital has automated mechanisms that alert the in-hospital tissue extractor team once the organ extraction has finalised, the donor/body is then transferred to the relevant operating theatre. It is only for the cases of cornea donation that a TC would perform the extraction in the morgue. The cornea extraction procedure only takes a few minutes and it ends with the placement of prostheses to simulate the ocular volume and closing the eyes with glue. TCs comment that reconstruction actually takes longer than extraction in the case of tissue. Especially for those cases that have also consented to bone extraction, usually from the legs and hips, and skin, taken from the back area. Reconstructive surgery can last up to one hour and a half as the tissue extractor team need to reproduce the former volume of the body. The materials used are plaster for the bones and wet dressings for the muscles. During the donation interview, TCs caution the families that in the case of consenting to tissue donation, donors will not be able to be dressed for an open casket funeral, as they need to be wrapped up in a shroud to prevent bodily leakage. More on that will follow in next chapter that will map the TCs practices and the eligible donors' families concerns at that time.

Once organ and tissue extraction and bodily reconstruction are finalised, a porter takes the donor/corpse, or as TCs put it then, the post-donation body, to the morgue. The latter will then follow what is commonly referred to in the hospital as the 'funerary circuit', TCs stress that this is the habitual procedure for any other deceased patient in the hospital. Here too the figure of the donor/patient and the donor/corpse appear simultaneously as donors are deceased patients from the hospital. This means that the hospital is legally responsible for their custody, and for those cases that have become donors the TCs are responsible, up until the donor/corpse is picked up from the hospital morgue and transferred to the funerary premises to be prepared for the wake and/or funeral or

incineration. The next chapter will describe the responsibilities of donor's families whilst in the hospital in regards to funerary arrangements with the in-hospital funerary services.

When dealing with judicial cases, the TC team are then responsible for ensuring that the postmortem team picks up the body as previously arranged, and afterwards, they must confirm that they brought it back to the morgue and left it ready to be picked up by the funerary staff. For that to happen it is paramount that TCs identify the donor/body accordingly; special care is taken in promptly placing adhesive labels with the donor sequence number that matches their computerised and physical donor file.

#### **6.4.4 – TCs' Assembling of the Donor File**

While tissue extraction is taking place in an operating theatre, or right after supervising organ extraction and transfer, TCs are in their office busy with their then main responsibility, that is, assembling the donor file. To do that they need to gather all the documentation produced throughout the different evaluations and the necessary official forms, such as signed family consent, forensic consent and death certificate amongst others. If any of these forms is missing from tissue donation processes, such as the results of the second serologic tests that take longer, the hospital computer programme does not allow TCs to activate the tissue pick up order. The consequence of an incomplete donor file is inaction; the extracted tissue is halted in the hospital and doesn't continue on the automated circuit transfer that would take it to the tissue bank located in another part of the city. For cases of organ donation, completing the donor file is also crucial, it will not only record the particular case and prepare the material for auditing processes, but also it will be accessible by transplantation professionals that will be taking care of the organ recipient/patient's post-transplant treatment. The assembled donor file provides another illustration of the *No heroics, please I* proposition; donation practices are thoroughly embedded in hospital activities, donation is both procurement and healthcare. The final section of this chapter will build on the initiated theoretical discussion in section 6.3, and will further analyse the donor/body figure through an examination of the evaluative practices within which organs are enacted, for organs under evaluation are bounded within practices of donation as procurement for healthcare. This also brings forward the intervention of another cast of patients, the prospective organ transplant recipient/patients, and it also includes the organs' intervention as responsive entities embedded in such practices.

## 6.5 – Circulating Organs across Collective Bodies

This final discussion will, similarly to section 6.3, refer to previously introduced empirical stories to assist in conveying the *No heroics, please IV* proposition that organs are both acting and enacted; embedded and responsive as per practices of assembling donations that they are part of. Accounts from the hospital in former sections have largely featured organs under TCs' and surgeons' examination, organs that need to be deemed viable for transplantation or ruled out as pathological. For organs to be considered viable, certain evaluative practices need to progressively unfold. As was shown in the previous chapter on detection and initial evaluation, viability is aligned along the organ's functionality level and risk of disease transfer. Continuing the analytical thread exposed in section 6.3, during the preparatory phase for organ extraction surgery, it is paramount to maintain the donor/body as a circulated organ-ism, to prevent losing the donor altogether and end up with a disassembling donor/body and a disassembled donation process respectively. The circulated donor/body is enacted in these practices as a more or less stable assemblage of functions to be maintained up until surgery. The TCs' responsibility, carried out with the collaboration of other health practitioners (*No heroics, please III*), is to keep organs continually perfused so that they can keep performing their interrelated bodily functions. Functionality levels are monitored closely by different technological means, and added to the growing corpus of information on the particular donor/organ file. Recall that the initial evaluation includes medical history, clinical tests and social history information. Hence, even when organs are evaluated individually, in vivo or inside the donor/body with the use of organ-specific monitoring technologies, the results are analysed in juxtaposition with former global donors' screening. Chapter 8 will expand on the specialised TC profile that enables such donor/organ relational approach as opposed to transplant surgeons' focus on the appearance of the individual organ.

The relational organ under evaluation is also a responsive entity, organs-in-procurement-practices are rendered active, organs that function: kidneys that produce urine, livers that filter, hearts that pump blood and lungs that oxygenate it. Nevertheless, they are not autonomous agents, organs are embedded and materialise entangled within the given technoscientific practices, upon which they simultaneously intervene as they become afforded with different response-abilities.

Acting organs are inexorably entangled and interdependent within their setting of emergence, even after extraction when they become indeed organs without bodies. Viable

organs for transplants are optimally preserved if they are kept active, refrigeration might slow down ischemic processes setting in, but it is the use of perfusion technologies that allows TCs to obtain additional organ-specific information and extended timeframes. Yet if organs are to be kept active, then they cannot be fully disentangled from a body – be it the donor/body, the recipient/body, or in-between the perfusion machine as body's simulacra. The specialised perfusion machines that adapt to each organ's function and optimum preservation modality – cold liquid for kidneys, warm blood for livers, and hot or cold circulation for hearts and livers - illustrate the internal frictions within the body. The body-in-donation-practices is not a coherent whole, as Mol writes: "The organism in hospital Z (and other places like it) has gaps and tensions inside it. It hangs together, but not quite as a whole. It is more than one and less than many" (2002, 84). In organ procurement practices particularly, the body is enacted as a circulated organ-ism, a shifting and fragile assemblage of functions. Every organ executes a differential function and presents variable performance levels associated with particular age cut off points. The age of the donor/person does not necessarily map into the current standardised age eligibility criteria for each organ, pancreas functionality is considered to rapidly decrease after the age of 45, hearts and lungs of donors over the age of 55-60 are not evaluated, and yet the livers of 89 years old donors are still examined, and kidneys, given that their resistance levels can be measured with the perfusion machine, present no age limit. As previously explained the transplant recipients/patients also intervene in organ donation practices, and influence the different acceptability criteria of different organs. At the individual level of allocated organ recipients, which inform the transplant surgeon's decision on whether to transplant the organ or not. And also at a more general level, with the shifting characteristics of the patients that are included in the transplant waiting lists, as in expanding to older patients and also those suffering from diseases such as HIV, hepatitis C or B and cancer.

Hence, the body that is being done in donation for transplantation medical practices is not singular or individually bounded. Rather, it is enacted as a collective body; the commonality across different bodies is foregrounded with the circulation of organs across donors/bodies and recipients/bodies. Such collective bodies are not *a priori* entities but effects of particular practical configurations. They do not map into 'the natural immunological body' that Joralemon (1995) appeals to when he asserts that 'cultural resistance' to transplantation and thus donation, mirrors the rejection process of a transplanted organ, and that highlights that "the intuition of bodily integrity has a solid biological foundation" (347). Or by extension, the renderings of organs as gifts that embody the donor/person's identity and that are thus defined by notions of individuality

and further reify the body/self as organic wholeness. The collective body that emerges from the given hospital practices is a situated accomplishment; made possible within a particular sociomaterial technoscientific configuration that includes, amongst many others, immunosuppressant medication to disable the organ recipients/bodies' rejection reaction. Ultimately, it is the current landscape of possibilities with regards to organ donation and transplantation that makes the here proposed collective body intelligible, extending beyond the boundary of individuality and including anybody and everybody.

The organs that become circulated across collective bodies do so enabled by the particular technoscientific medical practices; they are not universal spare parts *per se* or alienable commodities. Rather it is their materialisation within the evaluative practices, as viable for particular transplant patients, which affords them with the capacity to continue functioning inside another body. As previously explained, viable organs are those which adequate functionality has been confirmed, and that are not supposed to pose a significant risk of disease transfer to the recipient/body. The threshold for disease transferability varies according to particular recipients; note that high mortality rates in the transplant waiting list entail higher levels of risk accepted. Alternatively, certain disease conditions like local blood clotting or bacterial and viral infections are not considered a contraindication given that they can be treated once the organ has been transplanted and is functioning inside the recipient/body. Once more, it is the collective body that comes to matter in the medical practices of organ circulation; the self is not reduced to the atomised individual person/body but rather encompasses the collective body. In fact, the contrasting other that delimits the confines of the collective body/self is the threat of disease.

A testament to this assertion is the trope of infection, contamination, corruption, invasion that permeates TCs' accounts and practical responsibilities towards procuring safe organs for recipients/patients. This can also be illustrated with the acceptance of organs from HIV positive donors/patients to be transplanted to HIV positive recipients/patients. For those cases, disease is no other given that recipients are already diagnosed with such condition. As Haraway suggested when talking about the immunological body "disease is a process of misrecognition or transgression of the boundaries of a strategic assemblage called self" (1991, 212). Disease as a process of invasion is akin to that of corporeal death processes that gradually colonise and disassemble the body. Death and disease are the constitutive other that bound the collective body being done in the practices of organ donation for transplantation. A body that is neither singular, clearly bounded, or

internally coherent; it is a collective body both in the sense of a collected assemblage of functions, and a collective body as the shared commonality amongst bodies.

To conclude this section that has analysed how organs are enacted in the given donation practices at stake, and that has built upon formerly presented notions of donors/bodies as assemblages, I wish to emphasise that attending to the intervening and response-able bodies and organs has located the here advanced accounts of organ donation practices outside the noted constraints entailed by the subject/object dualism. Firstly, it has highlighted that circulated organs are not objects or alienable commodities *per se*; an organ could never 'go alone' as David put it when talking about the information that must accompany an extracted organ in transfer. Instead, it has been claimed that is the organs' embeddedness within the medical processes of evaluation that enable some to become circulated from particular donors/patients to allocated recipients/patients. And secondly, by mapping the associated responsibilities of TCs along the different stages of assembling a donation process, this empirical inquiry attests that organs within donation practices do not become available through the legal mechanism of consent alone (*No heroics, please II*). In the particular practices encountered in the Hospital Clinic, the stage of consent is decentered; it is one more condition that must be met within the process of assembling a donation. TCs' responsibilities towards procuring high rates of viable organs for transplants are premised on their activities to detect all potential donors/patients in the hospital, and to evaluate and rule out any non-eligible cases, as well as to their attempts to maintain the responsive donor/body as a more or less stable circulated organ-ism, those are the conditions that ultimately enable the possibility of donation for families of eligible donors and the circulation of organs to recipients/patients. This will be the subject matter of the next and final empirical chapter 7, on how TCs' practices amount to the making of the choice of donation for some families of deceased patients in the hospital, and on the practicalities and specific configuration that situates such a choice.

# Chapter 7 – Requesting Consent to Extraction

## 7.1 – Introduction

The final empirical chapter will concentrate on the consent request stage within the process of assembling donations in the hospital. Chapter 5 and 6 have covered the practices and the TCs' respective responsibilities within the other constitutive stages of the donation process; donor detection, evaluation and maintenance, together they represent the trajectory of making donation a possibility or the making of the choice. In contrast, this chapter will address the choice in itself, the stage when families of eligible donors are approached by TCs to make the consent request. Their decision will either allow the assembling process to proceed to the final extraction stage, or else lead to a completely disassembled process.

The temporalities may vary across donation processes; consent may be sought before, during or after different maintenance and evaluation practices take place. However, in this account of donation processes it is presented at the end, so as to emphasise the separation between the making of the choice and the moment when the choice is offered to families of deceased patients at the hospital. The move responds to the *No heroics, please I* proposition and intends to illustrate that within the particular practices under scrutiny, donation has become an integrated part of healthcare activities, the required consent request is presented as an end of life choice that families of eligible donors/patients are made responsible for. Nevertheless this chapter reiterates the message that families' consent is decentered, it is neither the start of a donation process, nor is it the only factor that intervenes in the assembling of donations (*No heroics, please II*). The analysis will unravel the practicalities and specificities of the type of choice donation becomes within the situated practices in the given hospital. Primary issues will be the hospital's institutional setting, the professional interdependencies and the various entanglements that shape the given enactments of the consent request, and donation in general.

This chapter shifts its attention to the subject figure, in particular to the TCs and families who are interacting during the donation conversation in which eligible donors/patients are also enacted simultaneously as donors/persons and donors/corpses. The thesis' premise to map distributed processes and entangled relational action (*No heroics, please*

IV), previously deployed to analyse the intervention of bodies and organs as responsive entities in chapter 6, will be further mobilised here to ask how the different enacted/acting subjects are intervening and conditioning the consent request stage. For human actors are not autonomous agents either, they are embedded and made responsive along multidirectional relationships that both enable and constrain their response-ability (Mol and Law 2004, Law and Mol 2008, Haraway 2008). Thus, the actors are examined within the practices, decentered and entangled and, as such this approach does not encompass, like cited works in the literature review, the personal experiences of families about the choice of donation (Fox & Swazey 1992, Lock 2002, Sharp 2006, Jensen 2011). Fieldwork observations and research interviews inquired only about how the consent request is presented by TCs and how the families' responses condition the process of assembling a donation differently. Similarly, this research did not inquire into the reasons that underpin, or not, the decision taken by families about donation (Joralemon 1995, Siminoff and Chillag 1999, Sanner 2001, Sque et al 2008, Shaw 2010). In the hospital accounts that follow, TCs do not place the emphasis in providing families with the reasons to donate, and nor do families discuss them and make them available to TCs.

Notably, an essential difference with the reviewed literature is that in these donation practices there are no references to the gift of life discourse, instead TCs enact the choice of donation as an option to help others, and moreover, allusions to the patients on the transplant waiting lists are kept to the minimum. Donation is a routinized hospital practice and so is transplantation; in the Hospital Clinic transplantation is not heralded as a heroic medical accomplishment, and donation is not promoted through the gift rhetoric (*No heroics, please I*). This will become more salient when analysing the different ways that donors are enacted through the consent request. Donors are not heroes whose identity is said to transcend to the organ transplants recipients, and donation is not a way to offer hope for a meaningless loss (Fox and Swazey 1992, Hogle 1999, Lock 2002, Sharp 2006, Jensen 2011). For in these donation practices donors are also decentered (*No heroics, please II*), the choice families are given is an end of life choice, the donor/person's preference over donation is invoked by TCs, and the decision offered by families is said to either transfer or presume such preference. Donors are deceased patients and as such they are simultaneously enacted as corpses whose families are responsible for their disposal through funerary preparations that take place shortly after the death communication in the hospital. These are the type of practicalities and specificities that become foregrounded in the following empirical accounts because, as I would argue, they

intervene and shape the type of choice donation becomes when analysed as a situated hospital practice.

The distribution of responsibilities will highlight the division between TCs, as those who make the consent request, and families, as those who take a decision about it. TCs' practices diverge from Spanish model official protocols that attest to the importance of the TC to provide families with the reasons to donate and extol the moral value of such decision, or that deploy a set of strategies to reverse their refusals (Gomez et al. 2008, Caballero and Manzano 2012, Caballero, Leal et al. 2014). Ultimately, the TCs' actions are limited by the families' response to the request, when they refuse, their decision can only be accepted and the donation disassembled. TCs are also decentered here (*No heroics, please III*), they are not the active agents who mobilise gift of life rhetorical devices, such as the medical professionals in the works of Lock (2002), Sharp (2006), Jensen (2011), Siminoff & Chillag (1999), Joralemon (1995) and Healy (2006); nor are families the passive agents whose experiences and meanings are defined by the latter's discursive strategies. During the consent request, TCs and eligible donors' families mutually respond to each other, and thus enable or disable certain response-abilities that, as will be explained, constitute a defining characteristic of the donation practices under scrutiny.

The distribution of responsibilities, with a particular emphasis both on scope and limitations, will be further examined in the second part of the chapter, in particular it will focus on the donation-oriented activities for which families' consent is not sought, namely for organ preservation interventions that take place prior to families' consent being ascertained. The latter have spurred some extended ethical debates, and the relevant literature will be provided prior to presenting the TCs' responses to the subject of unconsented interventions. The objective of the analysis will be to finalise this thesis' mapping of the particular donation practices as integrated healthcare, to identify its constitutive interdependencies and restate that donation is a procuring practice and as such it comes with a set of inevitable frictions.

## **7.2 – The Consent Request Process**

The first part of the chapter will cover the consent request process, and as introduced, this will be examined through the TCs' practices and the particular distribution of responsibilities amongst them and eligible donors' families, as encountered in the Hospital Clinic. The different sections will explore the TCs' interaction with families,

from initial introduction as generic hospital coordinators, to their gradual disclosure and consent request. There will be no differences being made according to the typology of donors – brain-dead donors, cardiac-dead donors or tissue donors – nor on whether the request is for organs and tissue or tissue only. For TCs, the required request is the same for any donation process being assembled, and it is enacted as an end of life choice given to the families of deceased patients that become, according to their evaluative practices, eligible donors/patients. The relevant links with previously presented literature, mostly policy works dealing with Spanish model protocols for the donation interview, will be included and further discussed throughout the sections.

The families' responses, either consent or refusal, and their consequences for the process of assembling donations are made explicit. The differential enactments of donors during the consent request will concentrate on the figures of the donor/patient, the donor/person and the donor/corpse. At the end, a general discussion will be launched with the objective of refining the presented distribution of responsibilities that emphasises the crucial role families play at the hospital in regards to donation. The elucidations will inform chapter 8's final discussion on responsible donation practices. These convey a particular message and entail significant consequences for this thesis' intended contribution to the current organ shortage problematisation, and in particular the proposed strategies to increase national donation rates debated in the UK and the Scottish setting.

### **7.2.1 – TCs' Introduction and Initial Interaction with Families**

The consent request's timing, and type of practitioners involved, varies according to the type of donation process being assembled. With cases of eligible brain-dead donors and cardiac-dead donors, once the relevant medical professional/s has communicated the respective death diagnosis to the donor/patient's family, then a doctor TC is introduced as a hospital coordinator who will provide information about end of life processes. For cases of eligible tissue donors, as noted in chapter 5, TCs locate the family in the unit where the donor/patient was admitted and introduce themselves (it may be one or two TCs) as hospital coordinators who need to discuss a few issues with them. The gradual disclosure process and the type of information provided by TCs will be discussed later on in this section.

First, the question of where the communication takes place needs to be addressed. TCs remark that their practice does not follow the Spanish model donation interview

protocols (Gomez et al. 2008, Matesanz, R., et al. 2012) that, as introduced in chapter 2, state that the TC should take families to a private room, so that they can all sit comfortably, offer them water, tissues and a phone to contact other relatives. In the Hospital Clinic, death diagnosis communication and subsequent TC introduction takes place where the deceased patient was admitted, mostly in a waiting area of an ICU, A&E or general unit. Once the TC is left alone with the eligible donor's relatives, the initial concern is to ensure as much privacy as possible. However, the three offices the TC team have in the hospital are too far to use for this purpose; it would take ten minutes to go through a labyrinth of corridors to get there from most sites where donors are detected. On some occasions, TCs ask if they can use the ICU director's office to talk to the family, or in A&E they might ask for the social worker's office, but it is never guaranteed they will be free or that their occupants will not need them soon after. Instead, TCs take families away from busy waiting areas to some quiet corner nearby, or sometimes, if there are only a few people in the waiting area they might ask them to leave for a while so they can sit down with the distressed family. As noted earlier, the TC is introduced generically as a hospital coordinator who will assist families with matters to be discussed following the death of a patient. TCs initiate the conversation by expressing their condolences for the death of their relative and inquiring about the situation that led to it, the experiences of the family during patient hospitalisation, and whether the death had been anticipated for a while or it came as a shock to them. Usually, the families of brain-dead donors/patients have had ample information beforehand about the poor expectation of recovery and deteriorating situation prior to death diagnosis. Conversely, families of eligible donors after cardiac death have just rushed to the hospital following cardiorespiratory arrest communication and the news of the death is mostly unexpected. In these cases, TCs remark that the initial conversation with the family will inevitably entail a further medical explanation of the sudden death than that offered by the A&E doctor that communicated the death diagnosis. It is the TCs' general view that it is not their responsibility to inform families about cause of death and unsuccessful treatment provided, as healthcare practitioners should do this, thus ensuring a separation or decoupling of the death diagnosis and the donation request. Nevertheless in practice, most A&E doctors communicate the news succinctly; deliver the death certificate and leave promptly to attend to other patients. To the TC team such a quick 'handover' is symptomatic of the overcrowded and understaffed hospital emergency services, but also, as David and Marc remarked, A&E doctors don't consider deceased patients their responsibility anymore, and as eligible donors/patients it then falls on the TCs to continue attending to the families' needs.

Once in conversation with grieving families, TCs ask them if they are aware about the necessary hospital procedures to initiate funerary arrangements. Most of the times they are not, and TCs then explain the steps they need to take, such as getting a death certificate and other documents that they need to gather, prior to visiting the funerary services office located on the grounds of the hospital. The amount and complexity of the paperwork is remarkable and it also involves issues about health and funerary insurance plans. During fieldwork in the hospital I followed the training sessions for new members of the team, and even though the most important and initial lessons were on donor detection and evaluation, soon afterwards, junior TCs would be informed about what senior TCs call the Catalan death culture. That is, about the necessary documents that families need to gather inside and outside the hospital so as to register the death of their relative, and the procedures to initiate funeral preparations with the in-hospital funerary services office. Training for visiting students from other countries would highlight that habitually funerals take place the following day or maximum two days after someone dies. Thus, given that the families' foremost responsibilities after receiving the death communication is finding out about funerary procedures, TCs provide such practical information prior to broaching the topic of donation.

During individual interviews with TCs we discussed the issue about their initial introduction as generic hospital coordinators. They all argued that the disclosure of their TCs' role, and correspondingly the consent request, has to be done in a gradual manner so as to give families time to initiate the grieving process. Some, like David, explain that their initial role with the families is to be there with them, to support them and help them initiate the grieving process. Others, like Camino, argue that even though her job is not to provide bereavement counselling, unlike in the Spanish model protocols that define the TC as a therapeutic support figure, the disclosure has to be gradual due to the emotional intensity of the situation:

The so-called therapeutic support relationship is simply giving a more scientific name to something pseudoscientific which is respect, the respect that one must have during those difficult situations, you simply cannot arrive at a time that a family are initiating the grieving process and ask about donation, no! You need to have enough respect to wait for the right moment which is when the family tells you 'we have nothing else left to do here' or 'and now what?'...Because when a mother is clutching your arm tightly and says 'I cannot believe it', you can only but say 'well you are right, this is unbelievable, it is like a bad dream, I don't know how I would be in your place, what do you need? What can I give you?' (Camino).

Additionally, TCs during initial conversation are attentive to details such as which family members are present at the hospital, which other ones are expected to arrive, and their emotional state and expected responsiveness to the question about donation. Overall, members of the TC team state that it is a matter of giving each family the required time up until the consent request can be initiated. Mostly, the timing is marked by the families themselves, as in Camino's quote, this is when families show an awareness that there are decisions to be taken after someone dies in hospital, that they have responsibilities in regards to end of life choices, and in the Hospital Clinic donation is another one of those choices as the next section discusses.

### **7.2.2 – The Required Consent Request: An End of Life Choice for Eligible Donors/Patients' Families**

The decision about donation is, according to TCs, part of the end of life choices that the families of eligible donors/patients have to deal with in the hours following death communication. Thus, the cue TCs follow is the time when families realise that they must attend to necessary procedures, such as hospital documents to obtain and take to the funerary office or dealing with insurance issues. Some TCs with the longest experience, like Camino, David and Ferran, assert that it is a matter of perceiving in the families' general attitude that they understand the TC is there for a reason. There is not a fixed way to introduce the topic of donation as it varies greatly amongst TCs' styles and particular circumstances. However, most of them start by telling the group of relatives that 'there is only one last issue to discuss which can only be talked about now, and that is donation'. Ferran during an interview exemplifies his particular style of opening up the discussion:

I always tell them that in this hospital at the same time that we offer healthcare sometimes this is done with a transplant, and then that I am sorry the situation is inevitably complicated for these families but it is the only time I have to approach them, and then I ask them directly about donation, if the deceased person would have liked to help other people (Ferran).

TCs, when initially broaching donation, do so in general terms, that is, without making distinctions on organs and/or tissue, those are specified later on in the conversation. On the whole, the shared approach to the question about donation is that it is a required request that is always carried out in the hospital with the families of eligible donors/patients. And the question itself is posed in terms of whether the family knew

what the deceased person, in this analysis the donor/person, would have wanted in regards to donation. Angel clarifies on the type of choice given to families:

I am enquiring if the deceased person wanted or not and more than asking them it is about giving them two options which are to consent or to refuse and then they choose the option that comforts them the most (Angel).

TCs, when referring to the choice offered to families, would emphasize that they offer them the possibility to help other people through donation. And that even though the consent request is mandatory, the decision to donate or not is entirely optional and hinges upon what the families know, or otherwise presume, about the donor/person's opinion. Sandra, also adds that donation is an end of life choice that some families have, unlike funerary procedures that are obligatory for all deceased patients' relatives:

I try to bring it up as something that is normal to the moment families are experiencing after losing someone, I mean that families aside from assimilating the death and starting grieving they also have to deal with funerary procedures, because that, unfortunately in this country, is something that no one can avoid, and it is expensive whether they had insurance or not, and it needs to be done, on the other hand, you can also do this which unlike the funerary arrangements that involve a great deal of paperwork and an elevated cost, what I propose to you, donation, is a possibility that you have to help other people that will not involve any effort or cost on your behalf (Sandra).

Later on in this chapter more will be said on the specific funerary procedures and the most usual concerns that families express during the consent request. In the next section, the analysis will move on to examine the TCs' expressed views on the applicability of protocols to the consent request, in particular to the Spanish model protocols and strategies to conduct, as officially called, the donation interview.

### On the Use of Spanish Model Donation Interview Protocols and Consent Strategies

It was already introduced in the previous section that TCs' practices do not follow Spanish model protocols, both on the issue of where the consent request takes place, and on the ascribed therapeutic support role as part of the TCs' responsibilities. TCs state that they do not follow any particular guidelines to conduct donation interviews. Rather, their interaction with eligible donors' families adapts to each particular group and most of the conversation is directed at answering their questions and attending to their concerns of

the moment. It is their view that Spanish model protocols have become out-dated and that they only cover brain death donation processes. About the latter, they contend that it should not be the TCs' responsibility to clarify about brain death diagnosis, as the general population are not only aware of the diagnosis but also anticipate being asked about donation when in that situation. Similarly, they claim that their practices differ from Spanish model guidelines in that they do not deploy a set of communicative strategies to increase consent, such as focalising the interaction with families to providing reasons to donate, along the lines of altruism and solidarity, and techniques to reverse families' expressed refusals. Camino, a doctor TC with over twenty years' experience in the hospital, advances a strong opinion on the topic:

In our country with nearly forty years' experience of donation what matters is that society knows that they can be donors, and the TC figure and the donation interview must take a secondary position, because it is, our experience here is that it is not the most important step of the donation process, it is something that we do in the snap of a finger, and that is it, people have already decided and only in some particular cases we can scratch something but people have already made a decision and it does not depend on the skills of the TC or the support relationship and empathy you can achieve with families (Camino).

Camino clarifies, and this is a shared view amongst the TC team, that her responsibility is limited to making the consent request, and hence it does not extend to providing families with the reasons to donate, besides from defining donation as a way to help others, on the contrary, it is the families who provide their own reasons to consent or to refuse, and that ultimately those remain largely unarticulated during the consent request and thus TCs are mostly unaware of them.

A testament to the TC team's approach to the consent request without the use of specific strategies is the fact that there is no training provided on the matter for new members of the team. Instead, junior members shadow senior TCs for a week or two prior to carrying out the donation request by themselves. Some, like Xavi a few years ago, attended a workshop outside the hospital run by 'Transplant Project Management', the company runs a five-day intensive international course on donation practices. He explained that there he was taught about the Spanish model tactics but that in the practice he uses his own approach as one learns by doing it. Nevertheless, he stated that the commonality with the Spanish model is simply to approach the families with respect and care, and make the request in a gradual manner. Other new members of the team, like Maria, Marc and Samuel were expected to undergo the same external training, to fulfil official hospital

requirements, but at the time there was no available funding for it. They all explained that the only way to learn is by doing it and gaining confidence gradually. Samuel, in particular, after shadowing senior TCs wrote his own guidelines to assist him during his first experiences:

I wanted to have a script so that if I went blank or got very nervous I would know how to proceed, but what matters really is being respectful, having the right tone, not rushing them, showing them it is whatever they want and however they want it, it is their own decision, I am guiding the situation but they are the ones that decide in the end (Samuel)

Samuel, since starting as a TC had done a total of forty consent requests and according to his records four families had so far refused. He remarked that he never felt his objective was to get families to consent to donation, but rather to help them reach a joint decision that they would be content about. Likewise, Marc commented that any consent request is never 'a struggle for consent', on the contrary, he reflected on the necessary caution when talking to families in such a difficult position. For, as he explained, it is a very sensitive time for grieving relatives and being approached by a hospital professional 'wearing a white coat' can already be quite imposing, hence it is the TCs' responsibility to exercise their authority carefully. This is especially, Marc added, for those cases where families remain undecided, which he estimates is a third of the cases. Marc indicated that is this kind of case in which the TC's communicative skills could have an effect on the final decision. However, he concluded that his job ends once he has placed the request and confirmed it has been understood and families are sufficiently responsive so as to make a decision about it.

On the whole the phrase most widely used by all TCs when referring to deceased donation rests on the general terms of 'helping others'. Angel and Sandra in particular, when faced with a family reluctant to make a decision they would sometimes briefly mention the transplant waiting lists or more often inform families on the specific uses of donated tissue<sup>60</sup>, which, they claim, is not as well known as the use of organs for transplants. However, the rest of the team agreed that it is better to leave transplant recipients out of the consent request, mainly because the grieving families are already going through a very difficult time, and thus, it would be unnecessary, and even unfair, to add to their situation the suffering of other people. The next section will provide more details on the specifics that are usually discussed with families, including consideration of

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<sup>60</sup> Skin for burnt patients, bone for cancer patients, heart valves for children and corneas to restore the vision of two blind people

the information TCs provide which responds to families' most frequent enquiries and that characterises largely their interaction.

### **7.2.3 – Families' Response to the Consent Request**

The main message put forward in the previous sections is that the consent request is a requirement for all those cases of deceased patients that after TCs' evaluation are considered eligible donors. TCs are then responsible for making the consent request to the eligible donors/patients' families; the process is enacted as an end of life choice to be decided on in the hospital in the hours following the death of a patient.

The families' response to the consent request is crucial, it can either allow the donation process to be further assembled and proceed to organ and/or tissue extraction, or otherwise it can lead to a disassembled process altogether. It is also important to note that, as introduced in chapter 5, no donation process can proceed unless some relative of the detected donor/patient can be located. In the absence of relatives to be requested for consent, the detected donor/patient becomes automatically ruled out as non-eligible. The intervention of families serves a twofold purpose; they are the only ones that can sign the legal document to authorize extraction, and if they decide to do so, they then become key informants in regards to the social history of the eligible donor/patient. The latter offers necessary information to be incorporated into the TCs' consideration of the viability of the organs and/or tissue under evaluation, which in turn responds to the TCs' responsibility towards procuring safe organs and tissue for transplants recipients/patients.

The analysis will now move on to consider the type of practicalities and specificities that intervene and thus shape the type of choice that families are made responsible for. Special consideration will be given to the different enactments of the donor/patient figure during the consent request process, namely, as a donor/person and as a donor/corpse.

During fieldwork I observed that once the TCs have established a conversation with eligible donors/patients' families, and after they have explained to them about their choice about donation, as previously noted, invoking the preferences of the donor/person, then the conversation would usually revolve around TCs answering families' questions about the practical consequences of organ and/or tissue extraction. Most frequently, and that was always the first question, about possible time delays to the prospective funeral. As observed in the past section, funerals habitually take place the following day, or at the

latest two days after, the death determination. Relatives of any deceased patient at the hospital are responsible for dealing with the necessary funeral preparations prior to leaving the hospital. The funerary company has an office located in the hospital grounds. Families go there, once they have gathered the right documentation, such as copies of death certificate and identity documents of the deceased person, to initiate the funerary procedures according to their chosen characteristics of type of coffin, ceremony, location of the wake and/or funeral, burial or cremation.

Another question that most families posed, as observed during fieldwork and also present in TCs' accounts, was on whether the extraction intervention would leave visibly noticeable marks on the body, or the figure used in this analysis, the donor/corpse. Sandra, during an interview, explained that families inevitably enquire about such issues:

I think that what they really value is that the decision does not have any detrimental effects in regards to body's deformation or time delays in all that they need to do, so that when they go to see him he still looks like before, I believe they evaluate these negative issues about the effects of donation rather than even the benefits for others, because as much as it can help others, if they think that you are going to slit them open from top to bottom and dismantle all, they will donate nothing so I think that for families a significant concern is the body's integrity (Sandra).

Thus, in conversation with families, TCs' tend to respond to their demands of information on the potential negative consequences of the organ and/or tissue extraction. The donor/corpse figure deployed here, serves the purpose to situate the specificities that become foregrounded during the consent request, and it highlights the differential way in which donors/patients are enacted, by the families and correspondingly by TCs. For the eligible donors/patients detected by TCs, and the evoked donors/persons whose preferences are to be transferred or presumed by their families, are also corpses who are to be buried or cremated shortly after. The bodily integrity that TCs inform families about is limited to the donor/corpse, that is, it only takes into account the visible funerary body. Likewise, as noted in previous chapter, the primary concern of surgeons when reconstructing donors/bodies after extraction surgery is to attend to the features that will become visible during the wake and funeral, their actions respond to the donor/corpse that will shortly be displayed during the funerary ceremony.

For cases of organ donations, families are told that there will be no visible alterations on the donor/corpse. TCs remark that sometimes families enquire whether donation would

impede an open-casket funeral and the possibility to dress up the donor/corpse. When the donation requested involves tissue like skin and bone, TCs inform families that after extraction the donor/corpse will be wrapped in a shroud and thus only the face could be shown for the wake and/or funeral. According to TCs' accounts, this is the most habitual type of funeral hence families do not usually consider it a problem if they have decided to consent to extraction. Nevertheless, TCs recall a particular case of a family that quickly consented to tissue donation - it was what the deceased donor/person had expressed in life - but when told about the shroud they decided to refuse because there was another wish that at that moment prevailed donation. She had left clear instructions for the family to have her buried in her Chanel dress and Swarovski crystal sandals. Ferran commented on the subject, that according to his experience, any known posthumous wishes like funerary outfit always prevail over the decision about donation.

On the whole, TCs argue that when talking to families of a recently deceased person one has to be aware that by then their concern is about their immediate responsibility to take care of the funerary arrangements, about the necessary paperwork and decisions concerning the burial or cremation that will be taking place in short. Thus, TCs during the consent request respond to such concerns and in conversation with families the figure of the donor/corpse is further enacted.

David, a senior TC originally from Colombia with nearly twenty years' experience in the hospital Clinic, remarks that issues about funeral delays and the corpse's integrity are the most significant for Catalan families, but he adds that when dealing with foreign-born families, there are other issues that come to matter:

I think that here the death culture is to finish off quickly, in Catalonia especially, here what we see is that most people want the mourning to be very private, only the family, they don't want to make a lot of noise, they don't want to tell about donation either, they rather keep it as something personal and something to get done quickly, "donation, yes doctor do whatever you need to do and then we can get on with the burial and that is it", but there are other families, of migrant origin, which they need to think about the body's repatriation, so their concerns are very different from a national family, because of things like the financial cost of the corpse transfer (David).

David explains that predominantly the nationalities that TCs deal with are South American, Indian, Pakistani and from the Philippines. The Catalan government runs a scheme of financial assistance for families of donors/patients who have donated more

than one organ and type of tissue, it covers the international body repatriation costs of up to 6000 euros.

Camino and David, in particular, prefer to inform families about the financial assistance during the consent request, whereas Ferran prefers to let them know about the scheme once they have signed the consent form. There is also financial assistance to cover funeral costs, around 3500 euros, offered to families of Spanish-born organ donors, but only for those cases that did not have a funeral plan insurance. During the consent request, TCs ask families whether there was a funeral insurance plan in place, and according to their experience, less than a third of eligible donors/patients wouldn't have one. Camino especially, prefers to inform eligible families that such financial assistance is available. She does so specifically in those cases that, according to her perception, appear to be experiencing financial difficulties at very unfortunate times, and that could not face the elevated cost of a funeral<sup>61</sup>. All TCs note that in the current economic crisis and context of severe health budget cuts the continuation of the financial assistance scheme remains uncertain.

### Families' Refusals

During fieldwork observations of TCs' interaction with families, I noticed that generally the decision to consent or to refuse is taken by the family as a group. As explained beforehand, groups are heterogeneous and there is no hierarchy applied to closest next of kin. For those cases that only one person wishes to consent – even for those in which it is argued that it is what the donor/person wanted – TCs might try to talk to reluctant family members and enquire about their refusal, but ultimately, as TCs confirm, the refusal prevails over consent in case of conflict within the family group. In section 7.3 the scope and limits of TCs' responsibilities in regards to the family's decision will be further discussed, as well as contrasted with available literature on Spanish practices of deceased donation.

Those families that directly refuse, and state that it is what the eligible donor/person had expressed in life, comprise the largest majority of refusals according to TCs. On those instances, TCs would generally enquire about the reasons the deceased person had given so as to, as they say, provide the correct information to dispel any misunderstandings. However, this is only possible if families are willing to engage in further conversation with

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<sup>61</sup> Barcelona is the most expensive city in Europe to die in, 5000 euros minimum per basic funeral (<http://www.ccma.cat/tv3/alcanta/30-minuts/passi-per-caixa/video/5361091/>).

TCs, otherwise TCs thank them for their time and leave. Contrary to the Spanish model's strategies of refusal reversal, TCs assert that their job is to make the required donation request and if the resolute answer is refusal then it is accepted. The consent request is mandatory and it is the TCs' responsibility to make it, nevertheless, donation is optional and the decision to either consent or refuse rests in the hands of the bereaved families. There are some instances in that families argue that they don't feel entitled to take such a decision without any knowledge on the donor/person's preference. On those cases, TCs insist that as relatives they are the ones that knew them and the ones that are there and face the choice given; not taking a decision is not an option they have. TCs advise families to presume the option that the donor/person would have chosen if asked in life. All TCs remark that it is their responsibility to make sure that whatever decision the family takes is made in an informed and joint manner, that is that there is agreement within the group on one preferred option. Sometimes TCs might leave the undecided families to discuss the matter by themselves, they indicate that their phone number is on the documents provided, and recommend them to call when they are ready for the TC to come back. Likewise, even if families have already communicated their refusal, TCs upon taking leave remind them that there is time to change their mind and to let them know if they do so. It might happen that families that initially refuse, with the arrival of other family members to the hospital and intervention to the group discussion, can come to change their decision later on. There are no rigid time constraints that would urge families to take a decision. Only in cases of donors after cardiac death, where extraction has to take place maximum five hours after death determination, are undecided families informed about the time limit available to discuss it further or wait for other relatives to arrive. However, TCs' experience indicates that most families usually leave the hospital within a few hours of the death communication, once all necessary paperwork and funeral preparations have been dealt with. For those cases where families refuse, the immediate consequence is that the process of donation becomes disassembled; any initiated actions such as organ preservation interventions are discontinued. The donor/patient becomes a deceased patient who follows the routine 'funerary circuit' in the hospital, from hospital bed to morgue refrigerator, up until the corpse is picked up by the funerary services contracted by the families.

### Consent to Extraction

During fieldwork, in the multiple instances in which families consented to the TCs' request, I observed that there was never any clear separation between the invoked

preference of the donor/person and the ultimate decision taken by the family about donation. Whether the decision was directly inferred from the donor/person's known preferences on donation or presumed by the family as a group, was not a distinction that was sought after during the interaction between TCs and eligible donor/patient's families. Neither was there generally any articulation of the reasons that might underpin the decision to consent. As noted above, TCs are not necessarily aware of the decision-making processes of every particular family group, unless those are directly verbalized and directed at the TCs present. It is important to clarify that this research project does not address the question of the reasons or circumstances that lead families to take a particular decision, thus fieldwork observations and interviews with TCs did not seek to establish those. The focus instead is on advancing an encompassing mapping of the intervening practicalities and specificities during the consent request stage with a special attention to the distribution of responsibilities amongst TCs and families. The objective is to define the differential course of action that the donation process being assembled will take following the consulted families' decision about donation. The last section already covered that when the answer is refusal then the donation process is disassembled. The analysis will now turn to the ensuing donation practices after families agree to consent to donation.

The response to consent to donation translates into the necessary legal authorization to the organ and/or tissue extraction; note that for judiciary cases the forensic authorization to extraction also needs to be obtained. The official document that TCs ask families to sign does not mention consent to donation; rather it follows presumed consent legislation precepts. It states that the person that signs declares 'absence of any knowledge of expressed opposition on behalf of the deceased person in regards to having organs and tissue extracted for the above stated purposes'. The latter refers to the two options given in the form, therapeutic, meaning transplantation, and scientific research. Usually, after signing this form, TCs proceed with the social history questionnaire, the procedure was described in chapter 5, and finalize the interaction by further expressing their condolences for their loss and thanking them for their gesture.

### Families' Responsibilities and the Donor/Patient, Donor/Corpse in the Hospital

This section will briefly cover the responsibilities that families of donors/patients have whilst in the hospital. It refers to the time after they have been approached by TCs with the consent request. The objective is to signal the overlap between donors/patients and

non-donors/patients in the hospital, hence, adding to the already developed figure of the donor/patient. The stress is also on the embeddedness of donation practices within the hospital, a public health institution with particular rules and regulations that apply to all patients, in this case to all deceased patients, and consequentially to all donors/patients. Families of eligible and consented donors are given some time, as the expression goes, to say goodbye to their deceased relative in the hospital bed. The conditions vary depending on the type of donation process. Brain-dead donors are in an ICU and connected to a ventilator, extraction usually takes place in the twelve hours following death diagnosis. However, as shown in the previous chapter, there might be some maintenance difficulties due to the donor/body instability, that will bring forward extraction surgery time. Usually, by the time donors are transferred to the operating theatre the relatives have already left the hospital. Once someone dies in an ICU of the hospital Clinic, nurses inform the relatives that they will be given some privacy with the deceased patient. The only means available for that are a set of three curtains that when drawn form a cubicle around the patient's bed; ICUs follow a circular distribution so that all monitors and patients can be seen from the main central desk. ICUs are always at their full capacity and nurses are quite strict about the imperative to keep numbers of visitors at its minimum, due to reduced space around patients' beds. Relatives are made aware that the same rules on brief and quiet family visits still apply; there is no difference made depending on whether the deceased patient is a donor or not. In these hospital practices, donors are like any other deceased patient, thus here the donor/patient figure becomes foregrounded.

Cardiac-dead donors/patients' families are allowed to see their deceased relative only after they have consented or refused donation. Regardless of the answer, families are then given a few minutes in the A&E emergency room alone with the deceased patient; nurses inform them about the importance of vacating the room shortly so that it can be prepared for the next emergency. Similarly, the same institutional rules apply to both donors/patients and non-donors/patients for those cases of tissue donation in the general units across the hospital. Families are made aware that deceased patients are to be transferred to the morgue in the next hours following death determination. Thus, sometimes, by the time TCs locate the families and carry out the consent request, donor/patients have already been taken to the morgue, for as this chapter wishes to foreground, the donor/patient is also a donor/corpse.

After a patient dies in the hospital, the family's immediate responsibility is to initiate the necessary funerary arrangements so that burial or cremation can take place shortly.

Families of donors/patients, a very small minority amongst the deceased patients in the hospital, attend to the same funerary procedures as any other deceased patient's relatives. The custody of the corpses is held by the hospital in general, and in the case of donors/corpses, by the TC team in particular. Sandra describes in an interview how she usually informs families about the aforementioned distribution of responsibilities:

I always tell them that until they sort out all paperwork with the funerary services the custody of the dead body belongs to the hospital so they don't need to worry about anything that it will be kept here, and once all the funerary arrangements have been done then the body will be handled by funerary services to do whatever they decide on, wake, funeral, incineration, there are thousands of versions, but up until the transfer to funerary services, just like any other admitted patient whose custody belongs to the hospital, it continues to be so, the relationship between the patient and the hospital stays the same after death, we keep looking after this man or woman up until they [families] do all necessary arrangements to transfer the corpse (Sandra).

The quote illustrates the overlap between the donor/patient and the donor/corpse and it differentiates the distributed responsibilities amongst families and the TC team or the hospital in general. The message advanced is that donors are enacted simultaneously as patients, persons and corpses during the consent request and the following hospital practices. The purpose of the analysis is to situate the specificities of the given donation practices that take place in a public hospital, to define the type of choice donation is made to be, and correspondingly to foreground the differential enactments of donors that intervene and thus shape the process of assembling donations along the stage of the consent request. The following section will elucidate the particular mapping of distributed responsibilities that emerges from the donation practices under scrutiny.

### **7.3 – Mapping Distributed Responsibilities along the Consent Request Process**

This section will launch a discussion on the particular distribution of responsibilities along the consent request process as presented with empirical accounts from the hospital Clinic. Firstly, the TCs' responsibilities will be outlined, defining both their scope and limitations, and secondly, those of the families of donors/patients in the hospital will be given further consideration.

## TCs' Responsibilities, Scope and Limitations

It has been made clear that the TC team approach to families does not follow Spanish model protocols for the donation interview, these are considered out-dated and restricted to brain death donation processes only. Firstly, TCs separate their task from the death diagnosis and the responsibility to explain it to families. Unlike in Spanish model protocols, those state that the TC will provide brain death diagnosis clarifications to grieving families. The TCs' emphasis in decoupling the death communication and the donation request separate their procurement-oriented practice from that of healthcare practitioners involved with the treatment of particular donors/patients. Secondly, the TC team highlight that they are not responsible for providing bereavement counselling to the grieving families during the consent request. Note that this is a crucial feature of the TC role in the Spanish model protocols, it is claimed that the emotional support offered is beneficial both for the families' experience and to increase consent rates (Gomez et al. 2008). The TC team practices are similar to those presented in the 'family interview guide' developed by a TC in another hospital in Barcelona (Caballero and Manzano 2012, Caballero, Leal et al. 2014)<sup>62</sup> that differentiates the consent request from bereavement support that should be instead undertaken by specialised psychological services. Nevertheless, the TCs' initial interaction with families is sensitive to the emotional intensity that the situation of the death of a relative entails, and as shown in former sections, their gradual disclosure as TCs and deferred consent request responds to the need to give families some time to initiate their own grieving process. Ultimately, TCs cannot make the consent request unless families are responsive enough to their newly acquired responsibilities, or end of life choices, that will need to be decided upon, one of them being the required request for consent to donation.

During the consent request TCs present donation generically as an option to help others, a choice to be decided upon depending on the donor/person's expressed preference in life, or in its absence, the family as a group are encouraged to presume it. As already explained, TCs, when making the consent request, and during interaction with families, make no clear separation between the donor/person's decision and that taken by families. Thus, the analysis highlights that the donor/person, albeit invoked during the request, also becomes decentered throughout the relational decision-making process; the deceased individual's transferred or presumed preference is thoroughly entangled with

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<sup>62</sup> The comparison is my own analysis, TCs were not aware of these publications about another large hospital in Barcelona.

the family as a heterogeneous gathering of relatives and sometimes friends (*No heroics, please II*). TCs' responsibility is not to establish whose decision it is, rather that the decision is shared by all the family members present at the hospital. The following, and final, chapter 8 will address the import that the presented empirical accounts, that attest to the essential intervention that families of eligible donors make at the hospital, entail both for the clinical practice and public policy sphere in the UK and the proposed strategies to increase national organ donation rates. Firstly, the presence of families of donors/patients at the hospital is a necessary requirement to assemble any process of donation. The consent request carried out by TCs endows them with the responsibility to either grant their legal authorisation for the initiated process to proceed to organ and/or tissue extraction, or alternatively to refuse, in which case the donation process would then become disassembled. And secondly, when the families' response is to consent to donation, they then additionally become providers of crucial information in regards to the donors/patients' social history. As noted beforehand, their answers contribute to the TCs' evaluation of the donation viability, particularly about the risks of disease transferability that could affect the transplant recipients/patients.

Another major divergence between the TC team's approach to the consent request and that defined by Spanish model protocols is that they do not employ the prescribed strategies to obtain consent to donation, nor do they use refusal reversal techniques. Fieldwork observations and TCs' accounts indicate that the TCs' responsibility ends once the required consent request has been made. After that the families are responsible for coming to an agreed decision and notifying it to the TCs whilst in the hospital. TCs do not consider it their job to extol the moral worth of donation such as in the Spanish model protocols that emphasise notions like altruism and solidarity. The TCs' opinion is that generally families are already sufficiently aware of the importance of donation for transplantation. This is also a testament of a situation of routinised transplants and embedded donation practices (*No heroics, please I*), donation is not justified by the gift of life narrative and appealing to transplants as life-saving interventions. Moreover, TCs express their view that bereaved families consulted about donation should not be made responsible for the suffering of others, that is, the needs of recipients/patients waiting for a transplant. The TC team in the hospital Clinic differ from the practices described in Caballero, Leal et al.'s (2014) study that, following the Spanish model literature, advances a 'family interview guide' that is focused on obtaining consent and reversing refusals, and that recommends that TCs should make consulted families aware of the benefits their decision to donate would represent to patients on the waiting lists.

The practices of the TC team in the hospital Clinic exemplify a particular distribution of responsibilities between TCs and families of eligible donors/patients. TCs make the consent request and families decide to either consent or refuse, according to whichever reasons or circumstances that come to intervene in the particular decision-making process, and these are mostly not available to the TCs' knowledge. TCs are aware that when families refuse, the already initiated process of assembling a donation – this being more or less advanced depending on the type of donors – will inevitably be halted altogether and become a disassembled donation process. Nevertheless, they claim that there is little that can be done when families plainly refuse and do not wish to continue engaging with the TCs' interaction; no refusal can be reversed unless families respond to and hence enable the TCs to continue to discuss their negative answer to the consent request. During research interviews I inquired about the TCs' personal feelings when families of eligible donors refuse, in particular referring to those very rare cases that present viability for several organs and tissue. The TCs' shared response is that the family's decision is ultimately outside their control or domain of action, just like when, as they put it, a donor is lost during the maintenance stage or when extracted organs are finally discarded by transplant surgeons as pathological. This definition of the scope and limits of the TCs' responsibilities as per the consent request further illustrates the *No heroics, please II* proposition developed in chapter 5 and 6. In that consent to donation is decentered within the larger process of assembling donations in the hospital, it is a necessary, albeit not sufficient condition for the procurement of viable organs for transplants. And this simultaneously foregrounds the *No heroics, please III* point to decenter the TC figure, as one more integrating part of the donation programme in the hospital, with some affordances and constraints for action along the different stages. Ferran's answer to the question of family refusal can contribute to the definition of the TCs' scope of action and its limitations:

Well, you feel bad about it because you might be aware, if you have the transplant waiting lists there, that there are two people waiting for a liver and a heart from that same blood group and you can see that they will die tomorrow, but what can you do? Steal the organs? It is like when you have a patient that is dying, and you want to help and you do CPR massage but that person is dying and you know it (Ferran).

TCs, as Ferran quote states, might be aware of the numbers of patients in the hospital's transplant waiting lists, as the OCATT allocation criteria follows a radial distribution criteria. That is, that the hospital that procures the organs has priority over others to

transplant them to their own patients. It is the TCs' responsibility to procure viable organs and tissue for the prospective transplant recipients/patients, and their task will be carried out adapting to the circumstances and constraints posed by every process of donation being assembled; there are multiple opportunities for a donation process to become disassembled before, during or after the consent request. Thus, TCs are not directly responsible for the recipients/patients on the waiting lists, whether they get the transplant or not, or whether they live or die is not an action that depends solely on the TCs' practices of donation. The TC team are essential for the procurement of organs and tissue but are nevertheless decentered, or as Angel puts it, they are 'the central cog in the wheel', an intermediary figure that oversees all the stages of a donation process in the hospital. Or else as Ferran and Sandra describe the TC profession when addressing medical university students, evoking a metaphor about the Paris underground tunnels: 'the stations are quite impressively and lavishly decorated but the tunnel that connects them is long and dark'. The image of the tunnel enacts the separation or decoupling of the TCs' job both from the healthcare of critical dying patients who will become eligible donors/patients after death diagnosis, and the healthcare of prospective transplant recipient/patients. Donation is not an individual-based healthcare, it is a practice concerned with the procurement of viable organs and tissue for healthcare purposes, transplantation to eligible patients, and this entails a given set of responsibilities to the TC figure in the Hospital Clinic. One of them is the task of requesting consent to eligible donors' families, this is done so that the assembling process can proceed to the final stage of extraction. TCs' practices are responsive to the emotional difficulties that bereaved families are experiencing and thus proceed with the consent request with respect and care. It is their task to endow the families with the choice of donation and this is done in a supportive manner without the emphasis being on consent or reversing refusals.

### Families' Responsibilities, Hospital Regulations and the Donor/Patient

The analysis now moves to examine the particular responsibilities of families of deceased patients in the hospital Clinic. As already noted, this research does not bear any claims on the reasons that families might have, or not, to decide on the choice of donation. The analysis and previous fieldwork observations and interviews with TCs were restricted to the TCs' responsibilities and their accounts of families' respective responsibilities during their interaction throughout the consent request process. The specific contribution this examination seeks to advance is to provide an in-depth scrutiny of the situatedness of the choice of donation in the given practices in the hospital Clinic, to provide information on

the institutional setting, configuration of interdependencies, and outlining the relational ways in which donors are enacted during the consent request, simultaneously as patients, persons and corpses. The objective is not to elucidate the causal mechanisms these might be said to have in respects to the high consent rates encountered in the hospital. Nevertheless, the analysis is concerned with highlighting how this particular configuration, of defining characteristics and enactments of donors, with its affordances and constraints for distributed action, comes to intervene and shapes donation as an integrated part of healthcare practices (*No heroics, please I*), and in particular for this section, on the presentation of donation as an end of life choice that eligible donors' families become responsible for once the TCs deliver the consent request.

With respects to the defining characteristics of the consent request, firstly I would stress the importance of the specialised TC figure as a hospital practitioner who bestows families with the responsibility. As was noted in their accounts, TCs are aware of their professional authority and influential status within the hospital setting when making the donation request with bereaved families. Secondly, about the way in which donation is enacted in the hospital practices as an end of life choice that families are to decide about based on the preferences of the donor/person. And thirdly, about the embeddedness of the choice about donation within the families' immediate responsibility to initiate funerary arrangements prior to leaving the hospital. The empirical accounts this research has advanced, indicate that TCs' conversations with families foreground the donor/corpse figure, for donors are relational persons with previous preferences to be transferred or presumed by their families, but they are also deceased patients under hospital custody, and dying in this particular institutional setting entails that the inexorable responsibility of families is then to initiate funeral preparations – deciding on type of coffin, wake and/or burial or cremation services – with the funerary company staff whilst at the hospital. It is important to reiterate that body disposal preparations are obligatory for all families of deceased/patients, and the choice of donation is enacted as part of those during the consent request by TCs. Nevertheless, donation is optional, it is a choice given to some families.

This research emphasises that the specificities and practicalities that intervene during the consent request need to be foregrounded as they present a particular distribution of responsibilities within the Hospital Clinic's institutional setting. Families faced with the choice of donation will respond within a given configuration of affordances and limitations for their actions in respects to their deceased relative. Regardless of whether

they consent or refuse, whether their deceased relative becomes a donor or not, families' actions are subjected to the Hospital Clinic's rules about the custody of deceased patients, they become corpses to be handled according to institutional regulations. All corpses are under the hospital's legal custody for a period of twelve hours following death determination, after that the funerary services pick up the bodies and they become officially responsible for them to carry out the funerary preparations as decided by the families. Whilst at the hospital, after death diagnosis and communication, relatives of deceased patients are allowed to spend some time by the hospital bed. However, the contact, time and privacy afforded are limited according to hospital's rules on deceased patients. Donors/patients are no different in this respect, their families are given the same instructions, only brief and quiet visits allowed. They might be donors, or at least eligible and consented so far, but within the hospital Clinic's practices they are still patients under their custody, thus, they are enacted as donors/patients. They are also donors/bodies to be monitored, stabilised and taken to the operating theater for extraction surgery under TCs' responsibility and with the collaboration of several other healthcare practitioners. They are as well donors/corpses that will be transferred to the morgue where they will be kept in a refrigeration unit until the hospital's custodianship will be handed over to the funerary company agreed to by the families. And during the consent request they are also enacted as donors/persons with certain preferences in regards to donation, whether families might know those or presume them, or whether they respect them or decide against them in the final decision taken at the hospital, falls outside the scope of this research study.

Nonetheless, the message advanced here is that families' presence at the hospital is essential for the process of assembling donations, they are the only ones that as a group can grant the necessary legal authorisation for the donation process to proceed to the final stage of extraction. Additionally, those that consent then become crucial informants about the donors/patients' social history, which in turn contributes to the TCs' evaluative procedures to determine the donation's viability and the safety of transplants for recipients/patients. The next chapter will further elucidate on how this is one of the lessons from the Hospital Clinic that will be mobilised so as to intervene in current organ shortage problematisation and proposed strategies to increase donation rates in the UK. The second half of this chapter will be shifting the analysis to specific donation-oriented practices that dispense with family's consent over interventions carried out on the donor/body; the focus will be on mapping the extent and source of frictions as identified in ethical literature and discussed by the TC team.

## 7.4 – Discussing Pre-Consent Organ Preservation Intervention in DCD Practices with the TCs

This last section of the block of empirical chapters 5, 6, and 7, stands as a bridge to the final discussion chapter 8. It will focus specifically on organ preservation measures in DCD<sup>63</sup>, the details of the practice have been provided in chapter 5 and 6 correspondingly, but from a different angle. The objective is now to interrogate the given practices and practitioners about a set of ethical concerns that such practices raise and that became prevalent whilst doing fieldwork. Or more particularly, ethical discussions I was exposed to during my participation at the ELPAT conference on organ donation and transplantation<sup>64</sup>, and that I transposed to the TC team during final research interviews to open up for discussion. The purpose of the inquiry was to cover a gap that I felt such discussions reified. In short, that the ethical tenor of the heated exchanges, infused with the language and arguments of contemporary bioethics, was glossing over the practicalities and specificities of the given DCD processes. Thus, my intention was to engage TCs to consider such ethical debates, that some of them were already aware of, but that were not discussed or openly articulated during fieldwork observations of their daily activities.

Firstly, I will present a brief overview of the problematic under scrutiny; it will only focus on the issues brought about by the organ preservation intervention that takes place prior to requesting consent to families. The current prominent debates about the legitimacy of circulatory death diagnosis criteria are not part of this analysis but they confer a heightened importance onto the discussion of the associated donation procedures in DCD. This analysis is directed at a further examination of the distribution of responsibilities amongst TCs and families during different stages of the process of assembling donations, and particularly on the subject of consent, or lack thereof in this case. The previous section has identified that families' consent to donation is requested in order to proceed to the stage of organ extraction, that is, once TCs have already detected and evaluated an eligible donor/patient. For those cases of DCD, this means that organ preservation intervention, femoral cannulation, has already taken place prior to the TCs approach to the eligible donor's relatives at the hospital. Hence, the ethical predicament is on the acceptability of such invasive measures given that cannulation is a surgical

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<sup>63</sup> DCD only refers to uncontrolled DCD (uDCD) practices. See Appendix 2 for Glossary.

<sup>64</sup> ELPAT Congress 2013 Rotterdam – Ethical, legal and psychosocial aspects of Transplantation, it is part of ESOT (European Society for Organ Transplantation).

intervention that is carried out without consent from families. It was introduced in chapter 5 that the 1979 Spanish presumed consent legislation was amended in 1999 to allow for organ preservation measures to take place prior to ascertaining the absence of objection with families of potential donors. This was the start of a long trajectory, both legal and medical, that enabled the development of the DCD programme in Catalonia, CatAsistol that nominates the hospital Clinic as the reference centre for these types of donation processes. Subsequently in 2012, the latest version of Spanish transplantation law ratified the legitimacy of organ preservation manoeuvres, and it further specified that cannulation intervention was necessary so that families could later on be given the opportunity to take an informed decision in regards to donation.

David, a senior doctor-TC in the Hospital Clinic co-authored, with Rodriguez-Arias, Wright et al. (2010) an analysis of ‘the success factors and ethical challenges of the Spanish model of organ donation’. It was argued there that DCD protocols “raise some ethical issues, including how much information families receive and the acceptability of applying invasive measures to preserve organs before obtaining consent from the family or establishing the patient’s wishes” (1110). The ethical challenge posed by pre-consent organ preservation was further analysed and discussed during the ELPAT conference. With regards to the Spanish case in particular, the focus was on the legitimacy of cardiac death diagnosis, but it also encompassed a discussion on the role of families and whether they should be given the opportunity to decide on organ preservation measures. At an international level, a study was presented on ‘a systematic review of attitudes toward donation after cardiac death among healthcare providers and the general public’. This study suggested that cannulation without consent should be eliminated “if research shows that the majority of the public is against organ-preserving measures in uDCD, it may be sensible to discontinue them so as to avoid creating negative perceptions toward donation and the health care system” (Bastami, Matthes et al. 2013, 903). Another publication that followed from the conference, and this addresses the legal and ethical challenges of the practice of DCD in Spain, questions the legitimacy of unconsented organ preservation measures, initiated prior to official death diagnosis during transfer to the hospital and that are re-started right after the diagnosis, the latter referring to cannulation intervention. Lora (2014) denounces the 1999 and 2012 transplantation legislation lacking public exposure and deliberation, and that the Spanish public have not been duly informed about current donation practices, thus, he concludes “lacking that information, presumed consent is no more than a fiction disguising the temporary conscription of dying people.

There might be sound moral reasons to do so, but they are not based on honouring the individual's will" (410).

The controversial dimension of uncontrolled cardiac death donation has received very little attention within the social sciences, excluding bioethics that is, in comparison with brain death donation that characterises all the reviewed works on donation presented in chapter 2. A notable exception is Fox's (1993) early study of two protocols for cardiac death donation in two different hospitals; the author condemned the practice defined as an 'ignoble form of cannibalism'. The story narrates how a hospital's code of practices included families' informed consent to organ preservation and later on to donation, whilst the other one dispensed with the first measure and families were thus not consulted about the preservation intervention, and neither were they informed about it if they refused the consent request for donation. About the latter, Fox vilified such practice stating that "the story of the ROBI protocol dramatically and disturbingly illustrates how an evangelical attitude toward transplantation, combined with zealotry about procuring organs and unwillingness to accept limits, can result in grave violations of the moral practice of medicine and medical research, in ways that desecrate bodies and deaths of patients, disregard the rights and needs of patients' families" (1993, 267). To sum up, Fox's denunciation encapsulates what has recurrently been criticised about the development of uncontrolled DCD programs, that is, that it denies potential donors' families the right to provide informed consent, or transferring the patient's individual preference about donation, to authorise organ preservation measures. This is seen as a serious challenge to the ethical integrity of such practices given that they disrespect the rights of autonomy and consent of individual potential donors and their families.

Those were the issues that I summarised and offered up for discussion during final interviews with members of the TC team. The prompt was simple, to explore the practicalities and specificities of dealing with DCD processes and cannulation in particular. Note that in DCD, it is the TCs' sole responsibility to ensure that organ preserving actions will not incur any further damage to the abdominal organs, although as also explained, the cannulation intervention is carried out by a surgical team and A&E nurses. The conversations<sup>65</sup> addressed the question 'why is cannulation a necessity right after the death diagnosis?' and additionally encouraged TCs to speculate on possible ways to incorporate families' decision about organ preservation prior to the surgical intervention on eligible donors. The TCs' responses will be analysed in the following

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<sup>65</sup> See Appendix 8 for Interview Topic Guide II.

section, and later on discussed to further delineate the given distribution of responsibilities along different stages of the process of assembling donations.

#### **7.4.1 – TCs' Responses to the Subject of Cannulation Intervention**

On the whole, members of the TC team concur in indicating that the Spanish legislation about presumed consent enables them to initiate organ preservation procedures without consent from eligible donors' families. Some of them add that such measures do not require either any forensic authorization from coroners or judges, and that consent, both from families and forensic authorities, is sought later on as a legal requirement to proceed to organ and tissue extraction.

Most of the TCs compare cannulation to any other emergency intervention that takes place in the hospital and that as such dispenses with patients' consent, which is otherwise necessary for any surgical operation. The main issue brought forward is that if cannulation to re-circulate abdominal area were not done right after death determination then the organs would suffer irreversible ischemic damage. This would mean that the donation process could not be further assembled, as the organs would have become non-viable for transplantation purposes, and consequentially families could not then be given the choice of donation. Additionally, some of them highlight that mostly at the time when cannulation intervention is carried out, the donor/patient's relatives are not yet present at the hospital, as they would have only just been notified about the cardiac arrest. Sandra expands on the emergency character of preservation measures:

Patient's consent is always sought except in emergency cases, so I think that donors after cardiac death, because of the type of emerging process and urgency involved, are part of these cases, when someone is admitted with a severe head injury you are not going to ask the family, are you? No, you will do whatever the medical team finds necessary, and I think that with these donors, legally we have all the justifications to do so, so I think it is part of such exceptional cases in the hospital (Sandra).

During research interviews with TCs, the argument about emergency procedures that dispense with consent came up frequently, on those occasions I offered a clarification, in short, I highlighted that the key to the current bioethical debates is that the intervention is not for the individual benefit of the patient anymore unlike other emergency interventions undertaken in the hospital. To that, TCs' responses varied but above all they all coincided in arguing that intervention was nevertheless for the benefit of other

patients, specifically the prospective recipients/patients on the organ transplant waiting lists. And that organ preservation procedures did not pose any risks to donors/patients as they are by then officially declared death.

Angel is the head of the DCD programme in the Hospital Clinic; he has also played a key role in the creation and implementation of the CatAsistol public health protocols on donation after cardiac death in Catalonia. He particularly offered a strong take on the subject and argued that when the rights of donors/patients and the rights of recipients/patients collide, then to him, the rights of the living should prevail:

Consent? The patient is dead! I will ask consent from the family for the organ extraction and donation, if I need to cannulate, why would I ask permission from the family? I cannulate to give them the opportunity to donate! If I don't cannulate I cannot give them the choice! I don't see it as an invasion on the patient's right to autonomy; in fact first of all, does a corpse have the right to autonomy? Obviously, dead people have rights that need to be respected but I think that the living are more important than the dead, so for me it is the rights of the living that must prevail when in conflict, therefore, for the possible benefit of third parties, why cannot I cannulate? I am not separating the head from the body; I am not doing any amoral actions against that person, against that corpse, not a person but a corpse! We do a series of respectful measures that additionally are to respect the wishes of the dead in case he wanted to become a donor, and if they refuse then we stop everything and remove the cannulas and that is it. I mean, to me it seems absurd that we are considering such ethical dilemmas 'whether we can cannulate or not' and we are not discussing other ethical dilemmas about 'whether I am not giving more options to those that are alive and in the transplant waiting list?' (Angel).

On the theme of the patient's right of autonomy, Marc noted that even for living patients such rights are 'left outside the hospital door upon admission', he added that current ethical debates about consent neglect the question 'ultimately who decides the treatment the patient or the doctor?' On my prompt that intervention on donors/patients cannot be considered like a medical treatment – given that they stand no individual benefit from it – Marc replied, similarly to Angel's allusion to the benefits of prospective transplant patients, that it would be more detrimental 'to lose a potential donor with two kidneys, a liver and a pancreas because of a question of a raw incision to a non-patient'. Samuel also emphasised that the intervention responds to healthcare-purposes, albeit for the benefit of recipients/patients on the waiting lists. He praised the current situation in Spain, in that under presumed consent legislation 'all patients are potential donors', and

added that objections should always be communicated to one's family who will ultimately decide about donation. An extract of our conversation follows:

S: Yes but by the time families are asked the donor has already been cannulated

TC: But he has been cannulated? But only cannulated! He has already been pricked, he has had a tube down his throat that has broken his teeth, some ribs have been broken with the Lucas<sup>66</sup>, when so much has been done to a lifeless body what difference do two little incisions make?

S: Well, I guess the difference highlighted in these debates is that the intervention represents no benefit for the patient

TC: But it is for the benefit of a patient! Or other patients, it is a circle, it is the cycle of life, you are dead but it will be useful for others, I mean there is no stop, there is no clear stop.

Other TCs, Sandra, Xavi and Maria, also indicate that organ preservation measures already start in the ambulance when emergency practitioners activate the DCD code and continue mechanical CPR and ventilation, which entail risks like those Samuel pointed. Thus TCs, when considering the possibility of asking for consent to organ preservation measures, suggest that it would be the responsibility of emergency professionals while on transfer to the hospital. On that prospect, they all concur in pointing out the ethical conflict this would pose; EMS are healthcare professionals, so were they to raise the topic of donation prior to the official death diagnosis at the hospital, then this could foster families' mistrust on the resuscitative efforts made. This is the current practice in France (Thuong 2011), where DCD protocols were amended to incorporate families' decision over organ preservation and transfer to hospital, emergency services communicate the death diagnosis and request their consent to donation-oriented measures. However, some TCs, like Xavi, note that this would not be possible for them because in Spain emergency services medical personnel cannot conduct an official death diagnosis in the ambulance, there is a law against the transfer of corpses by medical vehicles, thus death diagnosis can only take place once the donor/patient is admitted to hospital.

Sandra and Camino, claim that they are aware that in particular instances, such as when relatives of donors/patients are present in the ambulance, EMS staff already request their consent to be transferred to the Hospital Clinic for the purpose of donation. Camino and Maria speculate whether EMS staff could be trained to deliver the consent request but point out the difficulties this would entail, both for EMS and families, given that a decision would be expected right away following the unofficial death communication.

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<sup>66</sup> Lucas: mechanical chest compression machine.

Additionally, they specified that such donors/patients usually arrive at the hospital unaccompanied given that mostly cardiac arrests happen in public places.

All in all, TCs agree that any conversation about donation should be carried out in the hospital, after the official death diagnosis, and by them, who are the specialized professionals with the necessary information on the subject and who have the right expertise in dealing with suddenly bereaved families. To that they add, Sandra in particular along the lines of Angel's previous quote, that cannulation is done precisely to give more time to families to get to the hospital, and to offer them the opportunity to take an informed choice about donation, after the death communication and in an unhurried manner.

Maria considers the possibility of TCs asking for consent, specifically for organ preservation measures, upon arrival at the hospital, but highlights that families are only approached along with the doctor that delivers the death communication. She also notes that the rate of utilized<sup>67</sup> donors after cardiac death is quite low, only 20% of activated cases end up with extraction of viable organs, thus, to her, TCs must do everything possible to carry forwards all detected cases:

Maybe there aren't enough resources in terms of numbers of TCs to do it all at the same time, maybe if we had more people? I don't know, maybe if the social worker was to collaborate and place the request? I don't know, the thing is that once we start preparations it is when the doctor starts writing the death certificate, so while you are preparing everything the doctor is doing the paperwork and when he is ready, he says 'let's go' and then you go with the doctor which is the moment when he says 'he is dead', he doesn't say it any earlier either (Maria).

To Maria, the fact that death communication usually takes place twenty minutes after the death diagnosis, which is when the TC initiates contact with the families, is incompatible with asking for consent for preservation then, as cannulation to enable re-circulation needs to be carried out straight away after death diagnosis, which includes five minutes with no mechanical CPR, which already aggravates the ischemic damage sustained by abdominal organs.

Other TCs who consider the possibility of asking for consent for cannulation raise different issues. Ferran states that he would rather ask families prior to initiating

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<sup>67</sup> Utilized donors refers to donors whose organs are extracted and transplanted according to current standardisation of terminology on 'the critical pathway of deceased donation for DCD and DBD (Dominguez-Gil et al. 2011).

preservation measures, but he clarifies that such a question prior to the death diagnosis could entail mistrust from families about whether sufficient patient treatment has been applied. Similarly, David ponders on the possibility to ask families about cannulation, 'because they have the right to know', but he also appeals to the ethical conflict associated with broaching the question of donation prior to the death diagnosis communication. Marc conveys that 'ideally consent should be sought', but emphasizes that TCs intervene on the donor only once the death diagnosis is complete and the doctor transfers responsibility to them, the eligible donor is by then a no-patient, and thus, issues about consent have a lesser legal weight:

I mean if you could give me an alternative I would be the first one to accept it, but currently no such alternative exists, it is a collateral damage so to say, I understand it is an aggression to the patient, I get that, but we should also see whether it is a patient or not a patient anymore? The ideal situation would be to find a method that granted us more waiting time without doing anything crude to the patient, to obtain, or not, but at least to be able to bring up donation, but this doesn't exist up until now (Marc).

On the subject of information given to families, TCs in general remark that when families refuse to authorise organ extraction, the cannulas are removed straightaway and abdominal blood recirculation discontinued. They explain to both donors' and non-donors' families about the intervention, in a very brief and simplified manner, and only Xavi has ever encountered opposition from a family, he was once told 'why did you touch him! I am going to sue you!' he recalls simply explaining about current legislation and medical protocols about donation to end the discussion. It is his view that families have to be told but afterwards, in a respectful and caring manner, and that in his experience mostly families appreciate the information. Samuel observes that by then the shattering news of the death of their relative is the only concern families have, and thus, when informed about cannulation they never comment or ask any more questions. Similarly, other TCs highlight that there are never any more questions or any issues about cannulation information, both from families that consented and those that refused donation.

To sum up, the themes that came up in conversation, and that will be further examined in the following discussion, emphasise the practical necessity to cannulate right after death diagnosis so as to preserve the organs' viability for transplantation and to enable families to respond to the donation request later on; the enabling presumed consent legislation that legitimises such procedure and the broader contextualisation of donation practices

within a public health scope. The latter correspondingly foregrounds the patients in the transplant waiting list as the ultimate beneficiaries of donation, and in turn backgrounds the individual rights of consent ascribed to donors, who are defined as non-patients given that the intervention takes place once death determination has been officially carried out in the hospital. The final section in this chapter will analyse the aforementioned themes drawing on the thesis' *No heroics, please* proposal, focusing on the different enactments of donors that coexist in the TCs' accounts – the donor/patient, donor/body, donor/person and donor/corpse – and further unravelling the distribution of responsibilities along the process of assembling donation in the hospital.

## **7.5 – Integrated Donation: a Procurement/Healthcare Practice with Frictions**

This section will conclude the empirical chapters. It will firstly address the questions raised by cannulation practice within current bioethical debates, and secondly it will offer a final mapping of the TCs' responsibilities, as procurement specialists in the hospital, and simultaneously a characterisation of the donation practices under scrutiny. The emphasis will be on accounting for donation as an integrated part of healthcare but with a set of frictions that stem from its procuring nature; it will be further explained that donation is procurement for healthcare but unlike healthcare it is not an individual-patient-based practice.

The examination of the TCs' responses, about the practice of cannulation and the reasons offered to justify the absence of choice given to eligible donors' families, is presented with the purpose of mapping the practicalities and addressing the frictions identified in the previously presented literature. It neither seeks to advance a solution nor to subscribe to the existing bioethical critique about the given practices. Rather, it wishes to furnish the debates and problematisation about cardiac death donation with a contribution from the practices and practitioners involved. This is valuable because any adaptation of current protocols for DCD will need to, in the first place, account for the complex configuration that undergirds such practices, and that inevitably comes with a set of affordances and constraints for particular changes such as the incorporation of families' consent to organ preservation.

The basic constraint identified by TCs is the practical necessity to initiate cannulation right after the death diagnosis, unless the donor/body is kept as a circulated organ-ism the option of donation is automatically disabled (*No heroics, please IV*). At the time that the donor/patient has just been diagnosed dead the TCs' principal responsibility is to ensure that the organs will remain viable, that is circulated and functioning, for transplantation uses. This in turn, as TCs argue, will also enable the eligible donor/patients' families the opportunity to decide about donation later on, during the consent request with TCs, when the preference of the donor/person will be inquired about. The TCs' ultimate responsibility is to procure safe organs for transplants recipients/patients, chapter 5, 6 and this one, have covered the different stages and associated TCs' responsibilities, that constitute the process of assembling donations in the hospital. The message reiterated is that donation is a situated medical practice and that in the Hospital Clinic it is an integrated part of healthcare, regulated both by hospital and national protocols and legitimated by Spanish transplantation legislation (*No heroics, please I*). TCs' practices enact donors as hospital patients, in the case of pre-consent preservation measures this is illustrated with the TCs' justification that cannulation is an emergency intervention on a patient, here a donor/patient. The significance and perceived weight of the individual patient's autonomy and right of consent is limited to the stage of consent request, in which legal authorisation, or lack thereof, to organ extraction is established during TCs' interaction with the eligible donor's relatives present at the hospital. Although consent is a necessity of any process of assembling a donation, nevertheless consent is decentered; it is neither the start nor a sufficient condition for a donation to be assembled (*No heroics, please II*).

Some TCs have considered other possibilities that would allow incorporating an earlier consent request for organ preservation. It is claimed here that such speculative exercises, that aim to prioritise eligible donors/families' consent, serve the analysis of the practice greatly. In that by showing the destabilising effect different alternatives would have for the current protocols for action, it also makes visible the interdependencies and entanglements that constitute such DCD practice inside and outside the hospital. This examination focuses particularly on how such speculations enact the distribution of responsibilities along the process of assembling donations. In particular it highlights the separation, reinforced by TCs, between the initial stages of donation – detection, evaluation and maintenance – that represent the enabling conditions of possibility for donation, and the subsequent stage of consent request. It differentiates between the TCs' responsibilities, as specialised in-hospital procurement professionals who are concerned

with the trajectory of making the choice possible, and respectively the families' role, as legal providers of consent to extraction and informants about social history evaluation. Notably, the families' responsibilities are restricted to the consent request, or their response to the choice of donation presented to them.

Pre-consent cannulation is a necessary part of the making of the choice, it responds to the constraint that the donor/body, as a circulated organ-ism to be kept stable, poses to the TCs' procurement task. Additionally, some TCs justify it, mainly Angel and Sandra, as a respectful measure that responds to and grants families the right to provide their informed consent, by transferring or presuming the donor/person's preference about donation. However, it is important to note that consent for donation simultaneously enacts the donor/corpse along the donor/person, as previously explained, the consent request is presented as an end of life choice and it is embedded within funerary arrangements procedures in the hospital. For the case of organ preservation measures, the donor/corpse is also repeatedly foregrounded in TCs' accounts, in that it is specified that given that the intervention takes place after the official death diagnosis, then the donor/patient has already become a no-patient, hence a donor/corpse. The consequence, as TCs' express, is that the legal weight of patient's consent ceases to fully apply to a situation that involves an intervention to a corpse and not a living patient. The donor/corpse is also enacted to emphasise that even though the intervention does not represent any benefit for the donor/patient, neither does it inflict any harm as the eligible donor is by then officially declared dead.

Principally, the figure that is mostly foregrounded in TCs' responses is that of the recipients/patients, as they are ultimately the beneficiaries of their procurement practices. However, the tenor of the justification does not move into any saving lives triumphalism (*No heroics, please I*), rather, and as also indicated in the consent request section, the expression most widely used is that organ donation can help others, meaning patients on the transplant lists. For the organ procurement responsibilities that comprise the professional role of the TC encompass both those that are considered eligible donors/patients, deceased patients admitted to the hospital, and those that are considered eligible recipients/patients waiting for a transplant. Thus, it is advanced here that donation is procurement from healthcare practices – organs from donors/patients in end of life care – for healthcare purposes, recipients/patients waiting for an organ transplant. Or in other words, that the individual patient is decentered in TCs' practices. Donation might be an integrated healthcare practice in the Hospital Clinic, but it is not directed at

the individual patient figure, it is a procuring practice concerned with the circulation of viable organs across public health patients. Hence, it carries a set of inevitable frictions that become intensified when examining the controversy over pre-consent preservation intervention. The analysis of the practices and the TCs' accounts has addressed and identified some of these frictions, it has highlighted that the individual patient's rights of inviolability and consent are restricted to the act of organ extraction, this is the scope and limitations of the choice of donation relayed to families. As a consequence, in current practices scrutinised, organ-oriented interventions that take place in any preceding stages of the donation process are foreclosed to the families' capacity of intervention.

Several TCs have considered different possibilities that could alter the donation process trajectory so as to open up a space for eligible donors' families to consent, or refuse to, organ preservation measures. The different speculations have brought to the fore the destabilising consequences that the incorporation of such a choice would represent for the existing practices. These are namely related to the distribution of responsibilities, their responses have underlined the interdependencies between TCs and other healthcare professionals that sustain the development of the CatAsistol DCD program (*No heroics, please III*). Thus, when speculating on ways to offer families the possibility to decide about preservation intervention, some TCs have identified EMS professionals as those that should have the responsibility to inform families about such choice, as they are responsible for continuing mechanical CPR after all resuscitative efforts have proven unsuccessful. But a major impediment has been acknowledged: any discussion about donation – be it about initial preservation measures or final organ extraction – should take place after the official death diagnosis, which following Spanish legislation can only be carried out in the hospital, and preferably by specialised donation professionals, TCs who have the relevant expertise and experience to deal with bereaved families and make the consent request. In TCs' accounts, the major difficulty brought about by granting families the choice of preservation intervention would be that it could jeopardise the separation between healthcare and procurement that is enshrined in their practices. Specifically this is the decoupling of the death diagnosis, executed and communicated to families by healthcare professionals, and the subsequent donation request, made by TCs as procurement specialists. The issue is that if donation is discussed prior to the death diagnosis, it could induce families' mistrust that an interest in organ donation has prevailed over resuscitative efforts. And that if families were to be asked in the hospital by a TC, then their response would be expected immediately, this could add to their

emotional distress and could also represent a problem as it is not always the case that relatives are present in the hospital at that time.

To conclude, I would stress that the aforementioned analysis has advanced the practical specificities, professional entanglements and enabling interdependencies that constitute the current configuration of DCD practices in the Hospital Clinic, along its associated distribution of responsibilities. It has presented the relational elements – responsive actors and factors – and outlined the frictions that would have to be tinkered with when considering the possibilities of addressing consent shortcomings like those raised in the presented ethical literature. The contribution, and this will be expanded in the following chapter, is addressed to the Spanish sphere, where it opens up a space for discussion about the ethical concerns mentioned in Rodriguez-Arias et al (2010), reiterated in Rodriguez-Arias and Ortega-Deballon (2012), and denounced in Lora (2014). This is also relevant to the international sphere that considers the implementation of uncontrolled DCD programmes as a measure to increase deceased donation rates. In particular it challenges Bastami, Matthes et al's (2013) study, which suggested that to continue with DCD practices, as a legitimate source of transplantable organs, cannulation intervention should be removed as it raised many negative attitudes both from healthcare practitioners and the general public. As has been shown, such suggestion would be an ideal solution, and one eagerly endorsed by TCs themselves, nevertheless, in practice this is not a choice currently available. The practical constraints to preserve organs' viability for transplants – imposed by the requirement to keep the donor/body as a circulated organism – stand as an insurmountable impediment to the possibility of discontinuing cannulation intervention.

This stands as a clear example of this thesis' contribution to the current debates and problematisation around deceased donation practices. The main message conveyed is that donation is a situated medical practice, and as such it needs to be further explored from the inside. This research has advanced an in-depth mapping of particular donation practices and practitioners' responsibilities, showing the various and complex sociomaterial entanglements that undergird different processes of donation. It is claimed here that the latter represent a relevant addition, and a necessary one, to intervene in the political discussions that are too often divided into polarised approaches, either advancing a denunciatory critique (Fox 1993, Lora 2014, Bastami, Mathes et al 2013, Rodriguez-Arias and Ortega Deballon 2012) or responding with legitimised justifications, such as the ONT's appeal to enabling Spanish donation legislation (Dominguez-Gil et al. 2011). The main problem with such opposed views is that further dialogue is precluded and hence

the frictions in the practice not only continue but are also left unaddressed. This research project wishes to attest to the importance of engaging the practitioners that take part in these practices, who can provide crucial information on how to go about asking the relevant questions so that changes can be considered and donation practices can become more responsible. Donation is, and will remain, a thorny medical practice: its procuring nature, not based on the care of the individual patient, will continue to spur many legal, political and ethical tensions. In the previous chapters I have tried to present a scrutiny of the practices, entanglements and interdependencies that compound to a particular distribution of affordances and constraints for action. This is, or so I contend, the first step in order to open them up for discussion, to address the frictions and complexities, and to attend to both questions of rights, rates and collective responsible practices. This will be the trajectory of the next and final chapter.

# Chapter 8 – No Heroics, Please: Discussing Responsible Donation Practices

## 8.1 – Introduction

This chapter will unfold as a dialogue between this research – drawing on presented ethnographic accounts from the Hospital Clinic – and the previously reviewed literature on the topic of organ donation, the latter encompassing both social studies and policy work approaches. The five *No heroics, please* themes will structure the chapter and bring together this research's findings, theoretical underpinnings and methodological approach to identify its contribution to the existing corpus of work about donation.

The first three sections will concentrate on: *No heroics, please I* – the analysis of donation as an integrated hospital practice with frictions, *No heroics, please II* – the unravelling of the donor figure enacted simultaneously as patient, body, person and corpse, and *No heroics, please III* – the outline of the TC professional profile through a mapping of their responsibilities. The fourth section will cover *No heroics, please IV* – the investigation on theorising the donor/body and organs in medical practices, and thus it will trace the connections with the theoretical literature presented in chapter 3. After that, the final proposition, *No heroics, please V* will be presented to make explicit the policy implications that this research study entails, and the discussion will be articulated and related to the problem of organ shortage. The in-depth scrutiny of medical practices with high donation rates this thesis has offered will be mobilised to furnish the ongoing deliberations and contestations about ways to increase deceased donation rates in the UK. The discussion will highlight how the thesis contributes crucial and much-needed information about donation as a medical practice to the policy sphere.

## 8.2 – No Heroics, Please I: Embedded Donation as Procurement and Healthcare Practice

The investigation's theoretical underpinnings, drawing on an STS material semiotics approach to the empirical study of technoscientific practices – aligned with authors such as Haraway's (1988, 1991, 1997, 2008), Law (2002, 2004), Law and Mol (2008), Latour (1983,

1988, 2000, 2004, 2005), Mol (1999, 2002, 2008), Mol and Law (2002, 2004), Mol, Moser and Pols (2010) – have been mobilised in order to answer the primary research question: how is donation being done in the practice? The empirical chapters have provided a rich in-depth mapping of the trajectory of donation processes at the Hospital Clinic of Barcelona. Donation has been rendered as a situated medical practice, a complex sociomaterial process that requires the intervention of, and collaboration amongst, a wide variety of actors and factors both inside and outside the hospital site. Ethnographic observations paired with TCs' accounts of their practices and associated responsibilities for each stage of the process have been put together to narrate the specificities and contingencies that compound to the process of assembling donations. Crucially this has been enabled by the study's theoretic-methodological strategy of decentering both subjects and objects so as to broaden out the scope of the inquiry and focusing on processes. As a result this thesis offers an exhaustive examination of the practicalities and interdependencies of the making of the choice, or in other words, the conditions of possibility for donation to become an option in the first place. It has illustrated the argument that consent in practice is decentered, it does not start a donation process, and neither is it the only necessary factor to take into account. Instead, this study has foregrounded the complexity, interdependencies and indeterminacy that undergird the process of assembling donations. This has been additionally instantiated by showing the many ways, and temporalities throughout the different stages of the process, that a process can become disassembled. Chapter 5 in particular has demonstrated that consent is a necessary but not sufficient condition of donation by presenting accounts about the primary stages of detection and evaluation of eligible donors amongst hospital patients. It has been advanced that donation is an institutionalised practice thoroughly embedded in the existing healthcare configuration within the hospital. The latter has been exemplified through a scrutiny of donor detection mechanisms based on available hospital resources, such as computer databases, admission book, beeper system, as well as donation protocols that distribute donation responsibilities amongst HCPs in the key sites of A&E and ICUs. Moreover, it has elucidated on how these localised clinical practices are in turn inserted in, and thus enabled by, particular Catalan public health regulations and Spanish presumed consent legislation.

This thesis complements existing social science literature that has documented organ donation ethnographically (Fox and Swazey 1974, 1992, Hogle 1995, 1999, Lock 2002, Sharp 2006, Jensen 2011). It provides an up-to-date, unique study of clinical practices with distinctively high donation rates that encompass both organ and tissue donation after

brain death and cardiac death diagnoses, and a comprehensive delineation of the specialised TC figure profile. This information, as will be discussed in section 8.6 is of great value to the organ shortage problematisation internationally, but it does also offer a valuable contribution to the corpus of social science studies of donation. Principally because this research makes visible a different type of contemporary donation practices, it is important to note that available social studies have only covered brain death donation. Further, they have tended to have polarised concerns. One approach has provided highly charged critical accounts of the US context with high donation rates (Fox and Swazey 1974, 1992, Hogle 1995, Lock 2002, Sharp 2006). As explained in chapter 3, I contend that such critique of the commodification of the body in medical practice need to be understood in the US private healthcare setting and directed at the outside-hospital OPOs that are defined as operating under private company rationales. The other approach has researched sites with lower donation rates, such as Hogle (1999) in Germany, Lock (2002) in Japan, Lock and Crowley-Makota (2008) in Mexico, Jensen (2011), Hoeyer and Jensen (2011, 2012), Hoeyer, Jensen et al. (2015) in Denmark, Hadders and Alnaes (2013) in Norway, Paul, Avezaat et al. (2014) in the Netherlands, Cooper and Kierans (2015) in England. Unsurprisingly, the aforementioned works have focused on identifying the controversial nature of donation, which has been largely pinned down to brain death disputes, they have stressed the emotional difficulties it entails both for donors' families, recipients and medical practitioners involved. In contrast, this thesis documents highly routinized donation practices, and as stated above, it proceeds without employing the interpretative approach that characterises the aforementioned social studies of donation.

I argue that the social science literature reviewed in chapter 2 has approached the study of donation through actor-based narratives, meanings and personal experiences, and that in the majority of cases this has reinforced the divide between the families and the public's personal and emotional conceptualisations of donation versus the rational and depersonalised accounts from the medical practitioners (Fox and Swazey 1974, 1992, Hogle 1995, 1999, Lock 2002, Sharp 2006, Joralemon 1995, Siminoff et al. 2004, Siminoff and Chillag 1999, Sanner 2001, 2003, Sque and Payne 2007). This thesis' answer to the former works is that an exclusively discursive focus on personal meanings, reasons and experiences of patients and families about the choice of donation has deflected attention from the situated medical practices and the practitioners who primarily make the choice of donation a possibility for a very few. As a response to such exclusion this research contributes by opening up another way to articulate donation, to situate the specificities and practicalities of the medical practices that include many crucial but decentered

actors. The latter has been encapsulated in the *No heroics, please I* proposition that donation is at the Hospital Clinic an integrated practice, and that as such it is enacted as both procurement and healthcare, the empirical chapters have provided ample illustrative material to support the claim. In this respect this work has responded to Healy's (2006) and Manzano and Pawson's (2014) call to investigate, in their words, 'the social organisation of altruism', which is too often neglected when donation is reduced to a matter of individual choice. The research findings presented here advance a novel characterisation of donation as an embedded hospital practice concerned with the circulation of viable organs and tissue across patients, some of them being eligible donors and some of them being eligible recipients. The situated practices enact a collective of patients under public health provision, they decenter the individual patient and encompass both donors/patients and recipients/patients. Chapter 7 in particular has depicted donation as an integrated healthcare practice whilst also identifying the recurring tensions that emerge from its procuring nature. The discussion about the consent request, or the lack thereof for the case of organ preservation intervention, has further located donation practices within the medical institution setting, and it has restated that both the making of the choice and the setting of the choice need to be understood as emerging and conditioned by the hospital context. Correspondingly, this study has suggested that the embedded donor/patient figure needs to be unpacked with a close scrutiny of the multiple enactments in practice and this is the subject matter of the following section.

### **8.3 – No Heroics, Please II: The Donor/Patient Configuration**

Previous empirical chapters have traced the particular configuration of different situated and relational enactments of donors that take place simultaneously throughout the process of assembling donations; it includes the donor/patient, the donor/body, the donor/person and the donor/corpse. The core figure that runs through all the stages of the donation process is the donor/patient and several exemplifications have been identified to reinforce the argument that donation is a medical practice that happens at the hospital and hence it follows that donors are also patients, before, during and after a donation process is assembled or disassembled. This is a novel rendering of donors that contributes to the existing social studies about organ donation. There are several points of dis/connection with other characterisations that have grappled with the slipperiness of the term donor, I suggest starting the discussion by revisiting a crucial question that the influential study of Younger, Allen et al. posed to readers over thirty years ago:

“And what should we call these dead patients whose organs and organ systems continue to function? They are hardly “corpses” in the traditional sense. Although they are “dead patients,” they do not resemble our other dead patients. The expression “brain-dead” is accurate but seems to avoid the crucial issues. Most would agree that these donors are no longer “persons”. When the patient is admitted to the operating room, the recorded diagnosis is “beating-heart cadaver” – a term that is offensive to many people. Gaylin coined the term “neomort” 10 years ago, but it has not become popular. Perhaps we will only be able to give these artificially maintained organ donors an appropriate name when we ourselves have made the necessary emotional and cultural adjustments” (1985, 323)

This research provides a simple answer: there is no need to find another name for donors rather it is the very term donor that first needs to be unpacked in particular settings. And when doing that then all the concepts that appear in the quote become suitable. There is no need to choose one of the terms or to make up a new one because the concept donor already encapsulates them all; donors are indeed dead patients, bodies, persons and corpses simultaneously. The empirical accounts I have provided, emerge from and hence are bounded to the particular setting of the Hospital Clinic, the type of practices that include DBD, DCD and tissue donation, and the specific responsibilities of TCs as procurement specialists. The main divergence with available literature is that this study has not been concerned with documenting the problematic transition from patient to donor, either through the ambivalences of the ‘living cadaver’ figure (Fox and Swazey 1974, 1992; Hogle 1995, 1999; Lock 2002, Sharp 2006), or through the medical professionals’ experiences of the troubling shift from caring for a patient to maintaining an organ donor (Youngner, Allen et al. 1985, Hadders and Alnaes 2013, Hoeyer and Jensen 2011, 2012, Hoeyer, Jensen et al. 2015, Paul, Avezaat et al. 2014, Cooper and Kierans 2015). Ultimately both these approaches render the term patient and donor as mutually exclusive categories. Moreover they are premised and further reify the anthropomorphic subject or object dualism, for it is the reductionist transition from the centered person to thing, or ends to means, that articulates their accounts of donation and donors. By contrast, this research has studied empirically how the terms donor and patient overlap and become mutually inclusive and exclusive in the situated donation practices that enact them. Chapter 5 in particular has traced the embedded donor/patient figure through a detailed analysis of the trajectory that goes from detected potential donor/patient, which becomes inserted through various processes of evaluation of viability, to eligible donor/patient if not ruled out in the process or the donation having been disassembled for several reasons, such as lack of forensic consent or absence of relatives at the hospital. The TCs’ practices and development of hospital protocols attest to the institutionalised donor/patient figure,

the analysis has also highlighted that the donor/patient is decentered and that the different enactments are also conditioned by another set of patients the recipients/patients whose safety is one of the key responsibilities of TCs when assembling a donation process.

Chapter 6 has concentrated on the responsive donor/body as enacted during maintenance and organ extraction stages; section 8.5 will extensively cover this topic. Finally, chapter 7 has situated donation as an end of life choice, the analysis of the consent request with eligible donors' families has foregrounded that donors/patients are also relational donors/persons, whose individual's preferences are to be transferred or presumed by the relatives that are present at the hospital when approached by TCs. This study makes no claims about whether families experience the choice of donation like another end of life choice to be decided upon at the hospital, or on how this particular enactment of donation as an option might come to influence, or not, their group decision to consent or to refuse. Nevertheless I argue that the specificities and practicalities of the type of choice donation is made to be, and the associated enactments of donors during the TCs interaction with bereaved families are to be understood and situated within the hospital setting, through the donation practices that make donation a possibility in the first place. In doing that this study has maintained that donors are also enacted as corpses, whose burial or cremation needs to be arranged by their families at the hospital shortly after the communication of their deaths, and that they are like any other deceased patient under hospital custodianship up until they are handed over to the funerary company. This is the particular configuration of institutional affordances and limitations that characterise the site, timings and intervening actors' distributed responsibilities that compound to the choice of donation in the Hospital Clinic.

Naturally, donors will be enacted differently when mapping other national settings, with particular hospital practices, and medical professionals' associated responsibilities. The donor/corpse mapped here is not enshrined in aesthetic practices that choreograph a beautiful and meaningful death for the families as in Jensen's accounts from Denmark (2011). In the Hospital Clinic, as the *No heroics, please II* proposition indicated, donors are no different from other deceased patients at the hospital, their deaths are both ordinary and extraordinary regardless of donation.

Chapter 7 has also emphasised the crucial role of families at the hospital, in this respects this work is aligned with formerly reviewed social studies of donation, such as Lock (2002),

Lock and Crowley-Makota (2008), Sharp (2006), Jensen (2011), Sque et al. (2008), Hoeyer, Jensen et al (2015). Families of donors/patients in the Hospital Clinic are not in control, unlike the Japanese families that directly participate in the death processes at the hospital (Lock 2002). Neither are they allowed to stand by the bedside of their deceased relatives while nurses ‘orchestrate an exceptional death’ as in Jensen’s accounts of brain death donation in Denmark (2011), or similarly in Sque et al. in the UK (2008). I would not state, like Sharp (2006), that donors’ families are ‘the unsung heroes of donation’, this account of donation heralds no heroes and persistently repeats the claim *No heroics, please* so as to make space for a different account of donation to emerge. Yet, in this version of decentered processes of assembling donations in the hospital, the intervention of families is also claimed as indispensable for deceased donation. And I would like to point out that even though this research did not include families as participants, this does not mean that their difficulties and suffering are not acknowledged. Donation has become normalised in the Hospital Clinic, and the consent request is now a requirement for every case of eligible donation, TCs make the request in a responsive manner to the bereaved families’ emotional distress.

The findings are similar to Caballero and Manzano’s (2012) study about a ‘family interview guide’ in another hospital in Barcelona, that assert that the donation request has to be done in a brief and clear manner, although I do not share their claim that “death is hard, not donation” (165). The ethnographic accounts presented in chapter 7 have shown that TCs’ caring approach to bereaved families attests to the fact that death is indeed hard but so is donation. The trouble is that there is no way to disentangle the suffering that results from both overlapping processes. Likewise I would stress that a situation of high consent rates, over 80% of the cases, should not be associated with an absence of complications for the families involved.

#### **8.4 – No Heroics, Please III: The TCs Responsibilities**

The professional figure of the TC has been studied by tracing the scope and limitations of their distributed responsibilities throughout the process of assembling a donation. As explained in section 8.2 the focus of the analysis has not been on the individual actors’ perspectives, rather the ethnographic observations and the TCs’ accounts of their activities have been put together to map the practicalities and contingencies of the donation process. TCs coordinate the whole process but they are nevertheless decentered in the practice, this is the main message that has been reiterated through the *No heroics, please III* point. TCs do not work alone, their work is deeply embedded, enabled and

conditioned by the present hospital's healthcare activities, which are in turn inscribed within a particular regulatory landscape defined by presumed consent legislation and national public health policies.

The implications and contribution this work offers to current discussions on finding ways to increase donation rates will be dealt with in section 8.6. The examination advanced here will further define how this thesis situates itself amongst contemporary literature on organ donation. This study contributes to the available corpus of work that has scrutinised the work sphere of donation, that situates it in the hospital site and that highlights the complexities and practicalities that donation engenders to the healthcare professionals involved (Hadders and Alnaes 2013, Jensen 2011, Hoeyer and Jensen 2011, 2012, Hoeyer, Jensen et al. 2015, Paul, Avezaat, et al. 2014, Cooper and Kierans 2015). On a par with Hoeyer and Jensen (2012), this work also wishes to move away from denunciatory critique that casts medical professionals as 'mere instruments of procurement' and that condemns the spread of 'increasingly aggressive organ harvesting' (Fox and Swazey 1974, 1992, Sharp 2006, Lock 2002 and Scheper-Hughes 2001). Hoeyer and Jensen (2012) do so by showing that practitioners, in their studies mostly ICU nurses, are respectful and caring towards donors and their families, and that their priorities lay with the needs of donors' families rather than in increasing the supply of organs for transplantation. In their accounts the moral prerogative experienced by medical professionals is dealt with the mechanism of 'self-imposed deliberate ignorance', it separates their healthcare work with patients from the procurement of organs for transplants, it thus renders transplants as an abstract good (Hoeyer, Jensen et al 2015). In contrast this study, based on a different national context, type of practices, professionals and donation rates, diverges from their practical ethics approach as it only focuses on individual practitioners' discursive strategies and choices. Instead I have mapped collective sociomaterial practices with decentered practitioners.

Moreover, the restated premise is that TCs' work is contingent and responds to a set of affordances and limitations for action. They are not free subjects of choice whose actions can be modulated according to different moral reasoning mechanisms.

Ultimately, this thesis' proposal to think with responsibilities has situated the TCs' actions and enabled an in-depth scrutiny of donation as both healthcare and procurement, highlighting both their responsibilities towards donors/patients and recipients/patients. Thus, I claim it complements Hoeyer and Jensen's (2011, 2012), and Hoeyer, Jensen et al.'s (2015) studies with healthcare professionals that bracket transplantation and recipients, and it has demonstrated that a responsibility towards procuring organs for

transplantation does not preclude caring and responsible practices towards donors and their families.

The empirical chapters' examination of TCs' responsibilities have also stressed that the latter are executed within a certain configuration of availabilities and limitations for action. The interrelated contingencies and indeterminacies of every donation process being assembled entail a great deal of constraints to TCs' procurement task. This point has been illustrated most poignantly by the several exemplifications of disassembled donation processes, such as during the initial stage of evaluation when a contraindication is identified, or when the donor/body does not respond to maintenance intervention, or when a family refuses to the TCs' request for consent to extraction.

This research project provides an answer to Paul, Avezaat et al.'s (2014) call for more information on the type of work and ambivalences donation practices entail for health professionals. However, I would not endorse their contention that instead of addressing the problem of organ shortage, more needs to be known about the difficulties and ambivalences of donation in practice. As this thesis has shown, producing work that is committed to the question of how to increase donation rates is not incompatible with a meticulous scrutiny of the enduring frictions in clinical practice, as well as to a mapping of routinized practices integrated within healthcare. It is important to note that Paul, Avezaat et al.'s (2014) work emerges from a different situation altogether, the Netherlands' lower donation rates and the policy efforts to increase them through national protocols. Their objective is to show the discrepancies between protocols and medical practice, to highlight the difficulties that healthcare professionals experience under the pressure of increasing organ procurement rates. The same concern has also been voiced by Hadders and Alnaes' (2013) work on contested donation practices in ICUs in Norway, and Cooper and Kierans' (2015) ethnographic work in an English hospital. Both countries also have lower donation rates, and the participants of the studies are ICU nurses in charge of patient care. In comparison, this thesis adds that in the case of TCs, protocols are a mechanism to help distribute responsibilities towards donation across hospital professionals, namely ICU, A&E and EMS practitioners. TCs themselves suggest and draft new protocols in accordance with the hospital directive and OCATT. It is not a case of standard national guidelines being imposed, such as those of the Spanish model, but rather a hospital-based design and implementation of protocols. Further, the type and weight of protocols apply differently at different stages of the process; TCs strictly follow Spanish-wide protocols of donor eligibility criteria but at the same time dispense with Spanish model strategies of refusal reversal during the consent request with families. To

sum up, TCs are neither free agents of moral choice nor are they subjected to protocols and under pressure to increase rates of organ donation. Their scope and limitations for action is afforded and constrained within the contingencies of the process of assembling donations, and the particular variations that each case will pose to them and demand an adequate response.

#### **8.4.1 – Further Work with the TC team: Discussing Pre-Consent Intervention and the Family’s Role**

The analytical approach that undergirds this thesis has been put to use in chapter 7 so as to open up a discussion on the problematic about organ preservation intervention prior to ascertaining families’ consent to donation. This research method to trace TCs’ responsibilities along the process of assembling a donation, and the different enactments of the donor/patient figure has been mobilised to address the Spanish bioethicists’ concerns (Rodriguez-Arias et al 2010, Rodriguez-Arias and Ortega-Deballon 2012, Lora 2014), and other literature on the topic (Bastami, Matthes et al 2013). As explained in chapter 7, I contend that the analysis offers a valuable addition to the discussions about DCD practices that are gathering growing international attention as a key alternative to increase donation rates at times of decreased brain death cases. The Hospital Clinic is a unique site given that it has the only DCD programme in Catalonia, and it holds the second highest rates of this type of donation in the Spanish territory (Matesanz et al.). The hospital also holds a yearly international workshop on DCD donors<sup>68</sup> addressed to medical teams that wish to learn how to implement and develop a DCD programme. A delegation from the UK took part in this workshop prior to designing the current DCD pilot at Edinburgh (Scottish Government 2013).

This research provides timely information about the practicalities and contingencies that intervene in the practice of DCD, and as expressed in chapter 7, this is a novel contribution as available studies within the social sciences, mostly bioethics, have largely excluded those. Furthermore, it offers a unique take on starting up a dialogue with key practitioners involved, and it accounts for their collective practices and personal approaches but from a decentered perspective, unlike survey-based available literature that only covers individual professionals’ attitudes (Bastami, Matthes et al 2013, Rodriguez-Arias et al. (2013). Thus, I would contend that the value of this research is that it

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<sup>68</sup> Hospital Clinic International DCD Workshop: ([http://www.aulaclinic.com/media/upload/pdf/trip\\_dcd\\_donors\\_2014\\_v10\\_editora\\_3\\_227\\_1.pdf](http://www.aulaclinic.com/media/upload/pdf/trip_dcd_donors_2014_v10_editora_3_227_1.pdf)).

highlights the importance of TCs for DCD practices whilst at the same time it situates them within larger sociomaterial processes. This is crucial because after all if the practices need to be further discussed and changes implemented, and I expect that this will be a matter of increased consideration both in Spain and in the UK in the following years, then the primary step is to produce knowledge that maps the contingencies of the practices, the type of professional interdependencies, and the legal and political frameworks that make it possible.

The analysis presented in chapter 7 has stressed that TCs are not free to change their current practices and easily incorporate families' consent to organ preservation. It is not all a matter of ethics and making sure the right principles are guiding the practice, as in Fox's (1993) denunciation of practitioners' lack of ethical integrity and unwillingness to accept moral limits. In practice, there are other limits that TCs simply have to accept and work around, such as the constraints imposed, in the first place, by the donor/body and the requirements to keep the circulatory flow so as to avoid the organs' ischemic deterioration. This is important to foreground, as studies like Bastami, Matthes et al (2013) also seem to imply that medical practices could and should easily accommodate the ethical demands for integrity as for patients and families' rights. This research argues that there is no easy solution and any changes will demand active tinkering with various practical constraints, such as those expressed by TCs' speculations of possible alternatives. As explained in chapter 3 and 7, this study does not wish to subscribe to the polarised approaches to either criticise or justify DCD; rather its purchase rests on addressing the difficulties in practice. Current legislation, protocols and donor/body justification are all sound reasons to legitimise the practices, however, and following Haraway's statement (2008), reasons are necessary but not sufficient to close the case, as an appeal to reasons "does not end the question; it opens it up" (92). Hence, it is my intention that upon thesis examination, and when presenting the PhD work to the TC team, I will press on the need to continue the conversation and highlight that the question of the family's consent cannot be restricted to the bioethical sphere as it is also the TCs' responsibility. I would like to propose to the TC team that we arrange a focused discussion in the hospital with the presence of A&E doctors in charge of cardiac death determination, EMS director and some ambulance staff. I will offer to arrange and coordinate the event, the premise will be to assess how DCD could become more responsible towards donors' families. I would suggest considering two possible scenarios: 1) the situation in France, also under presumed consent, that changed the protocols in 2011 to incorporate families' consent over preservation (Thuong 2011). This would imply that the request would already be initiated during transfer to the hospital by EMS staff before

official death diagnosis; 2) A change in death communication timing, the A&E doctor in the hospital could inform families about the death diagnosis immediately after confirmation, a TC could then request consent for organ preservation so as to enable prospective choice about donation. Both alternatives present some difficulties, as already exposed in chapter 7, some concern the work of TCs, other healthcare professionals, the emotional experience of families and the rates of organs procured. I do not suggest that they could be easily implemented, but first of all they need to be explored, jointly, outside a deontological framework that opposes the rights of donors to the rights of recipients.

## **8.5 – No Heroics, Please IV: Theorising the Situated and Relational Donor/Body**

The hospital accounts of donors/bodies during maintenance in chapter 6 have addressed the research question that purported a speculative and pragmatic investigation on the intervention of bodies within the medical practices of assembling donation processes. The empirical illustrations have foregrounded that bodies in donation practices are indeed active and generative entities and that as such they need to be encompassed in the mapping of donation as a situated hospital practice. Principally, this has been achieved by tracing the TCs' responsibilities during the stage of donor maintenance, and by focusing on how throughout the practices the donor/body participates and places a shifting set of affordances and constraints to TCs' efforts to keep assembling the donation process. The latter refers to the struggle to 'avoid losing the donor' that TCs, with the collaboration of a host of other medical practitioners and a vast array of technoscientific means, face for each case of donation being assembled. The donor/body after death diagnosis presents high levels of instability that if not adjusted can lead to a disassembled donation, hence, it represents a matter of great concern to TCs' actions. The analysis has suggested that an answer to the guiding question 'how are donors *qua* bodies being done in these practices?' can be extracted from an in-depth examination of the routines and challenges of donor maintenance activities, that is, that the body is being enacted and acting as a circulated organ-ism. To do this the theoretical work of Mol (1999, 2002), Mol and Law (2004, 2008) has been mobilised through the notion of enactment, in particular considering the enacted and acting body embedded within specific hospital practices. As explained in chapter 3, thinking with enacted/acting actors helps to circumvent the limitations of the polarised and hierarchical binary that separates acting subjects from passive objects (Haraway 1991, 2008, Mol 2002, Law 2002, Mol and Law 2002, Law and Mol 2008, Latour

2000, 2004). This research has avoided an approach that relegates the body to mute externality without agency. The premise applied here has been to focus on distributed action and entangled actors, the unfolding processes and the ways in which different actors intervene and hence enable or preclude certain actions. This process-based account has attempted to decenter the actor, any actors involved, and to highlight that agency is not a property of the individual entity but rather it is rendered through processes of situated, relational and underdetermined action. The addition of Haraway's (2008) notion of response-ability, or the ability to respond, has drawn attention to interdependencies in action, entities that respond and enable responses from and through each other in interaction. It has also assisted in decentering the responsive donor/body as actor, and to shift the attention to joint actions that encompass the unstable donor/body as contingent and constrained by the different maintenance technologies, and the multiple corporeal death processes that unfold and mark the trajectory of the disassembling body.

Ultimately, the donor/body enacted in donation practices is a shifting and fragile assemblage of functions that TCs struggle to maintain as a more or less stable whole in order to keep organs circulated and functioning. The analysis has traced the associations with Haraway's (1991) problematisation of individuality and organic wholeness, and Mol's elucidation that the body's wholeness is accomplished in practice; it is neither singular nor an extrinsic and bounded coherent whole (2002). This thesis contributes to the aforementioned literature on situated and relational bodies as heterogeneous assemblages being done in practice, and it does so by making visible the end of the accomplished wholeness, the body being undone or gradually losing its oneness. The disassembling ischemic organism invaded by unbridled corporeal death processes signals the dis-integration, the de-composition of the constitutive boundaries of individuality, or as Haraway put it when referring to the immunological body, a "strategic assemblage called self" (1991, 212).

### **8.5.1 – The Unaddressed Question about Death Diagnosis and Suggested Future Research Direction**

The 'living cadaver' figure has been heavily deployed in organ donation studies by many authors, Lock (2002) being the most prominent one, to bring to the fore the difficulties brain death diagnosis effected in practice. It was intertwined with the critique of commodification of bodies in medical practice that enabled the transition from patient with human rights to corpse with downgraded legal status (Lock 2002). Addressing this

problem has been a shared pursuit in medical ethnography and the stress has been on documenting the ambivalences and doubts that the hybrid entity of “a-dead-person-in-a-living-body” entailed to different actors (Lock 141, 2004). Special attention has been given to troubling signs of life or “disconcerting reactions not considered to be characteristic of dead bodies” (Sharp 2006, 88) in brain-dead patients connected to a ventilator. And to the contradiction between brain-dead bodies and living organs, such as in Hogle: “But the organic material in the rest of the body retains its ability to function: to “live”, body parts can die at different rates” (1995, 210). I do not dispute that their works addressed the complex situation of brain death appropriately, and this thesis does not intend to offer an alternative, rather my questions, methods and case study were altogether different. The only message I would have for them is a note of caution, extreme caution when choosing our semantics to give an account of medical practices to do with death diagnosis and donation. Death is a phenomenon of life; hence life and death are not two separate domains when one attends to the corporeal death processes as this research has done. Death is indeed a process, as Lock taught us, but we only die once, though it takes a while. I would admit that we are simply poorly equipped, intellectually and linguistically, to deal with such conundrum. How do we talk about human life and death as mutually inclusive processes? How do we talk about the process of dying when this already denotes that there is still a living person entitled to such action? The semantics of human life and death are thoroughly inscribed within notions of personhood, individuality and anthropomorphic agency, they cannot be easily disentangled from the centered human actor endowed with agency and the body relegated to mute externality. Talking about “living bodies” and “living body parts” seems to induce metonymic associations that strengthen the hold of the person, the sovereign subject/mind that reigns over the subservient body/matter. I have tried to evade this linguistic trap so that I could focus on giving an account of responsive donors/bodies after death diagnosis, to investigate how death as a process unfolds in different types of donors under different maintenances. To do that I have shifted the semantic grounds to leave behind the misleading imposition of the life or death dualism and the subject or object hierarchy, thus, this account talks about disassembling bodies, not dying bodies, and functioning organs, not living organs, with a focus on decentered actors and entangled processes, as in corporeal death processes. Focusing on the technoscientific maintenance configurations in which the donor/body is enacted as a fragile assemblage of functions is connected with Youngner, Allen et al.s’ (1985) suggestion to inform healthcare practitioners about the finality of the brain death diagnosis, the authors asserted that in those situations the fact that “tissues and other organs are merely functioning is essentially different from a living human being” (323).

And I would reiterate that just as in 1985 the authors grappled with the complexities of maintained donors, as similar but yet different to other deceased patients, the friction still endures and encompasses the debates about cardiac death diagnosis. Neurological criteria have now become the gold standard for death diagnosis and the bioethical contention has moved to the disputed legitimacy of circulatory criteria to determine cardiac death diagnosis in organ donors. This is particularly because abdominal organs' recirculation is said to induce cerebral reperfusion, hence, authors such as Rodriguez-Arias et al. (2011); Marquis (2010) have argued that the levels of neurological activity would falsify the previous death determination. This research has not addressed such questions, but it advances that more needs to be known about the scientific and technological affordances to diagnose death by different criteria, and how the different donor maintenance configurations become entangled and complicate the procedures.

I suggest that an STS investigation would be appropriate to complement the normativity of the bioethical approach that is mostly concerned with signposting the shortcomings of "any attempt to meet organ shortage by way of redefining death" (Rodriguez-Arias 2013, 75). The inquiry would insert itself inside the scientific knowledge-production processes and practices that periodically adapt death diagnosis techniques and protocols. The analytical framework developed in this thesis, response-able bodies and corporeal death processes contingent to maintenance technologies, could be further mobilised, adapted and improved to interrogate how different technoscientific configurations shape and constrain the type of absence of signs of life that is measured, what can be measured and rendered visible and what is excluded? Which functions are considered essential to human life and thus included as diagnostic criteria? And which other functions are excluded and considered residual activity? It seems to me that such research could pose timely questions about the human body in life and death, being done and undone, assembling and disassembling, inescapably inscribed within our historical coordinates and embedded in a particular and forever shifting technoscientific configuration of possibilities and impossibilities, of certainties and uncertainties. The figure of the responsive body as a fragile assemblage of functions could pave the way out of dichotomised approaches that render the 'seat of life' as either ascribed to the brain or the heart. It would strengthen the interdependence that sustains the circulated organism as a more or less stable whole, to move away from considering discrete organic parts as hierarchical centres, and to encompass decentered processes and interrelated functionalities.

## 8.5.2 – Circulating Organs and Collective Bodies

The aforementioned rendering of bodies as assemblages of interdependent functions is indeed that which is persistently foregrounded in the hospital practices of deceased donation. TCs' responsibilities are directed at maintaining such shifting and fragile assemblage of functions as a more or less stable whole, so that organs will be kept circulated and performing their interdependent bodily functions. The figure of the circulated organ-ism is intended to emphasise that even though the objective of the practices is the procurement of particular organs, the donor/body as a responsive entity also needs a great deal of maintenance work so that it can be kept further assembled against the instability entailed by corporeal death processes. The empirical accounts have shown that organs are, as well as bodies, relationally responsive entities; their processes of materialisation are inscribed and intervene in the particular technoscientific configuration of procurement practices. Organs that are both enacted and acting, simultaneously response-enabled and responding-with, is the novel take that this research adds to previous accounts of organs defined as medical objects, such as in Hogle's early work (1995, 1996) that mapped the technoscientific processes that, in her words, transformed body parts into therapeutic tools, an argument also continued by Lock (2002b). The focus of their works was on organs as body parts, and the processes that they were submitted to in order to turn them into universal products or 'alienable commodities'. The hospital accounts presented here have shifted the focus away from "production of human organs" (Hogle 1995, 208) as therapeutic tools, and instead the stress is on functioning organs through processes of evaluation of viability for transplantation. In the Hospital Clinic, the TCs' practices are directed at ruling out those organs that might transfer infectious diseases to the recipients, or that would not function properly and exacerbate the difficulties of the transplant. Provided that an organ's risk of disease transfer and functionality are acceptable, and such decisions already respond to the changing characteristics of the prospective recipients/patients, then they can be circulated across collective bodies. The individualised body is decentered in donation practices and it is the collective body that is enacted. It is not simply the case that individualised organs need to be alienated and made universal, and hence Hogle's (1996) and Lock's (2002, 2002b) references to production of mechanised parts, but that these organs can continue to function as long as they are kept circulated, and hence active, in anybody, be it the donor/body, recipient/body or even the perfusion machine as body's simulacra. The singular, bounded, extrinsic and internally coherent body is thoroughly disrupted in the hospital practices of procuring viable organs to be circulated across collective bodies. The

boundaries of individuality and personhood that defined the atomised conceptualisations of the body/self – such as those reified in the gift rhetoric (Fox and Swazey 1974, 1992, Hogle 1999, Lock 2002, Sharp 2006, Jensen 2010, 2011, Sanner 2001, 2003) deployed through personal narratives and meanings about donation, donors and organs – are not foregrounded in this account of donation as a situated medical practice. The individual body boundary, just like the individual patient figure, becomes decentered and encompassed as effect and intervention throughout the process of assembling donations. The situated and relational body being done in the Hospital Clinic, and mapped by following the TCs' responsibilities, is a collected fragile assemblage of functions, a circulated organ-ism, and a collective body that accentuates the shared commonality amongst mortal bodies through the circulation of organs.

### **8.5.3 – No Heroics, Please: Agency as Collective Action and Decentered Actors**

This thesis has given an in-depth account of the hospital practices that make such circulation of organs a possibility; it has identified the different response-able entities that intervene, and their interrelationships, by following the different stages of assembling donation processes in the Hospital Clinic. This has been achieved by employing a material semiotics theoretical approach, drawing on the work of Haraway, Latour, Law and Mol, so as to provide a mapping of donation as a situated and relational practice with a host of differently embedded and decentered actors. The question of agency has been approached through the relational premise, advanced jointly by the aforementioned authors, that posits that an actor never acts alone, and hence renders agency a matter of distributed action. The empirical investigation has focused on entangled processes; the objective has been decentering the intentional subject. For in donation practices there are no heroes, no autonomous actors or agents of free choice, the centered individual that underpins dominant humanist and modernist notions, becomes in these hospital practices decentered, the sovereign subject dethroned. Similarly, objects are not simply brute externality devoid of capacity to intervene; in this particular case donors and organs are not the subservient docile objects that can be manipulated by all-powerful subjects.

In line with Abrahamsson et al. (2014) this investigation seeks to ascertain that when pondering about agency and materiality, perhaps the preliminary question to pose is how appropriate are terms like agency and actors, as they put it, “maybe it is not wise to spread liberal dreams about ‘acting’, infused as they are with civic notions of freedom and choice, from humanity to the rest of the world” (14). Acting as collective accomplishment is thus

better captured with 'modes of doing' that do not presuppose, as Haraway defined it, "an ultimate self untied at last from all dependency, a man in space" (1991, 151). This research has rehearsed ways of accounting for collective action and entangled actors throughout the empirical mapping of processes of assembling donations, Haraway's (2008) notion of response-ability has been mobilised along with Mol and Law's (2004, 2008) actor-enacted approach, to trace the shifting distribution of response-abilities and the different ways in which different actors intervene, from donors, bodies and organs to TCs, families, and recipients, and how their responses are enabled and they in turn open up different possibilities for action, the unfolding of which remain at all times indeterminate. The latter statement has been incorporated in the ethnographic accounts presented, the stress has been put on both the scope and limitations for action of particular actors, in particular the TCs. Overall, instances of the many ways that a donation process can become disassembled have reiteratively illustrated the point. The purpose this has served has been to endow this research project with the necessary political relevance to intervene in current problems of organ shortage. The message is clear; it pulsates underneath the whole thesis and it has been resurfaced, expanded and illustrated repeatedly, it could be simply put like this, deceased donation is a situated medical practice, it is not simply a matter of individual choice. Donation as a choice first needs to be made, and this can only happen in the hospital, and one with a donation programme. This research has shown how this choice is being made, in practice, by many people, things and politics, and it highlights that situated choices come within a given distribution of practical affordances and constraints for action. This is a crucial lesson that has been extracted from the hospital, by following TCs' practices, and so I will contend below, one that has to travel and contribute to joint discussions that are already taking place and that pose the question of how to make donation a more responsible practice.

## **8.6 – No Heroics, Please V: Implications for the Organ Shortage Problem in the UK and Scotland**

The final section of the thesis will deal with the issue of organ donation rates and the organ shortage problem in the UK in general, and particularly about Scotland's policy proposal to shift to presumed consent legislation in order to increase national deceased donation rates (Scottish Parliament 2016). This research contributes an in-depth examination of donation as a situated medical practice, and it brings to the current debates much-needed practical information from one Catalan hospital with particularly high donation rates. It was explained in chapter 2, that the 'success of the Spanish model'

is frequently referred to when trying to ascertain the best way to increase national donation rates. Some appeal to it as evidence that presumed consent legislation does indeed lead to an increase in donation rates (English 2007, Rhithalia et al. 2009, Scottish Parliament 2016) whilst others, those who wish to refute the aforementioned claims, highlight that the policy alone would not effect the changes, as the influential factors are to be found at the level of organisation and infrastructure of the donation and transplantation national coordination system (Wright 2007, Quigley et al. 2008, Murphy et al. 2010, Scottish Parliament 2016). Additionally, both the European Union (Watson 2010) and the World Health Organization (WHO 2011) have suggested that adapting the Spanish system of organ procurement – characterised by its national coordination system that regulates donation activities at the national, regional and hospital level, and by the appointment of specialised TCs in every hospital – would be an efficient strategy in order to enable different countries to work towards achieving national self-sufficiency in terms of organ availability for transplantation (Delmonico et al. 2011).

This investigation was designed as a response to the lack of practical information about the workings of presumed consent in practice, and the profile of the TC in the hospital (Rhithalia et al., 2009), thus a research site was chosen with particularly high donation rates, the Hospital Clinic in Barcelona. Throughout the empirical chapters 5, 6, and 7, the analysis of TCs' practices and responsibilities has highlighted, when relevant, how their actions are, or not, directed at procuring high rates of organs for transplants, the next section will provide a brief summary of the situation in the Hospital Clinic prior to considering the proposed solution to the problem of low donation rates in Scotland. As previously explained, this thesis' intervention is not about offering a solution to the problem of the organ shortage, rather it critically examines how the problem is defined through the offered solutions, and it sharpens the questions that are currently being addressed, whilst bringing attention to other questions that albeit excluded from current deliberations, yet are of significant importance to the ongoing dialogue about donation rates and responsible practices. Thus, prospective sections will analyse how the solution offered, a shift to opt-out policy, define the problem in particular ways, a consent-centered approach to donation, and it will identify what elements are being excluded and left out of the considerations, namely the medical practices that enable donation as a choice, and the families of eligible donors that are consulted about donation at the hospital.

### **8.6.1 – The TC team and the Hospital Clinic’s High Donation Rates**

The Hospital Clinic in Barcelona does not represent the official version of the Spanish model, in that the protocols for donation, practices and distribution of responsibilities are unique to the particular hospital. Further, the TCs are full-time in-hospital procurement specialists, as opposed to ICU healthcare personnel who develop the function of TCs part-time. The mapping of the practices concerns only the Hospital Clinic, but it nevertheless advances some significant information to be transposed to current debates that seek in the Spanish model evidence of successful measures to increase donation rates. Principally, it exemplifies that presumed consent legislation, albeit part of the enabling regulatory landscape of the practices, does not have a direct translation into increased donation rates. The research findings, firstly, corroborate the claim that high donation rates are associated with institutional factors, national coordination, and in particular the work of specialized TCs in the hospital (Healy 2006, Wright 2007, Quigley et al. 2008, Murphy et al. 2010, Manzano and Pawson 2014). And secondly, they provide the practicalities and specificities of organ procurement mechanisms and types of organs procured.

The empirical chapters have followed the different stages of the donation trajectory, this has encompassed organ and tissue donation after brain death and circulatory death diagnosis. It has been stated that donation is an integrated healthcare practice within the hospital, thus TCs’ work is embedded and enabled by the hospital’s donation programme, associated protocols and available material and human resources. TCs’ efforts are grounded on the objective to detect the totality of potential donors amongst the deceased patients in the hospital, and to evaluate and rule out any non-eligible cases. Donor detection, evaluation and maintenance represent the primary conditions of possibility to assemble a donation process; hence, hospital mechanisms and protocols have been implemented to ensure the collaboration of the relevant practitioners.

TCs’ are responsible for asking the families of eligible donors for consent; their objective is to obtain a resolute decision by the family as a group, and even though they will attempt to obtain consent from families that remain undecided, they do not follow Spanish model protocols for consent and refusal reversal strategies (Gomez, 2008). The stage of consent is decentered within the donation process, it is neither the start of the process nor the only factor that intervenes, nevertheless consent is an essential legal requirement to proceed to the extraction stage. Additionally, families provide the donors’ social history information, which is part of a comprehensive evaluation that includes medical history, clinical tests, physical exploration and individual organs’ functionality examination.

Throughout the different stages of the process the TCs' principal responsibility is to ensure that the organs to be procured are acceptable according to current viability criteria, that is, that they do not pose any significant risk of disease transfer to the prospective recipients, and that their functionality levels are adequate. The TC team, especially the three doctor-TCs, plays a key role in providing a complete evaluative file for each organ to the relevant transplant surgeons. The TCs' evaluative expertise, that incorporates both the donor's information and the organ under consideration, represents a valuable complement to the surgeons' focalized examination of the extracted organ. The use of kidney perfusion machines, operated by TCs, ensures optimum preservation and longer timeframes before transplantation, as well as providing additional information on the particular organs' functionality. TCs' evaluative expertise and organ-specific perfusion machines respond to a situation of extended criteria for organs' viability, and are aimed at ensuring that organs procured will be safe for particular transplant recipients. TCs, in accordance with the national framework and regulations by OCATT, procure organs from extended age donors, in particular kidneys and livers, which are considered because their functionality levels remain acceptable, and that extensive evaluative tests can be performed before and after extraction. TCs' procurement activities adapt to the changes in extended criteria for organ's viability, which in turn respond to changes in the type of patients that become eligible for a transplant, such as old age and disease history of HIV, hepatitis B or C. Higher risk organs will also be procured and balanced with the urgency of patients in the waiting lists that do not have any other therapeutic alternative.

### **8.6.2 – On the Opt-Out Policy Proposal to Increase National Donation Rates in Scotland**

The Transplantation Bill (Scottish Parliament 2016) that is currently under consideration in Scotland proposes a move to presumed consent legislation in order to increase national donation rates. The draft bill stresses that the policy would indeed strengthen the individual choice for donation, hence the terminology chosen is 'opt-out', and it signals that individuals will have three choices: to opt in, opt out or appoint three proxies. If none of the former choices were registered in life, consent would be deemed and organ removal would proceed. Families' right to object would be withdrawn and they would only be consulted to ascertain the deceased's lack of objection. An authorized investigating person (AIP) was nominated with the legal responsibility to contact proxies prior to relatives. The proposal was debated and rejected at the Scottish government in February 2016. However,

and given that it would have passed if three more MPs had supported the proposal (59/54 votes), it was decided that a public consultation was needed and that the bill would be reintroduced in 2017.

In this section I will examine how a move from an opt-in to an opt-out system, proposed as a solution to low donation rates, construes the organ shortage problematisation. I would argue that the current debate, constrained within the legal polarity of informed or presumed consent, indicates that the problem of low donation rates is being equated to low level of registrations and high levels of family refusals, thus, defining donation rates exclusively as a consent-centered issue, and identifying negative individual behaviours as the main barrier to increased organ availability. This research's findings contest such a problematisation, and point at the different exclusions it effects. Mainly, that it neglects the fact that donation is a situated medical practice, it is through the complex hospital organisational processes and professional interdependencies, as demonstrated in the former chapters 5, 6 and 7 and encapsulated in the notion of processes of assembling donations, that donation as choice is first enabled. Only a very small minority of patients that die in a hospital, which has to have a donation programme, will be deemed eligible donors, thus only then can donation be considered a choice and the response from family members, as well as organ donor registry information, will be essential. This research confirms Healy's (2006) and Manzano and Pawson's (2014) claims that organ procurement rates are directly linked to structural and organisational factors within the hospital institutional setting, and that those cannot be reduced to individual behaviour, either defined as altruism or reluctance to donate. This study provides the empirical evidence to support Manzano and Pawson's (2014) claim that any policy intervention would be severely limited if it only focuses on one phase of the donation process, and hence if only the stage of consent is being considered then the large numbers of professionals, interconnections and organisational arrangements are left out of the question. Ultimately, any question on how to increase donation rates needs to start by considering the primary stage of the process, potential donor detection at the hospital. That potential donor detection is the cornerstone of donation rates has also been advanced by Spanish authors (Matesanz 1998; Matesanz, Dominguez-Gil et al. 2011) and British studies (Wright 2007, Murphy et al. (2010); Quigley et al. (2008).

The British Medical Association in Scotland and the Nuffield Bioethics Council endorse an opt-out policy on the basis that this could ensure that the wishes of the deceased are carried out as well as "support families who are faced with these tough decisions"

(Scottish Parliament 2016, 20). I would argue against diminishing the role of families in regards to the decision, this research presents robust evidence to assert that their intervention is essential at the hospital. The ethnographic accounts offered in chapter 7 about the consent request demonstrated that approaching the families of eligible donors is simply a necessity, it is not easy but it can be done, as TCs do, in the most respectful and caring way possible. This is, and so it will remain, one of the enduring frictions of deceased organ procurement, the question is how to address it in a way that encompasses both the need to increase organ availability for transplants and the emotional situation of bereaved families? A legal shift to opt-out is directed at removing such friction from the process, nevertheless this is just not possible, and it carries more negative consequences than offers any solution to increasing donation rates. As Murphy et al. (2010) claimed, such a policy is premised on the fallacious rationale that if consent is problematic then the solution is to dispense with it. Proceeding to organ extraction without the consent from families raises profound ethical concerns, as well as practical. This research backs up the Scottish Government's and the Scottish NHS' objection to the policy, and stresses that families' intervention is essential to provide legal authorisation to extraction, and also as key informants of eligible donors' medical and social history. Without their input the safety of the prospective organ recipients would be put at risk. I would add that a move to an opt-out only addresses the procurement side of donation, the need to obtain organs for patients in the transplant waiting lists, it confines donation within the legal sphere of consent, and it ignores the fact that donation is both procurement and healthcare. Organs for transplantation cannot be considered 'transferable goods' released by the legal mechanism of consent only, rather it is the medical practices of donor and organ evaluation, vis-a-vis the characteristics of prospective recipients and role of donors' families, that makes some of these organs viable for transplantation. It is a troubling shortcoming of the policy that it does not take into account the practicalities and the views of the medical professionals involved in donation processes at hospital level. The policy not only ignores clinical practices in Scotland, but also poses serious threats to undermine the current ethos of integrating donation as a usual part of end of life care at hospitals, as was recommended by the Organ Donation Taskforce (Department of Health 2008), and that led to a 25% increase in donation rates in a period of five years (BMA 2012). In particular, the AIPs' legal competences to ascertain the lawfulness of the organ extraction would clash directly with the responsibilities for the care of donors and families that are undertaken by specialised nurses for organ donation (SNODs).

In response to the BMA Scotland's suggestion that "a move to an opt-out system which creates the default position could lead to a change in the philosophy within society where donation becomes seen as the norm" (Scottish Parliament 2016, 20), I would instead argue that this would not be achieved with such a legislative change. Rather, the integration of donation can only be expected at the level of hospital and national organisation, with the creation of specialised nurses and clinical leads for organ donation that consolidate the shared goal to make donation a usual process in end of life care. However, considering donation as a usual path in clinical practices does not entail that consulted families should be expected to consent, nor that such consent could be enforced by SNODs' strategic approach. At most, nursing staff can deliver the request in a caring and supportive manner towards the bereaved families' emotional difficulties.

The current legislation in Scotland, the Human Tissue Act from 2006, already enables the aforementioned changes in clinical practices to take place, and it does provide the necessary legal basis for the inclusion of other types of donors so as to increase organ availability; donors after cardiac death, mostly the controlled type<sup>69</sup>, but also a pilot of uncontrolled DCD in Edinburgh. This thesis attests to the paramount importance of the creation of specialised donation professionals, the TCs or SNODs in the UK, however, it also clarifies that SNODs would not work alone, and that it is a matter of integrating donation as a hospital activity, this entails a wide distribution of responsibilities and interdependencies amongst many diverse practitioners. A key area to work on at hospital level is to inform all practitioners about the changing eligibility criteria for donation, and about guidelines of extending criteria and including 'higher risk donor organs'. SNODs largely depend on other practitioners' notification about potential donors; thus, enlisting their collaboration and providing adequate training is essential. Designing and implementing a whole-hospital donation programme requires money as well, thus, government support needs to translate into financial investment<sup>70</sup>.

All in all, I would conclude that a change of legislation is neither necessary to increase donation rates, and nor is it desirable as it would put at risk the current donation plan in Scotland. The message I wish to convey is simple: opt-in or opt-out is simply not the

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<sup>69</sup> See Appendix 2 for Glossary, DCD controlled and uncontrolled types.

<sup>70</sup> An illustrative example can be read in the blog from the Midlands Clinical Lead for Donation, he reflects on the area's exponential increase in donation rates, 87.5% since the 2008 Taskforce report and government backing: "Money may not make the word go around but it certainly opens doors, doors into intensive care and the emergency departments, doors that had previously only been partially open" (<http://clodlog.com/log/files/517175e62fd3824bfe7e9c1688115b6c-11.html>).

question when trying to address the issue of how to increase national donation rates. Any policy proposals that are not informed by, and attuned to, the situated practicalities and specifics of organ procurement as a healthcare practice, and that exclude families' importance for donation, can not only be considered ineffective but also deeply irresponsible.

### **8.6.3 – No Heroics, Please or Another Way to Talk about Deceased Donation**

The thesis will end with a final reflection on the ways in which we talk about deceased donation; the discussion is particularly relevant for public campaigns in the UK setting. Since transplantation first started, donation has been articulated through the rhetoric of the gift of life, it is a robust and enduring paradigm to talk about donation. It features heavily in the media and it carries the symbolic weight and shapes the moral disposition of the appeal. It intends to enlist heroic donors who wish to change, improve, or even give, life to others in need. Naturally, the aim of donation campaigns is to promote donation, this is usually done by giving people the right reasons to register as donors, it extols the moral value of donation and it portrays donation as an individual choice to be decided upon in life. The message is addressed to, and further reifies, a rendering of the individual person, the one whose belief needs to be enlisted in the cause, as a sovereign subject. An autonomous, liberal and rational being that is the legitimate ruler over the body, here enacted as subservient matter defined along the legal notion of individual property. I would not dispute that such version of the body and individuality is indeed attuned to and shared by most people nowadays. I would also agree that the ideal of patient autonomy is, and should remain, of great significance in deceased donation. But – and this is what this thesis has intended to unravel as a practical matter – the problem is that such sovereign subject/mind owner of the body/matter is an ideal that becomes thoroughly disrupted in donation practices. It is an abstraction that simply loses its hold at the hospital, the site where donation actually and finally happens. Therefore, I propose that instead of looking for paradigms, metaphors, and narratives to talk about donation to the public, why not trying to talk about donation as a medical practice? Becoming an organ donor is an extremely rare possibility, for each year only twenty out of every million of UK citizens will actually become deceased donors (NHS 2016). And that for this to happen one has to first die a patient, in a hospital with a donation programme, be considered an eligible donor according to current criteria, one's body needs to respond to maintenance intervention and that can never be assured, and given that by the time this will happen one is dead, then it will befall on the family to take the final decision about it. This is just

what happens, it is not ideal, it cannot be justified with ethical principles or rights, as families are not a legal entity that can claim ownership on one's dead body. But they are there, and their intervention is necessary, as informers and authorisers, and their emotional experience can neither be minimised nor excluded altogether. Intention in donation is not all that counts, even though getting people to sign up on the donor register is important, and it certainly makes things easier for medical professionals and families involved, it is only but one great first step. As discussed above, donation cannot be problematized only along consent-centered frameworks, and it seems to me that nowadays the UK's media has conflated donation with promotion of it into one highly stylised version fit for public campaigns. Thus, I would like to suggest to those that design such campaigns that they should give further attention to how they talk about donation and how they imagine their public, as they too are responsible for construing donation in particular ways. My proposal is that instead of considering the public as an aggregate of healthy, rational and autonomous individuals whose minds needs to be persuaded so that their bodies can become available, some space could also be made to think about how to inform such individuals, who are after all also relational and embedded, part of an entangled collective of mortal beings.

Ultimately, there is no magic formula or ultimate reason that could convince or convert people to accept donation as the norm, like those who suggest that presumed consent legislation could change the culture of donation and normalise it (English 2007). And though registrations can increase, donation can never be expected to become a naturalised choice that individuals take whilst alive, because donation is thoroughly intertwined with death, and mortality is a topic that most of us would rather think about it later<sup>71</sup>, or even better, never. Death and donation is the impossible decoupling, the inescapable roughness of talking about donation. As well as the frontal attack that donation poses to one of our most sacred abstractions, of the atomised self-possessive sovereign subject. The foundational body boundaries of individuality and personhood become seriously destabilised through a procuring medical practice that circulates organs from the dead to the living.

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<sup>71</sup> Since 2011 in the UK anyone applying for a driving license is obliged to answer a question about the organ donor register. There are three choices: 1) Yes, I want to sign up 2) I am already on the register 3) I would like to think about it on another occasion (Walker 2011).



## APPENDIX 2: Glossary

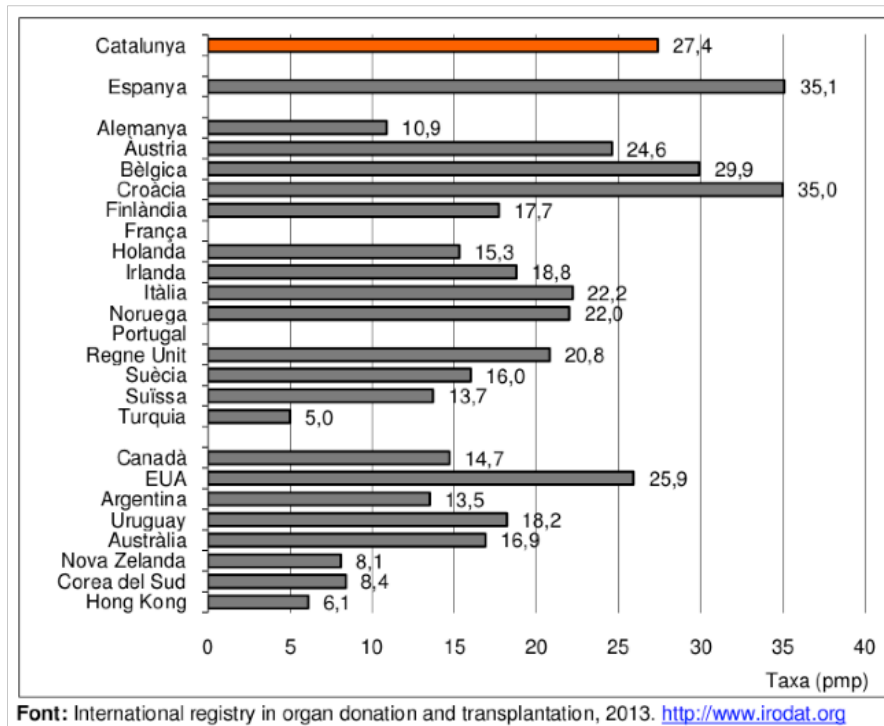
*Donation after Brain Death Diagnosis (DBD)* – Potential donors are ICU patients connected to a ventilator that are declared dead by neurological criteria

*Donation after Cardiac Death Diagnosis (DCD)* – Also called donation after circulatory death diagnosis. Potential donors are patients that are declared dead by cardio-respiratory criteria. There are two types of DCD, controlled and uncontrolled according to the Maastricht classification criteria of DCD. During fieldwork period 2012-13 the hospital Clinic DCD was mostly of the uncontrolled type. A programme of controlled DCD started in 2013 after the change of legislation in Spain that allowed for planned withdrawal of life sustaining treatments. In the UK it is only controlled DCD that is carried out with the exception of an uncontrolled DCD pilot in Edinburgh.

- *Uncontrolled DCD* (type II Maastricht classification criteria): out-of-hospital unexpected cardiac arrest, cardiopulmonary resuscitation unsuccessful. Emergency services transfer the potential donor to the hospital. Organ preservation measures are initiated right after the death determination by circulatory criteria. A cannula is inserted via the femoral vein and connected to an extracorporeal membrane oxygenation machine (ECMO) that will re-circulate the abdominal organs area.
- *Controlled DCD* (type III Maastricht classification criteria): in-hospital expected cardiac arrest that follows planned withdrawal of life sustaining treatments. Potential donors are patients in ICUs

## APPENDIX 3: OCATT Statistics and the Hospital Clinic

Catalonia's deceased donation rate and international comparisons 2013<sup>74</sup>



<sup>74</sup> OCATT 2013 Report: Organ Donation and Transplantation in Catalonia: (<http://www.idescat.cat/cat/idescat/biblioteca/docs/pec/paae2014/gi12372013.pdf>).

## Deceased Donation Rates in Catalan hospitals for 2013-14<sup>75</sup> (DBD [DCD])

Centre	Donants cadàver vàlids de mort encefàlica (ME) i mort en assistència (MA)		
	2013	2014	
HOSPITAL CLINIC I PROVINCIAL DE BARCELONA	36 (13)	45 (24)	↑
HOSPITAL GENERAL UNIVERSITARI VALL D'HEBRON	28	30	↑
HOSPITAL DE LA SANTA CREU I SANT PAU	13	30	↑
HOSPITAL UNIVERSITARI DE BELLVITGE	33 (2)	28 (5)	↓
HOSPITAL DEL MAR	16 (3)	20 (3)	↑
H. UNIVERSITARI GERMANS TRIAS I PUJOL DE BADALONA	21	13 (3)	↓
HOSPITAL UNIVERSITARI JOAN XXIII DE TARRAGONA	12	8	↓
HOSPITAL UNIVERSITARI DR. JOSEP TRUETA DE GIRONA	9	8	↓
HOSPITAL UNIVERSITARI ARNAU DE VILANOVA DE LLEIDA	9	7	↓
CONSORCI HOSPITALARI PARC TAULÍ DE SABADELL	6	6	≈
HOSPITAL MUTUA DE TERRASSA	5	5	≈
CENTRE HOSPITALARI ALTHAIA MANRESA	4	4	≈
HOSPITAL VERGE DE LA CINTA DE TORTOSA	4	4	≈
HOSPITAL GENERAL DE GRANOLLERS	2	3	↑
HOSPITAL DE SANT JOAN DE REUS	0	2	↑
HOSPITAL GENERAL DE CATALUNYA	3	1 (1)	↓
HOSPITAL DE SANT JOAN DE DÉU	2	1	↓
HOSPITAL DE MATARÓ	1	1	≈
HOSPITAL DE BARCELONA	2	1	↓
CENTRE MEDIC TEKNON	0	1	↑
HOSPITAL DE TERRASSA	1	0	↓
HOSPITAL DE SANT PAU I SANTA TECLA	0	0	
HOSPITAL SANT JOAN DESPÍ MOISÉS BROGGI	0	0	
<b>Total</b>	<b>207</b>	<b>218</b>	

*Entre parèntesi, donants de mort en assistència*

<sup>75</sup> OCATT 2013-14 Provisional results report: ([http://premsa.gencat.cat/pres\\_fsvp/docs/2015/01/12/13/39/f4af7a71-536f-4a80-86aa-49cc7dafib2b.pdf](http://premsa.gencat.cat/pres_fsvp/docs/2015/01/12/13/39/f4af7a71-536f-4a80-86aa-49cc7dafib2b.pdf)).

# APPENDIX 4: University of Edinburgh Ethics Level 2 submitted in 2012 with board paper



University of Edinburgh

School of Social and Political Studies

RESEARCH AND RESEARCH ETHICS COMMITTEE

Ethical review form for level 2 and level 3 auditing

This form should be used for any research projects carried out under the auspices of SSPS that have been identified by self-audit as requiring detailed assessment - i.e. level 2 and level 3 projects (see <http://www.sps.ed.ac.uk/research/ethics>). This form provides general School-wide provisions. Proposers should feel free to supplement these with detailed provisions that may be stipulated by research collaborators (e.g. NHS) or professional bodies (e.g. BSA, SRA). The signed and completed form should be submitted, along with a copy of the research proposal (or a description of the research goals and methodology where this is unavailable) to the relevant person:

- For staff applying for external funding, the PI should submit the form to Research Office
- For Postdoctoral Fellows, the Mentor should submit the form to Research Office
- For PG Research (PhD or MSc by Research), the Supervisor should submit the form to Director of the Graduate School.
- For UG Dissertations, the Supervisor should submit the form to the Programme/Dissertation Convenor.

Research and Research Ethics Committee will monitor level 2 proposals to satisfy themselves that the School Ethics Policy and Procedures are being complied with. They will revert to proposers in cases where there may be particular concerns or queries. For level 3 audits, work should not proceed until Research and Research Ethics Committee (or the Director of Graduate Studies, in the case of postdoctoral research) has considered the issues raised. Level 3 applications should be submitted well in advance of a required date of approval.

Research Office may monitor the implementation of arrangements for dealing with ethical issues through the lifetime of research projects. Please ensure you keep a record of how you are addressing ethics issues in the course of your research (e.g. consent forms, disclosure processes, storage of data, discussion of ethical issues by project advisory board). Do contact the Research Administrator if any unanticipated ethics issues arise in the course of your research/after the completion of your project.

#### SECTION I: PROJECT DETAILS

I.1 Title of Project:

Donation in Motion: a Hospital Ethnography of Organ and Tissue Donation Practices

I.2 Principal Investigator, and any Co-Investigator(s) (Please provide details of Name, Institution, Email and Telephone):

Sara Bea

School of Social and Political Sciences

PhD in Science and Technology Studies

Old Surgeon's Hall, High School Yards,

Edinburgh, EH1 1LZ. Room Number: 1.05

[S.Bea@sms.ed.ac.uk](mailto:S.Bea@sms.ed.ac.uk)

I.4 Does the sponsor require formal prior ethical review?

NO

I.5 Does the project require the approval of any other institution and/or ethics committee?

YES

If YES, give details and indicate the status of the application at each other institution or ethics committee (i.e. submitted, approved, deferred, rejected).

The hospital where fieldwork will be conducted does not have a relevant ethical committee board to contact as these are only put together to discuss medical cases. Once in the hospital, my gatekeepers will arrange a meeting with the hospital's communication department to discuss the project and obtain the institutional consent. Prior to the expected meeting in September, I will send via email a Catalan and Spanish translation of the research project summary in which it will be emphasised that its purpose and

objectives are akin to an audit of service delivery as it focuses exclusively on the medical professionals practices.

1.6 This project has been assessed using this checklist and is judged to be  
LEVEL 2  (for information to Research Ethics Committee)

LEVEL 3  (for discussion by Research Ethics Committee)

1.7 If Level 3, is there a date by which a response from the committee is required?  
Name...Sara Bea..... Signature.....

PLEASE ATTACH A COPY OF THE RESEARCH PROPOSAL (OR ALTERNATIVELY A DESCRIPTION OF THE RESEARCH)

## SECTION 2: POTENTIAL RISKS TO PARTICIPANTS

2.1 Is it likely that the research will induce any psychological stress or discomfort?  
NO

If YES, state the nature of the risk and what measures will be taken to deal with such problems.

2.2 Does the research require any physically invasive or potentially physically harmful procedures?  
NO

If YES, give details and outline procedures to be put in place to deal with potential problems.

2.3 Does the research involve sensitive topics, such as participants' sexual behaviour, illegal activities, their experience of violence, their abuse or exploitation, their mental health, or their ethnic status?  
NO

If YES, give details.

2.4 Is it likely that this research will lead to the disclosure of information about child abuse or neglect or other information that would require the researchers to breach

confidentiality conditions agreed with participants?

NO

If YES, indicate the likelihood of such disclosure and your proposed response to this.

If there is a real risk of such disclosure triggering an obligation to make a report to Police, Social Work or other authorities, a warning to this effect must be included in the Information and Consent documents.

2.5 Is it likely that the research findings could be used in a way that would adversely affect participants or particular groups of people?

NO

If YES, describe the potential risk for participants of this use of the data. Outline any steps that will be taken to protect participants.

2.6 Is it likely that participation in this research could adversely affect participants in any other way?

NO

If YES, give details and outline procedures to be put in place to deal with such problems.

2.7 Is this research expected to benefit the participants, directly or indirectly?

NO

If YES, give details.

2.8 Will the true purpose of the research be concealed from the participants?

NO

If YES, explain what information will be concealed and why. Will participants be debriefed at the conclusion of the study? If not, why not?

### **SECTION 3: POTENTIAL RISKS TO THE RESEARCHER/S**

3.1 Is the research likely to involve any psychological or physical risks to the researcher, and/or research assistants), including those recruited locally?

NO

If Yes, explain what measures will be taken to ensure adequate protection/support.

#### SECTION 4: PARTICIPANTS

4.1 How many participants is it hoped to include in the research?

30 medical professionals

4.2 What criteria will be used in deciding on the inclusion and exclusion of participants in the study?

Participants will be selected according to their role and contribution to the donation practices under observation

4.3 Are any of the participants likely to:

be under 18 years of age?	NO
be looked after children (including those living in local authority care or those living at home with a legal supervision requirement)?	NO
be physically or mentally ill?	NO
have a disability?	NO
be members of a vulnerable or stigmatized minority?	NO
be unlikely to be proficient in English?	YES
be in a client or professional relationship with the researchers?	NO
be in a student-teacher relationship with the researchers?	NO
be in any other dependent relationship with the researchers?	NO
have difficulty in reading and/or comprehending any printed material distributed as part of the research process?	NO
be vulnerable in other ways?	NO

If YES to any of the above, explain and describe the measures that will be used to protect and/or inform participants.

Research takes place in a Catalan hospital and the languages used are Catalan and Spanish, which are also my native languages.

Do the researchers need to be cleared through the Disclosure (Protecting Vulnerable Groups) Scheme? See [http://www.disclosurescotland.co.uk/pvg/pvg\\_index.html](http://www.disclosurescotland.co.uk/pvg/pvg_index.html) NO

Will it be difficult to ascertain whether participants are vulnerable in any of the ways listed above (e.g. where participants are recruited via the internet)? NO

If YES, what measures will be used to verify the identity of participants, or protect vulnerable participants?

4.4 How will the sample be recruited?

I will enlist the participation of practitioners during my stay in the hospital as a participant observer

4.5 Will participants receive any financial or other material benefits because of participation?

NO

If YES, what benefits will be offered to participants and why?

**Before completing Sections 5 & 6 please refer to the University Data Protection Policy to ensure that the relevant conditions relating to the processing of personal data under Schedule 2 and Schedule 3 are satisfied. Details are Available at:**

[www.recordsmanagement.ed.ac.uk](http://www.recordsmanagement.ed.ac.uk)

## **SECTION 5: CONFIDENTIALITY AND HANDLING OF DATA**

5.1 Will the research require the collection of personal information from e.g. universities, schools, employers, or other agencies about individuals without their direct consent?

NO

If YES, state what information will be sought and why written consent for access to this information will not be obtained from the participants themselves.

- 5.2 Does the research involve the collection of sensitive data (including visual images of respondents) through the internet? NO

If YES, describe measures taken to ensure written consent for access to this information.

- 5.3 Will any part of the research involving participants be audio/film/video taped or recorded using any other electronic medium?

YES

If YES, what medium is to be used and how will the recordings be used?

I will record the interviews, given the participants' consent to it, with a digital device. I will use the verbatim transcriptions for data analysis.

- 5.4 Who will have access to the raw data?

The researcher and interviewees will be offered the transcripts for revision.

- 5.5 Will participants be identifiable, including through internet searches? YES

If YES, how will their consent to quotations/identifications be sought?

The name of the hospitals and the practitioners will be anonymised with the use of pseudonyms. However, given the hospital's international reputation for organ donation programmes and specific roles of each professional this measure might not guarantee absolute anonymity. Participants have already been informed and accepted that anonymity will be pursued as much as possible but cannot nevertheless be guaranteed. Participants have agreed to the use of other safeguards, a part from an aspiration to anonymity, such as close collaboration with the project and reading of interview transcripts.

- 5.6 If not, how will anonymity be preserved?

- 5.7 Will the datafiles/audio/video tapes, etc. be disposed of after the study? NO

- 5.8 How long they will be retained? For a period of six months after completion of PhD

- 5.9 How will they eventually be disposed of? Audio files will be deleted and transcripts shredded

5.10 How do you intend for the results of the research to be used? They will be used for the completion of the PhD project, and potentially for future articles, books and conferences.

5.11 Will feedback of findings be given to participants? YES

If YES, how and when will this feedback be provided?

There will be a presentation of preliminary results prior to leaving the site to obtain the participants' feedback. They will be asked if they wish to receive feedback once thesis is completed. I will produce a summary of the thesis in Catalan and Spanish and distribute it to participants.

## SECTION 6: PARTICIPANT INFORMATION AND CONSENT

6.1 Will written consent be obtained from participants? YES

If YES, attach a copy of the information sheet and consent forms.

In some contexts of ethnographic research, written consent may not be obtainable or may not be meaningful. If written consent will NOT be obtained, please explain why circumstances make obtaining consent problematic.

Administrative consent may be deemed sufficient:

- a) for studies where the data collection involves aggregated (not individual) statistical information and where the collection of data presents:
  - (i) no invasion of privacy;
  - (ii) no potential social or emotional risks:
- b) for studies which focus on the development and evaluation of curriculum materials, resources, guidelines, test items, or programme evaluations rather than the study, observation, and evaluation of individuals.

6.2 Will administrative consent be obtained in lieu of participants' consent? YES

If YES, explain why individual consent is not considered necessary.

Although written consent will be sought to record interviews, there will be other situations in which people present during my observations in the hospitals will not be aware of my researcher's role. I will progressively disclose my role and research purpose to the medical professionals I come into contact with and pursue to enlist their participation. There will be other situations in the hospital that will include non-medical professionals whose consent cannot be sought. During the donation interview, I will be part of a medical team that discusses donation with the deceased's relatives. I will not be introduced and remain an observer like other medical students present. It will be ethically controversial to seek consent from the bereaved relatives when they have not yet been informed about the prospective donation discussion, and further to that it would interfere with the TCs' own practice of non-disclosure until the appropriate time. My role will be that of a covert researcher but the data collection will focus on the professionals' practice rather than on the relatives' reasons to authorise or refuse the donation process. The latter aspect of the research will be emphasised when requesting administrative consent from the hospital's communication department, the research project will be presented as an audit of service delivery in so far as it centres on the medical professionals' practices and not on information from patients and relatives present in the hospital.

Even though it is not anticipated to disclose my researcher's role to the potential donors' relatives, if the need for disclosure arose, such as if the relatives enquired about my role and reasons for attending the discussion, I would explain that I am a non-medical visiting student conducting research on the medical practices of organ donation in the hospital, and I would stress that if they wish I would withdraw from the situation without further discussion. If there was to be an extended discussion about the research project with the donors' relatives, then advice will be sought from supervisors on the need to subject the project to a revised ethical review.

In the case of research in online spaces or using online technology to access participants, will consent be obtained from participants?

If YES, explain how this consent will be obtained.

If NO, give reasons.

6.3 In the case of children under 16 participating in the research on an individual basis, will the consent or assent of parents be obtained? YES

NO

If YES, explain how this consent or assent will be obtained.

If NO, give reasons.

6.4 Will the consent or assent (at least verbal) of children under 16 participating in the research on an individual basis be obtained?

YES  NO

If YES, explain how this consent or assent will be obtained.

If NO, give reasons.

6.5 In the case of participants whose first language is not English, will arrangements be made to ensure informed consent? YES

NO

If YES, what arrangements will be made?

If NO, give reasons.

6.6 In the case of participants with disabilities (e.g. learning difficulties or mental health problems), will arrangements be made to ensure informed consent?

YES  NO

If YES, what arrangements will be made?

If NO, give reasons.

6.7 Many funders encourage making datasets available for use by other researchers. Will the data collected in this research be made available for secondary use?

NO

If YES, what arrangements are in place to ensure the consent of participants to secondary use?

Since the project is ESRC-funded thesis will be made available to the sponsor but not the raw data for secondary analysis.

### **SECTION 7: Unplanned/unforeseen problems**

7.1 Is the research likely to encounter any significant ethical risks that cannot be planned for at this stage? NO

If YES, please indicate what arrangements are being made to address these as they arise in the course of the project.

### **SECTION 8: CONFLICT OF INTEREST**

The University has a 'Policy on the Conflict of Interest', which states that a conflict of interest would arise in cases where an employee of the University might be "compromising research objectivity or independence in return for financial or non-financial benefit for him/herself or for a relative or friend." See:

[http://www.docs.csg.ed.ac.uk/HumanResources/Policy/Conflict\\_of\\_Interest.pdf](http://www.docs.csg.ed.ac.uk/HumanResources/Policy/Conflict_of_Interest.pdf)

Conflict of interest may also include cases where the source of funding raises ethical issues, either because of concerns about the moral standing or activities of the funder, or concerns about the funder's motivation for commissioning the research and the uses to which the research might be put.

The University policy states that the responsibility for avoiding a conflict of interest, in the first instance, lies with the individual, but that potential conflicts of interest should always be disclosed, normally to the line manager or Head of Department. Failure to disclose a conflict of interest or to cease involvement until the conflict has been resolved may result in disciplinary action and in serious cases could result in dismissal.

8.1 Does your research involve a conflict of interest as outlined above NO

If YES, give details.

## APPENDIX 5: Hospital Clinic approval of research placement

This is a copy of the official Hospital Clinic Research Placement Approval Document with details from the research project and researcher in Spanish and Catalan. The hospital research programme director and a senior TC, David who is responsible for research students within the TC team, signed it.

# APPENDIX 6: List of Research Participants

## The Transplant Coordination Team in the Hospital Clinic of Barcelona

### Senior TCs

Angel – Doctor-TC, head of the DCD programme, 15 years experience as TC

Camino – Doctor-TC, head of the tissue donation programme. 20 years experience as TC

David – Doctor-TC, head of the living donation programme. 16 years experience as TC

Ferran – Nurse-TC. 10 years experience as TC and previously oncological nurse

Sandra - Nurse-TC, 9 years experience as TC and previously surgical nurse

### Junior TCs

Marc - Nurse-TC, part-time TC and also emergency nurse

Maria - Nurse-TC, part-time TC and part-time pulmonary ICU nurse

Samuel - Nurse-TC, part-time TC and part-time A&E nurse

Xavi – Nurse-TC, full-time TC, previously pulmonary ICU nurse

### Donation Unit Director

Ramon – Non-executive director of the TC team and full-time Pulmonary ICU anaesthesiologist

# APPENDIX 7: Informed Consent Forms for the Interviews



ESRC INNOGEN CENTRE  
Institute for the Study of Science, Technology and Innovation  
COLLEGE of HUMANITIES and SOCIAL SCIENCE  
The University of Edinburgh  
Old Surgeons Hall  
High School Yards  
Edinburgh EH1 1LZ  
Telephone +44 131 650 9113  
Fax +44 131 651 4278  
[www.innogen.ac.uk](http://www.innogen.ac.uk)

## Participant's Consent for Interview

You have been invited to participate in Sara Bea's research project. I am a PhD student in Science and Technology Studies in the University of Edinburgh. I am currently conducting a sociological research about the practices of organ and tissue donation for transplantation in this hospital. The project is funded by the Economic and Social Research Council (ESRC) in the UK. The aim of the study is to gather information about the way donation processes are carried out in the hospital and the perspectives of the hospital practitioners involved. The project wishes to explore all the stages of the process of donation, from early detection to removal and delivery. The focus is on the medical and non-medical professionals' activities, hospital sites involved, technologies and procedures deployed to procure organs and tissue for transplantation.

I wish to supplement hospital observations with in-depth interviews with different practitioners that like you contribute to the process of donation in this hospital. If you agree to participate in the study we would arrange an individual interview in the time

and place that best suits you. I will ask you questions about your professional role and related activities to the process of organ and tissue procurement in order to gather accounts of your daily practice. Your participation is entirely voluntary and you remain free at all times to withdraw from the study without further discussion.

If you agree to it, the interview will be digitally recorded and later on transcribed and analysed by myself as part of the PhD programme. As previously discussed and jointly agreed your name and that of the hospital will not be anonymised. All interview data will be confidential and it will be kept under a password-protected system until completion of the PhD when recordings will be destroyed. If you wish you will be offered the interview transcript for revision as well as a final research report summary in Catalan/Spanish. Some excerpts of the interview will be translated into English and might figure in the thesis report as well as in potential prospective work such as academic articles, conference presentations and books.

As a research participant I agree that:

- I have been informed about the research project and its purpose
- I have been given the opportunity to discuss project details and ask questions
- My participation is entirely voluntary
- I can withdraw at any time or refuse to answer some questions without further discussion
- I accept that the interview will be digitally recorded and transcribed
- I accept that direct quotations might be used in thesis and publications
- 

I \_\_\_\_\_ consent to be interviewed under the above-mentioned terms.

Date and Signature

# APPENDIX 8 Interview Topic Guide

## Part I

### DETECTION STAGE

A process of donation starts with the detection of potential donors.

What is your job as a TC in this respect?

How do other healthcare professionals and other hospital practitioners intervene?

Collaborations and reticence

### EVALUATION STAGE

I have observed that after death diagnosis then it is your task to evaluate the viability of the donation. Could you tell me some more about the process?

What type of information and/or material is gathered?

Issues about Access and availability?

What type of data is not available and is it your task to get it?

What about access and interventions upon the potential donor body? Who collaborates?

Is the evaluation conducted globally or each strand is evaluated separately?

What is the purpose of these interventions and evaluations?

Is the method to rule out contraindications or there are also quality indicators to be identified?

As I have observed, once you have enough information to evaluate the donor's viability you take a decision. Is this right?

What matters at that time? Being fast, being thorough?

Is it an individual decision or team-based? Are there different roles for doctor-TCs and nurse-TCs?

What is the role of EU biovigilance criteria and protocols?

Is it possible to guarantee risk-free safety? What are the certainties and uncertainties that you take into consideration?

## THE CONSENT REQUEST

So once you have a potential donor detected and the donation is deemed viable then what?

When do you approach the eligible donor's family?

What do you do first of all when you approach them?

What type of help is offered?

When and how do you introduce the topic of donation to the family?

Some of you use phrases such as 'I know it is a terrible time but it is my job in this hospital...'. What about you?

The policy literature talks about the donation interview or the family interview but here I have observed that the shared attitude is that it is not a formal demand but an offer of a possibility. Is this view more attuned to your practice? Why?

In Spain there is no opt out registry and families are always asked about donation. According to your experience, do you think relatives accept their responsibility as decision-makers then?

What would you say is the role of the family in regards to the dead body?

Is the decision to donate, or not, another end of life choice to be taken in the hospital by the eligible donor's family?

I have often heard families consenting saying that 'it is what s/he would have wanted'.

What do you think is the role/s, if any, of the deceased person during the consent request? It is referred to as the donation interview but what I have observed have been mostly brief conversations that quickly end up with authorisation or refusal

How would you describe the interaction?

Based on your experience what is your opinion about 'donation interview strategies' such as those advanced by the Spanish model?

Is there anything that might fall outside your control, that which cannot be systematised or captured with a protocol?

I once observed that an intensivist already told the family about donation before you got there which was cause of conflict. Does it matter that it is a professional TC the one that introduces donation? What is the essential TC experience and expertise?

The Spanish model guidelines talk about the 'therapeutic and support relationship that the TC builds with the family'. What is your experience with such issues? Is it part of your job?

The families that consent will then be asked about the social history of the donor. They are not easy questions. Why is this information necessary?

I remember a case of a family that got in touch with you because the deceased wanted to be a donor. He was not listed as a potential. What do you say then? Are people aware that to become a donor there are more factors to consider than the individual or family wish? If there is a young and viable potential organ and multi-tissue donor whose family refuses to donate. How would you deal with the answer? How do you feel knowing that the organs and tissue will not be used for transplants?

#### **DONOR MAINTENANCE STAGE**

I have observed that an important part of your job is to follow the evolution of the potential/donor to ensure the less damage to the organs possible.

What type of interventions become necessary and why?

What is being monitored and how?

Are there specific interventions directed to individual organs?

What about general interventions on the body as a whole?

I remember a case of DBD in which the extraction had to be speeded up because the blood pressure dropped significantly. What was the risk in that case?

Could you tell me other examples of changes that need to be monitored and that can cause you to intervene to correct the situation?

What type of difficulties can the donor body present to the process of donation?

How frequent are those? Or most cases can be kept under control up until extraction?

#### **ORGAN AND TISSUE EXTRACTION STAGE**

What type of '*in vivo*' assessment of the quality of organs is done at the operating theatre?

What type of '*ex vivo*' assessment of the quality of organs is done at the operating theatre?

What is your task then? And the transplant surgeons?

Why are these evaluations necessary?

Are there any interventions done on the extracted organs?

After extraction surgery where is the donor body taken?

What is your responsibility in regards to the donor body? And that of the funerary services?

Who is in charge of restoring the appearance of the deceased patient?

## THE TC PROFESSION

Why are you called transplant coordinator and not donor coordinator?

How would you describe briefly what does the job of 'generating donors' involve?

We already discussed that in a recent health and safety evaluation your job was labelled as high risk due to the psychological impact of dealing with death and bereaved people on a daily basis. How do you cope with it?

After a two-year process of transition the TSF has finally joined the hospital Clinic. You are now a new unit of the hospital. Do you think this will benefit your work?

Can it help to prioritise donation activities within the hospital? How? Increased collaboration of other healthcare practitioners?

According to your experience as a TC in this hospital. Would you agree or disagree with the view that the recent incorporation represents another step in a trajectory of normalisation of organ and tissue donation as another service offered by the national public health service?

What do you think about Manyalich's phrase that 'TCs have gone from black coat to white coat'?

The hospital directive constantly demands 'good numbers'. What happens when the statistics are not what they would have expected?

Do you think the hospital directive is sensitive to the particularities of donation? Expectations and difficulties?

How do you see the process of professionalization of the figure of the TC?

Will it become a medical specialisation?

What are the differences between doctor-TCs and nurse-TCs?

Are the competencies and skills well defined so far?

What is the role of protocols in this area?

## DEATH DIAGNOSIS AND THE DEAD BODY

You work with newly-deceased bodies, some of them might even look alive unlike a two-day old corpse. Does this cause you any type of conflict? Is it the same with DBD, DCD and tissue donors?

Do you accept the death diagnosis as the point that marks the end of the life of a person?

How is death or absence of life measured? Neurological and circulatory criteria?

Difficulties of using two different criteria? Same irreversibility in DBD and DCD?

Can the moment of death be objectively identified?

What is your view in the irreversible versus permanent criteria?  
What about the heated debates about the 'violation of the dead donor rule' in uncontrolled DCD. What do you think about the claim that re-circulation can produce cerebral reperfusion and thus cancel the death diagnosis?  
So what is then identified as signs of life?  
Is the Fogarty catheter used to preclude brain reperfusion here?  
The standard here is five minutes 'non-touch period', in your view is it enough to ensure brain anoxia prior to ECMO recirculation?  
What would you like to add to these debates that usually take place in the bioethical sphere only?

## Interview Topic Guide PART II

### PUBLIC HEALTH POLICY

Let's talk about what is necessary to implement an effective donation programme at national level. What would you say about state support, legislation, financial support, OCATT regulatory functions, the medical professionals inside and outside the hospital?  
Are all the elements in place here?  
Would you like to comment on some current problems or deficiencies?  
What strategies are in place to maintain high levels of donations?

Following your work it is clear to me that donation is possible due to the effort of medical professionals, hospitals, OCATT, current public health policies and the contribution of those that decide to donate.

And what about the general public? What is the role of the public in this milieu?

In your opinion what should the public know?

What should the public do?

Who has to educate the public? And to what purpose?

Do the public need motivating? Why?

Would such matters be part of general public health education?

Some Spanish bioethicists claim that the Spanish model lacks transparency and that public debate is needed in order to assess the legitimacy of new practices like DCD. What do you think about this claim?

Is the public ready to discuss such matters?

## **TRANSPLANTS**

Transplants have evolved at a rapid pace and their therapeutical use seems unquestionable

They are so widespread that it could be said that nowadays instead of a privilege they have become a right?

What are the consequences of such increase in number of transplants in matters of procurement?

Has it greatly increased the expectation for higher volume of cadaveric organs and tissue?

Would you say that sufficient attention is given, within the medical world and the transplant professionals, to where these organs come from and the work of practitioners like you that make it possible?

And how would you say your procurement job and position relates to the sphere of transplants?

In the media there is a lot of talk about the generosity of families and donors and about skilful transplant surgeons, the two poles of the story that are visible. What about practitioners like you that provide the conditions for all these to happen, what is your role in the story?

In these hard times of cuts, would you say that investment in donation and transplantation has also been reduced?

Do they represent certain savings in public health expenditure?

Do more transplants mean more progress? In what way?

Does it matter to maintain world leadership and to look after the 'jewel of the Spanish public health system' like Matesanz calls it?

## **THE DONOR BODY AND CONSENT**

In the ELPAT conference at Rotterdam much was debated about uncontrolled DCD practices and the ethical concerns that they give rise to. I am interested in hearing about your views as practitioners that deal with these types of donors

Why is cannulation done without the consent from the family?

Would it be possible in practice to ask before cannulation?

At what point would you say that the potential donor is no longer a patient?

Do the dead have the same bodily rights as the living? Why?

To finish up, we could speculate about the future of deceased donation and transplants now that there is so much talk about stem cells, regenerative medicine and bioartificial organs. What are your thoughts on such issues?

Is there anything else that you would like to add, or a comment from some topic that we have not covered during the interview?

Thank you very much for your time.

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