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### **Practices of Medical Staff in Post-mortem Organ Procurement**

### **An Analysis of Interviews**

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## 1 Introduction

Post-mortem organ donation has long been credited with saving the lives of many individuals in need of a functioning organ. In many countries throughout the world, organ transplantation serves as a minimally contested therapeutic medical technology. In some of these countries, the organ donors are viewed as altruistic members of society enabling organ transplantation to save the lives of individuals whose health deteriorates rapidly (Healy 2006). Although organ transplantation benefits from these views and the life-saving characteristics attributed to it by societies who support organ transplantation, the practices in relation to organ procurement and transplantation are by and large invisible in most societies.

There are various individuals and institutions behind organ transplantation currently driving its success and changing the perceptions of societies worldwide. Initially an evolving biomedical technology, organ transplantation depended upon the enactment of policies and guidelines that defined and established death as a means for removing organs for transplantation, while ensuring that individuals' rights are protected. Most countries throughout Europe have established regulations that are meant to protect the individuals who are to receive organs, such as guidelines that work to ensure the quality of the organs being transplanted to maintain the safety and health of the recipient (European Commission 2003). Regulations are also established to protect the rights of donors and to help diminish the possibility of a black market (World Health Report 2003; Coppen et al. 2010). These regulations are aimed at outlining who can be a potential donor, thereby reducing the possibility for certain individuals to be preyed upon for their organs. Countries are typically free to adopt or enact legislation that dictates how individuals within a country become donors. Presently, there are a few consent systems that are generally utilized to procure organs. Informed consent generally implies that individuals must express their wish to be an organ donor and even have the opportunity to register on a donation registry. Presumed consent generally suggests that members of society are aware that their organs will be used for donation at time of death unless that have expressed their desire not to be a donor during their lifetime or they have opted-out on a registry. Required request implies that a medical staff member or coordinator must inform the next of kin of the possibility of organ donation after death, if the potential donor made no provisions regarding organ donation prior to death (Crowe and Cohen 2006). Each country can apply these regulations according to their current legislation and medical practices. Adherence to presumed consent, for instance, can be "soft" or "hard." Countries with "soft" presumed consent legislation, for instance, are likely to consider



the next of kin, whereas countries with “hard” presumed consent legislation are said to be strict in that they do not seek acceptance from next of kin (Rithalia et al. 2009).

Austria currently exercises presumed consent legislation to procure organs for donation. The policy maintained a fairly low profile with little to no controversy on behalf of the members of its society. Under the policy of presumed consent within Austria, all individuals are considered possible post-mortem organ donors without need for expressed consent from the individual, but approval from next of kin is neither required (Felt et al. 2010). Furthermore, the policy applies to all who are within Austrian territory at time of death, thereby allowing for non-citizens and visitors to be considered potential donors. If individuals have not expressed their disapproval, in writing or verbally, to a relative or friend who can bear witness to this testimony after he or she has passed away, they are considered organ donors under presumed consent.<sup>1</sup> Even with the strictness of presumed consent legislation, there seems to be a bit of flexibility as to how the legislation is interpreted and applied in Austria. The Opting-out Registry, which is linked to the Gesundheit Österreich webpage, states on its website that “oral refusal witnessed by relative” would be respected and that “person’s relatives are consulted” for individuals whose preferences are unknown.<sup>2</sup> Herein lies what may be an important aspect of the organ procurement process in Austria. Doctors, surgeons, and medical staff members are presumably the last members who consult with family members and ultimately decide the fate of an individual who has not opted-out or expressed refusal to donate his or her organs.

This study focuses on the individuals whose job it is to carry out the task at hand of removing and transplanting organs from donors to recipients. Doctors and medical staff, such as nurses and anesthesiologists, working at one of the 30 participating hospitals within Austria, are to remove the organs of individuals who may or may not have been aware of the policy of presumed consent prior to their death. Therefore, this study seeks to identify how doctors, surgeons, and medical staff members employ legislation and guidelines in practice to determine whether an individual will be an organ donor or not. In noting that the decision-making process over who should be a donor has been pre-framed by presumed consent legislation, I am interested in understanding how policies and practices within a medical setting play-out in accordance with legislation. By understanding how medical practitioners go about their daily duties, either by strictly adhering to policy guidelines or allowing some

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<sup>1</sup> German Reference Center for Ethics in the Life Science, DRZE, [http://www.drze.de/in-focus/organ-transplantation/modules/rechtliche-regelung-in-oesterreich?set\\_language=en](http://www.drze.de/in-focus/organ-transplantation/modules/rechtliche-regelung-in-oesterreich?set_language=en) (October 5, 2013)

<sup>2</sup> Gesundheit Österreich, <http://www.goeg.at/en/Opting-out-Registry> (October 21, 2013)

flexibility of choice to relatives of the deceased, we can learn more about how the practices of medical staff members are influenced and enacted.

For the purpose of situating my work, a brief historical context will also be explored in this chapter along with information about relevant policies and guidelines that are intended to guide medical staff members in Austria. Chapter 2 will discuss relevant literature within the field of Science, Technology, and Society as well as literature from other fields that address how practices are enacted in different settings. This chapter will also discuss guiding theories and concepts under which my research was framed. In Chapter 3 I will discuss my interests and discuss the research questions posed. Chapter 4 is dedicated to methods. Given that interviews were the chosen medium for data collection, I will discuss how interviews help to showcase medical staff members' practices in relation to organ procurement. This chapter will also introduce relevant actors in the procurement process within Austria, but also relevant actors for the purpose of completing this work. Chapter 5 discusses the relevant theories and concepts employed in the analysis of the data. In Chapter 6, I will present my analysis of the interviews. Chapter 7 of the thesis aims at summarizing results and findings. This last chapter will hopefully present readers and researchers with material to stimulate more interest in this domain on behalf of Science, Technology, and Society scholars, as I acknowledge that this thesis is a product of the achievements and limitations that its author encountered along the way.

## **1.1 Organ Transplantation: The Evolution of A Biomedical Technology**

In the early 1950s, when organ transplants began to gain momentum as a medical phenomenon, transplants were quite controversial in some areas of the world as they were considered experimental in many ways (Lock 2002). On more than one occasion, the unethical behavior of some surgeons who transplanted organs into patients whose health did not depend upon an organ transplant also affected the technologies credibility (Lock 2002). Although transplantation was viewed as a potential aid in saving the lives of individuals, organ transplantation was not as popular as it is today because the health of patients could be compromised if their body rejected the organ. Even though human to human organ transplants had occurred prior to the 1980s, many were deemed unsuccessful because the recipients died within months (at most) after transplantation (Ibid.). Immunosuppressant drugs paved the way for transplants to become more routine in medical settings, given that they suppressed the body's reaction to an unknown organism. Put in laymen's terms, the

body of an organ recipient “attacks [the newly transplanted organ]. Organ rejection is your own body's misguided attempt to protect you.”<sup>3</sup> In effect, “immunosuppressant drugs can block the effects of these natural defenses,”<sup>4</sup> thereby allowing for a successful recovery. Prior to immunosuppressant drugs, the transplants were not deemed successful because the patients who had received an organ passed away relatively quickly due to complications with immunosuppression. Given the success of transplants after the introduction of immunosuppressant drugs, more transplants began to take place and gained favor with the public who had previously viewed transplantation as a failure given its inability to enhance and maintain the health of organ recipients (Ibid.).

At present organ transplantation involves the effective coordination of organizations and individuals. It involves balancing the interests of the individuals who depend on organ transplantation to live, with the rights of potential organ donors. Setting standards for medical practices to ensure the safety of the procedures and setting standards to avoid organ trafficking are important in most countries where organ transplantations take place.

The procedure itself involves a multitude of actors. Once a potential donor has been identified – either by coordinators or doctors – a brain death diagnosis must take place to ensure that the organs may be removed. In some countries, brain death does not serve as a green light. Depending on the country's legislation, medical staff members are often tasked with speaking to next of kin before extracting the organs. Organ transplantation also depends upon an effective transportation network. After the organs have been extracted from a donor, transporting the organs to the recipient as quickly as possible is crucial because the organ's condition begins to deteriorate rapidly (Ibid.). Nowadays, more transportation options are readily available; organs can be transported via air to a transplant center or hospital in a foreign country relatively quickly. This is further facilitated by the fact that many countries form part of an organization which helps liaise among member countries to ensure that the donor organs are appropriately matched to recipients. Although organ transplantation has evolved dramatically over the past centuries, there are still issues that plague the technology and its image in society; organ trafficking happens to be one of the issues that governments and organizations try to prevent by enacting legislation and guidelines (WHO Guiding Principles on Human Cell, Tissue and Organ Donation 2010).

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<sup>3</sup> <http://www.webmd.com/heart-disease/living-with-an-organ-transplant/immunosuppression> (October 21, 2013)

<sup>4</sup> Ibid.

### **1.1.1 Useful Definitions**

Given that organ transplantation occurs worldwide, clear definitions are necessary to understand the effect of the factors that influence this biomedical technology. To start, presumed consent regulation has been defined as a law that allows for the procurement of organs from deceased individuals without explicit need for their approval (Abadie and Gay 2006). Although the meaning of presumed consent generally remains the same from country to country, the practices around presumed consent have necessitated further definitions.

#### **1.1.1.1 Soft versus Hard Presumed Consent**

Some scholars have noted that practices employed in different countries and regions tend to vary. For example, soft presumed consent and hard presumed consent are terms coined to define how strictly presumed consent regulation is employed in practice. In soft presumed consent, the opinions of next of kin are taken into consideration, whereas hard presumed consent tends to neglect the opinions of next of kin and medical staff members strictly adhere to legislation, which allows for the removal of organs without need to consult with next of kin (Rithalia et al. 2009). Instead, strict adherence to the law prevails and individuals who did not express their opposition to post-mortem organ donation become donors, so long as the organs are of use to another individual in need of a transplant. Therefore, how strict one adheres to the organ procurement legislation of a country tends to characterize the different approaches known as “soft” presumed consent and “hard” presumed consent.

Since soft presumed consent has been characterized by the allowance of next of kin to not only express their wish as to the possibility of organ extraction post-mortem, but also to exercise their will, studies have been conducted in efforts to understand how the application of such legislation affects procurement. Spain, has often been characterized as a “soft” presumed consent country, while Austria is often cited as a “hard” or strict presumed consent country (Abadie and Gay 2006; Kaushik 2009). Even so, others have noted that Austria does not strictly apply presumed consent legislation and often exercises a soft version of presumed consent legislation by allowing for next of kin to oppose post-mortem organ extraction (Gevers et al. 2004).

### 1.1.1.2 Definitions to Ensure Uniformity

The World Health Organization (WHO), in an attempt to reduce uncertainty, has compiled a list of terms central to organ transplantation and their definitions. In acknowledging that organ transplantation occurs worldwide, the terms have been defined to ensure that there are some levels of uniformity across borders. Uniformity helps ensure that practices are also standardized. The following terms have been defined with the help of the *Global Glossary of Terms and Definitions on Donation and Transplantation*:

Procurement:

“The process that includes donor identification, evaluation, obtaining consent for donation, donor maintenance and retrieval of cells, tissues or organs” (World Health Organization 2009, 13).

Brain death:

Taken from the United Network for Organ Sharing (UNOS) Glossary, brain death is defined as the “irreversible cessation of cerebral and brain stem function; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain dead person is dead, although his or her cardiopulmonary functioning may be artificially maintained for some time” (Ibid., 8). A brain-dead individual may also be referred to as a heart beating donor.

Non-heart beating donor:

A donor resulting from cardiac death by which death results “from the irreversible cessation of circulatory and respiratory function; an individual who is declared dead by circulatory and respiratory criteria may donate tissues and organs for transplantation” (Ibid., 12).

Deceased Donor:

“A human being declared, by established medical criteria, to be dead and from whom cells, tissues or organs were recovered for the purpose of transplantation. The possible medical criteria are:

- Deceased Heart Beating Donor (Donor after Brain Death): Is a donor who was declared dead and diagnosed by means of neurological criteria.

- Deceased Non-Heart Beating Donor (Donor after Cardiac Death) = Non-heart beating donor (NHBD): Is a donor who was declared dead and diagnosed by means of cardio-pulmonary criteria” (Ibid., 9).

## 1.2 History of Organ Transplantation in Austria

In Austria, a long standing tradition of autopsies may have impacted organ procurement by paving the way for presumed consent legislation (Matesanz 1998). The history of organ transplants in Austria “goes back to the second part of the eighteenth century when necropsy legislation was elaborated in Austria by Van Swieten, the personal physician to Empress Marie Theresa,” thus suggesting that there are long standing historical and cultural contexts that must be taken into account when conducting this study (Michielsen 1996, 664). Paul Michielsen goes on to state that “it was this law that allowed Carl von Rokitansky (1804-1878) to develop in Vienna a pathology school that became a model for teaching hospitals” (1996, 664). Due to these reforms, some argue that “when transplantation with cadaveric kidneys started in the 1960s in Austria and Belgium, organs were removed on the basis of this tradition” (Pondrom 2009, 1257). The historical context in which the policy is situated may help explain why there is so little discussion about the fact that awareness over the topic of organ donation is not mediated by the government. The fact that the policy is historically grounded also produces a viable interpretation as to why the policies of presumed consent and a policy of discretion (Felt et al. 2010) have managed to remain in effect without much controversy in comparison to other countries where the adoption of such policies would be (and has been) controversial (Lock 2002).

Although transplants occurred in the early 1900s using organs from animals, human organ transplants became more common in Austria in the mid-1960s and onward (Mayrhofer 2012). 1987 proved to be a successful year for Austria as it conducted its first lung transplant in Innsbruck and a heart transplant in Vienna.<sup>5</sup> Given that immunosuppressant drugs and type-matching were already around at this time, transplants became more successful (Mayrhofer 2012).

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<sup>5</sup> Eurotransplant, [http://www.eurotransplant.org/cms/index.php?page=about\\_timeline](http://www.eurotransplant.org/cms/index.php?page=about_timeline) (October 27, 2013)

## **1.3 Organizations**

Global, regional, and national organizations worldwide work to ensure the successful procurement of organs. On a global scale are organizations such as the World Health Organization, while the European Commission targets most of the Western European countries and those within the European Union. On a regional scale are organizations such as Eurotransplant, or the Organización Nacional de Trasplantes (ONT), which coordinate organ procurement within a given area or region.

Institutions and organizations such as the World Health Organization and the European Commission are all involved in producing guidelines to ensure the safety of organ transplantation on a broader scale. Throughout Europe, organs are transferred across country borders thereby necessitating comprehensive guidelines to ensure the safety of organs at all stages of the procurement process, including transportation. Although countries implement their own laws for organ transplantation, universal codes of ethics are established by organizations and countries are expected to adopt and abide by ethical practices suggested by these organizations and institutions. The guidelines help protect individual members of a society by calling for safe and ethical medical practices (European Commission 2003). A goal of the European Commission is to ensure that through the following of these principles, transparency in process of organ procurement deters any unethical practices such as organ trafficking. This in turn, could also be viewed as an effort to create trust in the system and organ transplantation as a technology.

### **1.3.1 Global and Regional Organizations**

The global organizations are generally aimed at establishing norms that should be adopted worldwide. These guidelines are intended to “prevent organ trafficking and financial gain from organ donation, to guarantee a transparent and fair allocation of organs, and to provide legal certainty” (Coppens et al. 2010a, 164). The organizations that encompass specific regions try to consolidate the various opinions toward organ donation and transplantation.

Guidelines set forth by institutions such as hospitals or organizations such as the European Commission or Eurotransplant also play an important role in the procurement practices of medical staff members. The European Commission, a relevant actor in the world of organ transplantation, for example, has set forth guidelines to ensure the quality and safety of organ transplantation as a medical

procedure (2008). In hospital settings, medical staff members are expected to abide by guidelines detailing the procedural aspects of organ procurement, but also those that stipulate who a potential donor might be. Individuals whose organs lack the ability to function properly are likely not to be considered as potential donors. Following these guidelines involves a certain level of interpretation and even acceptance among medical staff members. Thus, I hoped that my research would be able to provide some insight into the policies and guidelines that are meant to guide their daily practices in a professional setting. How and why are some guidelines accepted and implemented and are any ignored? Originally, I had hoped that these answers would provide insight into the process of organ procurement on behalf of medical staff members, but these answers best depict the individuals and collective mindsets and practices of medical staff members on organ transplantation. Furthermore, they convey how factors not directly related to organ transplantation may impinge on their likelihood to procure organs from individuals whose organs are in good health post-mortem.

Even without repercussions for failing to procure organs, transplant organizations issue guidelines to hospitals that medical staff members should follow. These guidelines help medical staff members identify potential donors based on a set of categories to which a patient might be (or become) part of. The guidelines also help ensure that individuals whose organs are considered inadequate based on factors such as age or health are not sought as donors. This ensures that organ recipients obtain organs that are in good condition. These guidelines serve to avoid “the transmission of disease by a deceased donor organ can result in loss of the allograft but also in the death of the immune suppressed recipient” (European Commission 2007). It may also distinguish between a patient and a potential donor, thereby framing such individuals for the medical staff members who appropriate these frames into daily practices.

On the global scale, the rights of the individuals are generally at the forefront guiding the establishment of ethical principles for organ donation and transplantation. Nonetheless, “these principles leave room for interpretation, and countries are, at least to some extent, free as to how they incorporate them into their national legislation. On the other hand citizens may seek to derive rights from these principles and countries should ensure that their legislation is in accordance with these principles” (Coppens et al. 2010a, 164).

Organizations that function at the regional or national level tend to be a bit more specific regarding the overarching guidelines that should be established by individual countries. These organizations help define who constitutes an organ donor and what steps must be taken for the procurement of organs. Even so, the countries



themselves are tasked with incorporating them into legislation, albeit with the flexibility to take into account the interests of their inhabitants.

### **1.3.2 Organizations: Austria**

At present, Austria forms part of the transnational procurement organization, Eurotransplant. The organization is entrusted with coordinating organ transplants among its eight member countries: Austria, Belgium, Croatia, Germany, Hungary, Luxemburg, the Netherlands, and Slovenia. Eurotransplant views itself as a mediator, working with eight member countries to. “Within this region there are 1,601 donor hospitals and 77 transplant centers,” thus allowing for the allocation of organs to expand across various borders.<sup>6</sup>

Under its umbrella, Austria and the member countries must conform to certain guidelines that stipulate practices for the retrieval of organs post-mortem. This organization also facilitates the transportation and exchange of organs among the eight member countries in efforts to ensure that organs are matched to the right individuals thereby ensuring that the recipient will benefit from the organ most will receive it. Most importantly, expanding the network of available organs across countries results in more organs available to more patients because they are better matched to those individuals in need of an organ. According to Eurotransplant, each participating country must have legislation providing for organ extraction, however, each member country has the option to decide which organ donation policy to abide by: presumed consent, informed consent, or required request.<sup>7</sup> The policy of presumed consent, currently in effect throughout Austria, allows for the procurement of organs without need for individuals to register or explicitly give their permission, and is thus believed to facilitate the process of organ procurement, given that each individual will be viewed as a potential donor at the time of death. However, not many individuals, including citizens, immigrants, and visitors of the country, are aware of the policy and how it affects them (Felt et al. 2010).

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<sup>6</sup> Eurotransplant, [http://www.eurotransplant.org/cms/index.php?page=et\\_region](http://www.eurotransplant.org/cms/index.php?page=et_region) (September 20, 2013)

<sup>7</sup> Eurotransplant, <http://www.eurotransplant.org/cms/index.php?page=legislation1> (October 18, 2013)

## **1.4 Regulations**

Policies surrounding organ donations throughout the world tend to be aimed at maximizing the number of organs available for transplants (Coppen et al. 2010; Mayrhofer 2012). Some have noted that “the shortage of procured post-mortem organs is forcing countries to develop policies to optimize efficiency in retrieving postmortem organs from potential donors” (Coppen et al. 2010). While many countries and policies share this common goal in attaining more organs for donation, the ways in which a country or society go about the process tend to vary.

### **1.4.1 Regulations on a Global Scale**

Guidelines on a global scale have the effect of creating some uniformity worldwide. The World Health Organization, for example, created a glossary of terms to better define the procedures that take place in relation to organ transplantation and that may be understood differently in different settings (2009). In trying to create some uniformity, these guidelines help establish a set of norms that should be adopted in all countries. Guidelines and regulations are also established by organizations and institutions to ensure that the rights of individuals are taken into consideration. Ethical guidelines are often set forth by the World Health Organization and even translated into various languages (WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation 2010). These Guiding Principles are an attempt at setting global standards to reduce the possibility of organ trafficking, for instance, by prohibiting monetary reimbursement for donated organs (2010).

The World Health Organization notes that “the Guiding Principles have greatly influenced professional codes and practices as well as legislation around the world” (2010, 1). Keeping in mind that these standards are adopted and interpreted by various countries worldwide, the World Health Organizations also notes that the “Guiding Principles are intended to provide an orderly, ethical and acceptable framework for the acquisition and transplantation of human cells, tissues and organs for therapeutic purposes. Each jurisdiction will determine the means of implementing the Guiding Principles” (ibid., 1). Thus, these guidelines are to be adopted independently, and ethical values should be upheld on a global level, but the varying cultural and societal values must also be taken into consideration. The countries are also tasked with enforcing these principles. The World Health Organizations would, therefore, not penalize a medical staff member involved in the illicit trade of organs.

Instead, the country should have adopted these Guiding Principles by establishing legislation that reflect the stated goals and should enforce legislation.

The regulations are aimed at creating standards and norms. In effect, however, each country must first adopt these guidelines and create legislation to match the goal of these guidelines. Breaking the rules won't necessarily mean that you will go to jail or pay a fine – the consequences would be dictated by the legislation of each country, but that also depends on whether or not the country or relevant institution chooses to enforce the legislation.

#### **1.4.2 Regulations within Austria**

Until recently, “transplantations in Austria [were] not governed by a specific organ transplantation law, but under the Federal Law on Hospitals and Health Clinics (Bundesgesetz über Krankenanstalten und Kuranstalten – KAKug), section 7, §§ 62a to 62c.”<sup>8</sup> The policy of presumed consent was established in 1982 and the non-donor registry was introduced in 1995 (Abadie and Gay, 2006). Presumed consent, as defined by Eurotransplant, “means that organ donation is automatically considered in patients diagnosed brain-dead, unless they have specifically stated their preference as not willing to donate. However, in some countries with a presumed consent law, doctors will still ask permission from relatives.”<sup>9</sup> The policy is territorial thereby allowing for the ex-plantation of organs of non-citizens or residents; thus, even those whose cultural or religious background would oppose to organ transplantation would be regarded as donors, if they failed to state their opposition.

As of October 2012, organ transplantation is monitored under its very own Organ Transplant Law (Organtransplantationsgesetz – OTPG). Under the new law, the same basic principles apply. Organ donations cannot be financially profitable, an opt-out registry must exist and must be consulted prior to organ extraction, the donor should remain anonymous, proper transportation and labeling of the containers in which the organs are transported must be followed. Penalties are also established and they are in the form of fines for those engaging in the commercialization of organs or those that fail to follow the safety standards or check the opt-out registry prior to organ

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<sup>8</sup> DRZE, [http://www.drze.de/in-focus/organ-transplantation/modules/rechtliche-regelung-in-oesterreich?set\\_language=en](http://www.drze.de/in-focus/organ-transplantation/modules/rechtliche-regelung-in-oesterreich?set_language=en) (October 5, 2013)

<sup>9</sup> Eurotransplant, <http://www.eurotransplant.org/cms/index.php?page=legislation1> (October 18, 2013)

extraction.<sup>10</sup> One main distinction is that living organ donations also receive acknowledgement (Mayrhofer 2012). In terms of presumed consent legislation, not much has changed. Organ in Austria are still procured under presumed consent, and a year after the law has gone into effect, relatively little information regarding organ transplantation exists in the media, thereby suggesting that the new law has not greatly impacted the general practices.

Historically and presently, under presumed consent regulation in Austria, doctors are not obligated to seek approval for organ extraction from a deceased individual's next of kin; this stems from the fact that *consent* has been *presumed*. Along with a policy of presumed consent, Austria exercises a policy of discretion (Felt et al. 2010). The policy of discretion surrounding organ donations, along with presumed consent legislation in Austria has been attributed as a main reason for the countries high number of donations (ibid.).

Although the opinions of next of kin are taken into account, in most instances the next of kin are expected to make a decision reflective of the deceased individual's wishes in relation to organ donation. This tends to be difficult for next of kin because they are tasked with evoking the wishes of the deceased – a task that becomes especially difficult when the deceased individual may have never even discussed his or her wishes about post-mortem organ donation, as studies have found (Sanner 2007). Anxiety over death, after all, often results in individuals ignoring any thoughts of death and the subsequent events that follow (Sanner 2006).

Nonetheless, organ transplantation is rarely featured in news publications and I did not find any information discussing the enforcement of the policy of presumed consent. From the interviews, I became aware that medical staff members such as doctors, it seems, are free to exercise their authority to the extent that they are not questioned or penalized by law for not actively procuring organs. In this regard, the law seems to be in effect to procure organs from deceased individuals who would have otherwise not voluntarily opted-in (perhaps because they did not think about their death), in essence making it easier for next of kin, given that they would not have to decide upon the fate of their deceased family member's organs. The policy of presumed consent also seems to grant privileges to medical staff members because they are free to take organs from deceased individuals without fear of repercussion for doing so.

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<sup>10</sup> Bundesgesetz über die Transplantation von menschlichen Organen (Organtransplantationsgesetz – OTPG), Organ Transplant Law <http://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=20008119> (October 20, 2013)

### 1.4.2.1 Opting-out

The opt-out registry allows individuals who do not wish to donate their organs to sign up on a registry that, according to the Organ Transplant Law, must be checked by medical staff at the time of death of an individual in order to avoid extracting organs for transplantation against the deceased wishes. “Organs, parts of organs or tissue may be removed from a potential donor if they did not object to organ donation during their lifetime. In order to ensure the effective documentation of objections against organ donation, Austria has established a dissent registry (Widerspruchregister gegen Organspende). Besides objections documented in this registry, any other form of declaration of a deceased person’s will regarding post-mortal organ donation, such as an informal document found among the identity papers of the deceased, or an oral declaration made in the presence of family members, is being respected.”<sup>11</sup> In this regard, Austria practices soft-presumed consent because they take into consideration the opinions of the next of kin.

Individuals who choose not to become donors should register, state their will in writing, or explicitly state this to friends or family which may serve as witnesses of the deceased when he or she can no longer make this request.<sup>12</sup> However, since few are aware of the policy of presumed consent, perhaps due to a ‘policy of discretion’ exercised in Austria, it could be assumed that few are aware that they must register or explicitly state that they wish not be organ donors at the time of their death.

## 1.5 Perceptions within Austria and European Countries

Although legislation within a country *tends* to be aimed at reflecting the values of its citizens, arguments have been made that suggest presumed consent legislation has been established in countries as an effort to increase the number of potential donors available (Kaushik 2009; Mayrhofer 2012). In effect, studies are conducted to assess the perceptions of individuals toward organ donation and transplantation (Felt et al. 2010; Rosenblum et al. 2012). Studies are aimed at addressing varying procurement rates across countries (Healy 2006), attitudes of next of kin toward organ donation and transplantation, and attitudes and practices of medical staff members (Gross et al. 2000). Within Europe, the European Commission has also authorized

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<sup>11</sup> DRZE, <http://www.drze.de/in-focus/organ-transplantation/modules/rechtliche-regelung-in-oesterreich> (October 5, 2013)

<sup>12</sup> *Ibid.*

quantitative studies comparing knowledge and perceptions of European inhabitants in relation to organ donation and transplantation within their home countries (European Commission Special Eurobarometer 333a 2010).

Perceptions of post-mortem organ donation and organ transplantation tend to vary. These variations have been attributed to differences in religion, socio-economic level, familiarity with the process of organ transplantation, as well as differences in cultural and national identities (European Commission Special Eurobarometer 333a 2010). The Eurobarometer set out to identify the issues that plague the successful procurement of organs across European borders by conducting a quantitative study focusing on twenty-seven European Union countries, as well as three neighboring countries were not part of the European Union at the time (2010). Inhabitants over the age of fifteen were surveyed with a “probability proportional to population size (for a total coverage of the country) and to population density of each countries’ population” (European Commission Special Eurobarometer 333a). In Austria, 1,005 individuals over the age of fifteen were surveyed – the Austrian population over the age of fifteen was estimated to be 6,973,277 at the time the survey was conducted (ibid.).

The questions were aimed at understanding the knowledge of survey participants about the topic of organ donation and the legislation, but it also surveyed their personal thoughts and assumptions on the topic. The Special Eurobarometer 333a notes that “there have been significant increases in levels of discussion in Italy (45% up from 39% in 2006) and Austria (37% up from 24% in 2006),” thereby suggesting that citizens have gained awareness regarding the topic in recent years (ibid.). Yet, the same survey notes that only nineteen percent of Austrians are aware of the current regulations governing organ donation and transplantation. This particular Special Eurobarometer 333a also attributes differences in gender, education, financial stability, age, and even occupation as possible explanations as to why some members of the European society are more likely to discuss organ donation with family members.

With these survey results in mind, the policy of presumed consent remains somewhat of a conundrum. While Eurotransplant praises each distinct legislation among its eight participating countries as a “reflect[ion of] the national public interest in caring for their transplant patients,”<sup>13</sup> the Special Eurobarometer 333a notes that only thirty-nine percent of the Austrians surveyed responded positively when asked about their willingness to donate organs after death (ibid.). When asked about their likeliness to agree to donate the organs of a deceased relative, only thirty-five percent of













































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<sup>13</sup> Eurotransplant, <http://www.eurotransplant.org/cms/index.php?page=legislation1> (October 18, 2013)

Austrians stated they would be in favor of donating. The Eurobarometer goes on to identify religion, “scare of manipulation of the body, and distrust in the system” as factors for which individuals would prefer not to donate their (or their relatives’) organs after death (ibid.). The Eurobarometer, therefore, leaves questions stemming from how medical staff members and their practices affect an individual’s willingness to donate the organ of a deceased relative unanswered.

In presenting this data from the Special Eurobarometer, I hope to contrast the conceptualizations of medical staff members in relation to organ transplantation and the next of kin, as analyzed in Chapter 6. I believe that medical staff members’ practices can be viewed as being dependent on the whole of their personal experiences with next of kin, but also on their constructions of the capabilities of organ transplantation. The Eurobarometer data also suggests that medical staff members may encounter next of kin and individuals whose distrust in the system may prevent them from willingly donating the organs of a family member. One might then assume that the practices of medical staff members must then be modified according to these experiences.

**QE5 If you would be unwilling to donate your organs or those of a close family member what would these reasons be?**  
**EU27 + Top ten countries for each item**

Scare of manipulation of the human body			Distrust in the system (this could include the transplantation system, consent system or in general the society system)			Religious reasons			Don't know		
 EU27	25%		 EU27	21%		 EU27	7%		 EU27	31%	
 CZ	45%		 EL	45%		 RO	17%		 MT	76%	
 PL	36%		 CZ	33%		 AT	15%		 IE	64%	
 LV	35%		 SK	31%		 SK	11%		 FI	53%	
 SK	33%		 IT	30%		 IT	10%		 EE	52%	
 CY	33%		 PT	28%		 EL	10%		 RO	48%	
 AT	32%		 DE	26%		 PT	9%		 BG	48%	
 EL	31%		 LV	26%		 CY	9%		 DK	37%	
 IT	29%		 BG	26%		 LT	9%		 UK	37%	
 BE	29%		 AT	24%		 HU	8%		 PT	37%	
 LT	27%		 HU	24%		 EE	7%		 SE	36%	

There were no significant socio-demographic differences in reasons for withholding consent to organ donation.

Figure 1: Special Eurobarometer 333a, published June 2010





## 2 Literature

While organ transplants have received much attention, not much has been written within the field of Science, Technology, and Society studies that addresses how medical staff members interpret and act in accordance with regulating policies and guidelines for organ procurement and transplantation. Most of the written work in existence surrounding organ procurement or transplantation resides in discussions arising from ethical aspects over the policies surrounding the technology or in literature seeking to understand how the technology is perceived by members of the community (Sanner 2006; Sanner 2007; Felt et al. 2010). Although much of the literature discussing organ procurement focuses on the policies governing different countries, and their success rates which are determined by the number of donors per million of population, few of these studies discuss the individual and collective practices shaped by policies and guidelines (Abadie and Gay 2006; Coppen et al. 2010; Gevers 2004; Matesanz 1998).

Susan Leigh Star notes that research in such areas tend to be slim because “medical anthropology and sociology are often categorized as “ethics” or “policy” (important in their own rights, but only partially overlapping with basic STS research)” as fact that, at the time, managed to restrict the number of available studies focusing on the social contexts in which a technology such as organ transplantation arises and how social orders are restructured with their introduction (Star 1995, 501). While these studies provide much information about organ transplantation and the individuals affected directly and indirectly by the organ transplantation, relatively few focus on the ways in which the biomedical technology itself manages to become part of society through the practices of certain individuals and how it is utilized by these individuals and institutions of society. Furthermore, medical staff members and their role in the procurement of organs for transplantation are generally analyzed differently. Instead of qualitative studies, the role of medical staff members and their opinions are often polled (see Floden et al. 2010; Gross et al. 2000) using surveys which deny medical staff members the ability to address topics surrounding organ transplantation in their own words, thereby hinting to how and why certain practices prevail over others. The social construction of organ transplantation as a technology by medical staff members impinges on subsequent interactions between medical staff members and next of kin. These issues are important because they allow us to understand why and how medical staff members’ practices are influenced and what this means for organ transplantation, for donors, and for organ recipients. Furthermore, the constructions and framing of individuals such as potential donors also determines how the technology affects

patients and next of kin. In order to observe the practices that are prevalent among medical staff members, the relationships between the human and nonhuman actors that make up the world of organ transplantation should be discussed, if only a bit.

## 2.1 Actors within the Network

In the words of Annemarie Mol, “an actor acts” (2010, 255). An actor, however, doesn’t need to be part of a theater production or a televised series; instead an *actor* can be *anyone* and *anything*. Of concern, are the relations and effects this actor creates within a setting (ibid.). No matter how big, small, or irrelevant we might assume the actor to be, the actor still fulfills a particular task and by doing so, influences a series of actors and a series of events that follow. Take for example the door-closer so ardently described by Bruno Latour in *Where are the Missing Masses?* (1992).

Of importance are the human and non-human actors that are part of a network of “people, institutions, and organizations” that influence each other in dynamic ways (Latour 1992, 151). In discussing a door, Latour notes that the invention requires actions on behalf of human (and non-human actors) to be successfully incorporated into the network (ibid.). The door functions as tool to keep a cold draft out of a room; better yet, a door lock keeps that pesky neighbor at bay. Even so, these inventions depend on their incorporation into society and on the characteristics that we, as individuals and collectives, attribute to them. In exchange, these non-human inventions shape our actions in relation to them and in relation to other humans within a network of actors (ibid.). Actor-Network Theory therefore allows researchers to use the approach to study how a biomedical technology such as organ transplantation is constructed by the medical staff and how these constructions shape the everyday practices of the individuals. Why stop there? This approach allows us to focus on the policies and guidelines themselves to understand how medical staff members’ practices are an effect of their implementation. Furthermore, Actor-Network Theory allows us to consider the independence of the actors to act within a network. The bodies of potential donors, the organs, institutions, and medical staff members, for example, are all actors within a network that evolves constantly based on the interactions of the human and non-human actors involved. Anything from a ventilator to the recipient of an organ has the possibility to impact the human and non-human actors involved.

## 2.2 Culture

Margaret Lock's book titled *Twice Dead: Organ Transplants and the Reinvention of Death* gained popularity within the Science, Technology, and Society community because it touches on the relations between human and non-human actors, as well as the definitions and constructions of death that ultimately impact a biomedical technology such as organ transplantation (2002). Although the text is a compilation of observational material, interviews, and historical facts about organ transplantation throughout Japan, the United States, and Canada, it focuses on organ transplantation and the issues that plague the technology in the Japanese context. Lock aptly discovers that Japanese culture, as many have mistakenly assumed, is not the only factor that disadvantages organ procurement in Japan. Instead, Lock concludes that the Japanese' views on brain death pose a challenge to organ procurement because it departs from the traditional standard of death that establishes the cessation of the heart as the end of life. Lock's book involves a large amount of research and a variety of interviews with individuals impacted by organ donation and transplantation. The text depicts all angles of a story, thereby allowing for those who initially opposed post-mortem organ donation of a loved one to share their thoughts alongside individuals who supported post-mortem organ donation in a past experience. Even recipients of organ transplantation are interviewed.

Most importantly, through her research Lock manages to shed light on the varying medical practices that occur from hospital to hospital. For example, variations on whether or not to anesthetize a deceased donor prior to organ extraction were discussed noting that some medical staff members feel there is no need to do so given that the deceased donor does not feel any pain, while others choose to anesthetize the donor to avoid sporadic movement from the body during surgery (Lock 2002). These differences may help to showcase how medical practices are guided by prior experiences or beliefs about the organ donor and about transplantation. Additionally, they suggest that the ways in which medical staff members construct a potential donor tends to also vary according these distinct experiences. While Lock did not conduct research in or about Austria, the text itself allowed me to focus on the Austrian context and search for answers that would enable me to understand the various dynamics at play surrounding organ procurement in Austria. Along with the actors (actively and inactively) involved in organ donation and transplantation, these cultural differences are only part of the web of factors that influences the organ procurement practices of medical staff members.

### 2.2.1 National Identities

The role of culture has been researched by Felt et al. to determine how individual agency of individuals is exercised in relation to different biomedical technologies (2010). *Coming to Terms with Biomedical Technologies in Different Techno-Political Cultures* discusses how individuals within a society frame biomedical technologies such as organ transplantation and genetic testing (ibid.). In conducting their study, Felt et al. gave voice to the individuals by analyzing focus groups.

The analysis by Felt et al. highlights the different conceptualizations of individuals in Austria toward organ transplantation and genetic testing, noting that the responses of individuals were diverse. Thus, although national identities are often related to individual perspectives of a technology, they do not always reflect the varying conceptualizations that exist within nations and cultures. The text notes that within any nation, there are generally amalgams of cultures, therefore, it would be relatively difficult to state that all Austrians are in favor of organ donation and presumed consent legislation. Another point of interest is the claim that “Austrian political culture and history, with its propensity to take decisions in a top-down manner” may be the reasons for a lack of resistance to presumed consent legislation and organ transplantation (ibid., 19). Hence, the practices of medical staff members, exercising a certain level of authority, may also be viewed as having more agency than the next of kin.

Not only are the conceptualizations of technology and policy relevant, of importance is the notion that “different ways of conceptualizing the body also affect the relationship between technology and the individual in the medical encounter (ibid., 5). The ways in which the body is conceptualized by other actors may also account for varying cultural and national practices toward organ donation and transplantation.

### 2.2.2 The Living and the Lifeless Body

Perhaps it is because “the margins between life and death are so socially and culturally constructed, mobile, multiple, and open to dispute and reformation” that brain death poses such a conundrum in some cultures (Lock 2002, 11). Brain-dead individuals are not typically seen as dead. Their bodies lay on a hospital bed, and although they depend upon machines to continue *living*, they do not look *dead*. As individuals and as collectives, we have attributed certain characteristics to the *living* and certain characteristics to the *dead*. Determining at what stage an individual is dead

can be an issue when the individual is brain-dead (Sanner 2007). In some instances, an individual who is brain-dead, but still on a ventilator, may not be viewed as dead until after he or she has been removed from life-support (Sanner 2007).

Medical tests are usually run prior to declaring a patient brain-dead. In essence, these tests serve as proof that the individual is dead. Just by looking at the individual, we might not know it; the ventilator and care provided by medical staff members allows for a brain-dead individual to remain as if he were *alive*, or perhaps sleeping (Lock 2002). Rafael Matesanz, director of the Organización Nacional Trasplantes (ONT) of Spain, noted that issues arose when first introducing brain death because society could not comprehend how “a person with a beating heart and machine-assisted respiration could be considered a cadaver” (Matesanz 1998, 1633). Death, at one point in time, was acknowledged as the cessation of the heart, but the introduction of brain death required cultural meanings of the *body* and *death* to be redefined. Even so, the term “living-cadavers” highlights how brain-death remains an enigmatic concept that might equally confuse layperson and expert (Lock 2002).

Margareta Sanner discusses the distinct opinions that arise amongst individuals affected by organ donation and transplantation. Sanner notes that “people’s opinions about organ donation are formed by their diverse conceptions of the intriguing phenomenon of the transplantation enterprise,” for she suggests that transplantation allows individuals to question “how we define death and life, the meaning of death, the constitution of human identity, the borders between individuals and species, and the differences between nature and culture” (2006, 134). The article, *People’s attitudes and reactions to organ donation*, traces the individual responses and reactions of individuals to organ donation, initially through a survey and later through a series of interviews with survey respondents (ibid.). The approach allows for data to be collected through quantitative and qualitative studies thereby allowing researchers the opportunity to understand why individuals chose certain responses as opposed to others in a survey. Although the article focuses on Swedish perspectives on organ transplantation, the text proved useful because the accounts and perspectives of individuals in the Swedish context may still apply in the Austrian context given that shared perspectives are common in many settings; albeit, Sanner herself notes that different perspectives may also arise depending on cultural or religious beliefs in different settings (ibid., 146).

The text is also notable because it addresses factors that may affect procurement rates since it sheds light on issues and obstacles that medical staff members deal with in their effort to procure organs. The survey responses and interviews allow for opinions about organ transplantation to be understood differently

because the interviews allow research to focus on *why* respondents might feel a particular way about organ transplantation. For example, the fact that, according to survey results, “young and well-educated individuals might have openness to scientific progress and feel more confident with medical developments than old and less educated persons, which might be reflected in these attitudes (Sanner 1991, 1994a)” (ibid., 136). The survey results addressed in the article also go on to highlight that individuals are keener on donating their own organs than those of a deceased relative.

The Journal of Clinical Research published the findings on a research study titled *Nurses Knowledge and Attitudes: Attitudes to organ donation among Swedish ICU nurses*. The research conducted by Floden et al. (2011) models research conducted by Sanner et al. (2006), noting that the same questionnaire was used, albeit modified to be used on ICU nurses. While Sanner et al. focuses on “exploring the attitudes of ICU doctors and neurosurgeons to identify obstacles to OD [organ donations] in Swedish ICUs,” this study focuses on the relationship between nurses and the donation process (Floden et al. 2011, 3185). Although both of these studies aim at understanding how medical staff and their surroundings impact the process of organ donation, they do not employ qualitative research methods. Both studies use questionnaires as a method to identify how the medical staff conceptualizes their role in the process. However, the study provides knowledge about privacy and confidentiality issues that are of relevance to the procurement of organs. Floden et al. also notes that the perceptions of ICU nurses tend to influence the ways in which they might approach next of kin to discuss organ donation.

### **2.2.2.1 Trust**

The texts authored by Sanner and Lock also look to understand how experiences and notions about life, death, and the body shape one’s understanding and construction of organ donation and transplantation. For instance, brain death diagnosis has been generally accepted as an end of life in many cultures and this diagnosis has allowed for the procurement of organs from brain-dead patients, but “breathing and blood circulation are artificially maintained although the patient is pronounced dead by brain related death criteria,” thereby making it difficult for some to come to terms with the diagnosis (Sanner 2006, 140). The fact that brain-dead individuals still look like a patient due to the body being maintained on a ventilator makes coming to terms with the death of the individual harder to comprehend for next of kin (Matesanz 1998). Therefore, Sanner notes that individuals “must trust the

handling of the diagnostic methods, believe in brain death as real death, and be convinced of death not being hastened for the sake of somebody more highly regarded in need of organs” (2006, 140). In this regard, trust in medical staff and the system as a whole dictates whether or not next of kin are comfortable with organ donation. Nonetheless, even when next of kin accept brain death as a sound diagnosis, there seems to be discordance with defining the appropriate time of death (Lock 2002; Sanner 2007). Sanner notes that “the semantics are complicated depending on the complex reality in which the patient displays signs of life and death simultaneously” (Sanner 2007, 300). In the research she conducted with next of kin and doctors, Sanner noted that although a declaration of death may have taken place prior to be taken off a ventilator – as is typical with brain death diagnosis – individuals still referred to the patient as having died once the ventilator was turned off (ibid.).

This separate study also focuses on the different paths that some intensive care physicians take when liaising with family members. In some instances, physicians chose to speak to the family about organ donation on their own, while others chose to do so in a team. These different approaches, while suggesting distinct notions of how to handle a precarious situation, also suggest that medical staff members depend on their own intuition and preconceptions. Yet it also shows that medical staff members also share certain views with next of kin. For example, some of the physicians discussed their own stance toward organ donation. These beliefs are often associated as stemming from next of kin, yet this article shows that even “physician[s] made exceptions for heart and cornea because he felt that symbolically they represented his identity” (ibid., 130).

Similarly, the surveys used help to present Sanner’s conclusion that families are often tasked with deciding the fate of a deceased loved one and their organs and “the load on the family can be considerable since the relatives might be afraid of doing wrong to the deceased either by saying ‘yes’ or ‘no’ (2006, 147). In some settings, anxiety over death or having to choose whether or not to donate the organs of a deceased next of kin, “many individuals block information on the topic or even distort or misrepresent any such information in an effort to escape cognitive dissonance” (ibid., 148). Issues such as these may then interfere with procurement efforts on behalf of medical staff members. In such cases, one would assume that difficulty following institutional guidelines may arise thereby making it more difficult for medical staff members to abide by guidelines or even legislative acts on behalf of government entities.



### 2.2.2.2 Images of the Imperceptible

Images have been appropriated by medical sciences because they enable one to see a given phenomenon that would otherwise go unnoticed (Sturken and Cartwright 2001). Scholars have sought to study the impact of incorporating images as evidence noting that images cannot be as objective as they are often deemed to be (Dumit 1999; Cartwright and Sturken 2001; Burri and Dumit 2008). Images, nonetheless, “convince viewers of the accuracy of the imaging system and hence the *authenticity* of the documents presented... lend[ing] authority to particular arguments” (Sturken and Cartwright 2001, 286; emphasis in the original). Sturken and Cartwright’s analysis of images in courtroom settings goes on to highlight how videos, in the Rodney King trial, may have been used to present a distinct truth, but they feature a comprehensive analysis of the use of images throughout in different settings – from courtrooms to visual images in medical settings.

Images are often used to help convey something, for instance, the use of CT scans in medical settings generally help medical doctors diagnose a patient, but they also serve as a means through which information is interpreted and communicated (Sturken and Cartwright 2001). Although images are generally viewed as helpful in conveying particular messages, they must be employed with caution because they are not devoid of subjectivity. Furthermore, Sturken and Cartwright state that “images do not embody truth, but always rely on context and interpretation for their meaning” (ibid., 290). Images in medical settings for example depend upon the interpretation of an individual with sufficient knowledge about the context. Nurses and doctors read patient charts and determine the treatment of a patient based on their knowledge and interpretation of the images. “Images are inextricable from the daily practices of science, knowledge representation, and dissemination” because they help highlight and represent a fact (Burri and Dumit 2008, 297).

The text by Burri and Dumit focuses on the “production, engagement, and deployment of visualizations” to show how images are used (ibid., 300). The analyses of the production of images highlights how images are produced focusing on the ability to modify an image by applying different colors to an image and changing, rotating, or focusing in on particular sections (ibid.). This section also allows one to focus on the creator of the image, thereby suggesting that individual preconceptions are inherently part of the final image. The analysis on engagement of images focuses “on how images are *used* in the course of scientific work and are made instrumental in the production of scientific knowledge” (ibid., 302). This suggests that the images are then an actor in their own right modifying practices of individuals and setting apart

categories for the different characteristics present in different images. Once the images are deployed, they help convey a particular reality. To the untrained eye, the CT scan of a brain-dead individual may not say much unless it is contrasted to the brain scan of a non-brain-dead individual or it is supplemented by a doctor's explanation. In fact, Dumit calls CT scans expert images and reduces them to "objects produced with mechanical assistance that *require* help in interpreting even though they may appear to be legible to a layperson (1999, 175 emphasis in the original). Although Dumit's work presents the use of images in court room settings to highlight something as evidence may be a questionable practice, one might expand that line of reasoning to include the use of CT scans by medical staff members as evidence of brain death for next of kin. While this would undoubtedly help convince next of kin of brain death diagnosis, these images are the creation of a technology, the selections of its maker and the opinion and expertise of the medical staff member who chooses to present it as evidence of brain death to next of kin.

### **2.2.3 Religion**

Within different cultures and countries, perspectives on organ donation and transplantation tend to vary. Religion may be cited as an obstacle to post-mortem organ donation because individuals with certain religious backgrounds may be less likely to donate their organ or those of a loved one. Some studies have taken the religious beliefs of respondents into account when conducting surveys on perceptions and attitudes towards organ transplantation to better understand how religious beliefs impact procurement rates (Sanner 2006; Sanner 2007; Gross et al. 2000). Even so, opposition to organ transplantation stemming from individuals claiming that their religion opposes transplantation is at odds with what religious leaders have to say about organ donation and transplantation. In *Religious Aspects of Organ Transplantation*, Paolo Bruzzone states that a religion has yet to explicitly oppose organ donation (2008). It seems obvious then, that individuals citing religion as a primary reason for not donating their organs or those of a loved one may be confusing certain religious stances as having to do with organ transplantation. For example, in Islam, the body of a deceased individual should be respected and in most, cases a quick burial should follow (Bilgel 2013).

Varying opinions on behalf of Muslim leaders also tend to be a factor that lead to obstacles for medical staff members in terms of their procurement practices. Mousawi et al. discusses "differences of opinion among religious scholars on issues related to

OD [organ donation] and brain death have caused major set-backs in the transplant programs of some [Muslim] countries” (1997, 3217). Although we are primarily concerned with the medical practices in relation to post-mortem organ donation and transplantation within Austria, there are many individuals who consider themselves Muslim living in Austria and it is therefore important to understand how medical practices shift in relation to religious concerns of individuals in relation to organ donation. The study conducted by Mousawi et al. highlights reasons why Muslim individuals may oppose organ donation even when religious leaders and Islam itself do not oppose organ donation. In fact, the study by Mousawi et al. notes that “after death, Islam encourages early burial and strongly prohibits mutilation or destruction of the body,” thus suggesting that individuals may be concerned with the process of organ extraction because it involves surgically removing the organs, which some individuals may liken to cutting-up the deceased body (ibid., 3217). According to the quantitative study in which the opinions of thirty-two religious scholars were sampled, “twenty-eight scholars (87.5%) allowed OD after death when it is absolutely necessary with the consent of the deceased during his life or his close relatives after his death,” whereas “twenty nine (90.6%) initially rejected the brain death concept and did not allow discontinuation of life support in brain-dead patients except when another patient with better prognosis urgently needed the life support machines” (ibid., 3217). These findings suggest that religious leaders (scholars) from Muslim countries are not opposed to organ transplantation as a viable technology for saving lives. Instead, issues stem from concerns over the definition of death. In fact, study also notes that when approached to discuss brain death, the scholars changed their mind about the notion of brain death. Taken together, these texts suggest that if more individuals are aware of brain death, many might be willing to change their perspectives on brain death and accept it as grounds for proceeding with organ donation.

### **2.3 Standardizing Practices**

Linda Hogle, author of *Recovering the Nation's Body: Cultural Memory, Medicine, and the Politics of Redemption*, aptly notes that “a particular combination of political, economic, historical, and cultural concepts shapes medical practices that concern the use of bodily material” in her study of organ procurement in Germany (1999, 15). It is her article on medical practices that I turned to for guidance on how practices are standardized through the introduction of policies or guidelines (Hogle 1995). The article describes her findings from interviews and observations with

transplant coordinators and helps to provide a background to how medical staff members conceptualize a given technology and how such conceptions interplay with their professional duties and the policies and guidelines surrounding organ transplantation.

Even when efforts are made on behalf of organizations to standardize practices to enhance the safety of procedures – by establishing characteristics for suitable organs, for example – the interpretations of these protocols shape the local practices (ibid.). *Standardization across Non-standard Domains: The Case of Organ Procurement*, therefore, suggests that “medical practice is heterogeneous and interactive in much the same way as are other techno-scientific domains” allowing for one to believe that the ways in which surgeons go about their daily labor is not standardized by policies (ibid., 482). Thus, while guidelines concerning organ procurement help establish some level of universal uniformity, they are strongly dependent on the individuals that enact them.

In her analysis, Hogle also discusses how organs supersede the body as the “focus of biomedical practices,” thereby suggesting that protocols help shift the practices of medical staff members from caring for the patient to caring for the organs (ibid., 483). Examples of the maintenance of the brain-dead patient illustrate this dynamic; care continues after brain death diagnosis in an effort to preserve the organs of the deceased, the new foci are the organs as the object of care and not the individual. This might also serve as a coping mechanism of sorts given that conceptualizing the potential donor as a patient makes the task of removing the organs for donation more difficult.

Another key finding from Hogle’s text lies in her analysis that “standards, techniques, theories, and work practices are constructed in use by individuals who bring their own values, interests, experiences, and knowledge to bear” (ibid., 496). This would imply practices are as much influenced by individuals as they are by collectives. The shared cultural values and experiences would help account for varying practices that occur even within the same hospital. Lastly, while the text focuses on coordinators as opposed to medical practitioners in an area where presumed consent was not the policy at hand, Hogle’s text makes interesting observations, mainly, that “reinterpretations, accommodations, and even resistance to standardized biomedical guidelines and definitions can be observed” in such settings (ibid., 483). Thus, it is local interpretations and situations that may play a significant role in the practices that govern organ transplantation in different hospitals and among different medical staff within Austria.

### 2.3.1 Frames

Along with Linda Hogle, Nicolas Dodier's work on medical practices helped me reflect on the ways in which practices in medical settings change according to the medical staff member employing such guidelines and protocols established by government laws or institutions, but also according to the ways in which the medical staff member frames the patient. Dodier distinguishes between a clinical frame, in which a doctor employs his or her own experiences to assess medical cases based on the patient as an individual, and the administrative frame, in which the doctor conforms to administrative guidelines to assess the health of an individual (1998). He goes on to note that "the framing of medical decisions by legal rules forces doctors to introduce an administrative frame that breaks with certain principles of the clinical frame (ibid., 79).

The work of Dodier highlights how different frames can determine the course of action a doctor will take in caring or assessing the health of an individual. Furthermore, Dodier discusses the authority of medical staff members in employing a clinical frame as opposed to an administrative frame noting that the "clinician accepts that other actors produce rules, norms, and epidemiological indications and uses them. They serve as points of reference," but by no means, do they impart a strict course of action, given that they are free to apply them in some instances and ignore them in others (ibid., 69). Ignoring, however, does not suggest that the medical staff member chooses not to do his job, but that he or she would rather employ a clinical frame and treat the patient as an individual as opposed to a part of a population. By employing the administrative frame, a medical staff member frames the individual as belonging to a given population and thereby attributes characteristics of that population to the individual. In effect, the medical staff member avoids the need to identify individual characteristics of patients, placing the patient into categories which dictate treatment, for example. An example of this might be when one visits a doctor who assesses that the weight of a child falls within the average specified for a particular age group and sex, thus acknowledging the child fit for certain activities, or unfit if he or she falls below or above the average.

Frames, however, need not only apply to doctors and their patients, but can also be explored in other relationships. Frames are employed by individuals across various situations and these frames are influenced by experiences, as well as rules, regulations, or guidelines that presuppose a specific course of action. I find Dodier's work to be of use for this particular research project because it focuses on the ways in which frames influence a course of action and because it highlights the ways "in which doctors frame the situation affects their attitude toward codified rules" (ibid., 54).

### 2.3.2 On Paper, In Practice

A short discussion on principles and practices seems relevant since it is not only the frames which one applies, nor the values that one has that shift practices. As Hogle noted, written protocols often effect some action on behalf of medical staff members. A text by Annemarie Mol and Marc Berg resonates well with these findings. In *Principles and Practices of Medicine*, Mol and Berg describe the principles that are to guide medical staff practices in different settings (1994). It is assumed that medical textbooks are available to medical staff members in different locations, so as to guide their practices, but even the writings are subject to interpretations of the medical staff member. These textbooks help create standards by which to judge and diagnose ailments, but in practice, other factors also influence how a diagnosis may take place. The work is relevant because medical textbooks are dependent upon the knowledge of an individual to correctly interpret and enact the principles stated, even so, the circumstances and experiences of the particular individual shape the practices in action. Thus, *The Co-existence of Various Anemias* helps highlight how, even with one set of guidelines trying to standardize practices, variations will still occur (ibid.). Although I am most concerned with the policies and guidelines concerning organ donation and transplantation, these texts are also dependent on the knowledge and interpretation of medical staff members working to procure organs.



### 3 Into the Field We Go: Research Interests

*“...medicine is not a coherent whole. It is not a unity. It is, rather, an amalgam of thoughts, a mixture of habits, an assemblage of techniques. Medicine is a heterogeneous coalition of ways of handling bodies, studying pictures, making numbers, conducting conversations. Wherever you look, in hospitals, in clinics, in laboratories, in general practitioners’ offices – there is multiplicity”* (Berg and Mol, 1998, 3).

And so, I set out to be witness to that multiplicity in an effort to understand how multiplicity among medical staff members within Austria impacted the ‘donation’ and (subsequently) transplantation of organs in Austria. Initially, however, I was not drawn to the multiplicity. I was drawn to what I considered a controversial policy that few in Austria were aware of regardless of their citizenship (Felt et al. 2010; European Commission Special Eurobarometer 333a). The policy of presumed consent exercised in Austria dictates that every deceased individual within Austrian territory is a potential donor unless he or she has stated otherwise prior to death. What most intrigued me was that many are not aware of the current policy and, therefore, are also unaware that they must object to organ donation during their lifetime or register in the opt-out registry (Felt et al. 2010).

That was it. Initially, I was not intrigued by the multiplicity that Mol and Berg discuss, my interest was piqued when I heard about the policy of ‘presumed’ consent and the policy of discretion that surrounded what I assumed, should be a well-spoken about topic (1998). I couldn’t quite comprehend how such policies were truly enabling the successful procurement of organs for transplantation if they failed to inform individuals that could (and likely will) at one point in time be affected by the policy. Furthermore, would not the next of kin opposed to the organ extraction of their relative be outraged, or at least distressed, when informed that their deceased relative was now an organ donor without his or her knowledge and without the need to consult them? Did such policies not result in backlash and subsequently reduce the number of potential donors? How did medical staff deal with next of kin who refused to allow their deceased family member’s organs to be extracted for organ transplantation? Therein lies the multiplicity to which Mol and Berg refer when discussing the compilations of studies carried out by individuals in the medical field. Surely, this multiplicity played a role in the process of organ transplantation and the procurement of organs post mortem. Could it be that doctors and medical staff were at their leisure to interpret the policy of presumed consent and in doing so helped thwart the potential backlash from



those opposed to the practice of organ extraction for the purpose of transplantation? And so I was intrigued by how doctors' collective or individual medical practices ensured the success of a technology vital to the many individuals who depend on organ transplantation to restore their health.

Furthermore, Vienna is only one of four transplant regions within Austria, each varying in the number of donors per year. Something or someone had to have an impact, direct or indirect, on this variation and in my mind, medical staff members were crucial to the successful procurement of organs, and it could well be that their influence, or lack of support for a given technology, could affect organ transplantation. For even when a policy mandates a given plan of action, interpretations of that policy are to vary widely among individuals. Could it be that medical staff members across different settings were interpreting this policy in different ways, thus accounting for some of the variation that exists across the different regions? That is what I set out to understand.

My goal was to identify the crucial actors involved. There were quite a few as Austria forms part of an organization called Eurotransplant who coordinates explantation and transplantation among its eight member countries. Given that I was interested in the local practices and their subsequent effect on organ transplantation, I was mostly concerned with the role of doctors, nurses, and in-house coordinators and I hoped that one-on-one interviews with these individuals would provide insight relating to the practices of medical staff as individuals, but also as representatives of an institution that promotes organ transplantation by adhering to the policy of presumed consent, while simultaneously ensuring the well-being of patients that may transition into potential organ donors after failure to respond to treatment.

Although my focus has changed since my first encounters with literature and the policies within Austria, my interest in the practices of medical staff members remained a focal interest and the possibilities for research seemed endless. The next step was to focus on establishing a set of research questions that would reflect my interests in the policy of presumed consent, but that would also showcase how medical staff members interpret such policies and employ them in everyday practices.

### **3.1 Research Questions**

In my own research, I was focused on understanding what experiences and preconceptions about organ transplantation guide the practices of medical staff members in relation to the procurement of organs post-mortem. While focusing on

their role in relation to the next of kin, I was intrigued by the distinct experiences and preconceptions of medical staff members in contrast to next of kin because this allowed me to focus on the unspoken realities that shift medical practices in the process of organ procurement. It is my belief that the collective and individuals practices of medical staff members are shaped by taking into account the varying opinions of next of kin, but also the past experiences with next of kin.

In efforts to simplify the task at hand, I focused on the following two questions:

How do medical staff members conceptualize actors in relation to organ transplantation and how do these conceptualizations lead to practices in action?

Do legal regulations guide the practices of individual medical staff members and if so, how are the practices reflective of these guidelines?

The belief systems of individuals and institutions affect medical staff members which may ultimately decide whether or not an organ extraction takes place after an individual has been declared brain-dead. This is important because, at present, the policy of presumed consent is viewed as one of the sole reasons for high organ transplant rates, however, we do not truly understand what other factors contribute to or hinder procurement rates (Oz et al. 2003). Medical staff members have the opportunity to use their authority without regard for next of kin, but they may also choose to engage next of kin in a way that allows for an advantageous compromise for all parties involved. The practices of medical staff members are telling because they are reflections of their interpretations and conceptualizations, which influence the procurement process at various stages.

In discussing the first question posed, my aim was to understand how all of the actors, from next of kin to the hospital bed, influence the practices of medical staff members in everyday settings. Are they influenced by their colleagues, by their personal convictions and beliefs about organ transplantation? How do conceptualizations of a human or non-human actor affect the procurement practices of medical staff members? Furthermore, how do their views of Austrians and next of kin play out in medical practices? The second question's aim was to focus more on the ways in which the policies and guidelines, also non-human actors, influence the procurement practices of medical staff members. The interpretations of policies and guidelines, but also the enforcement of such policies is of interest in understood how practices are shaped.

Even with these two questions in mind, many more fluttered around my head and made their way into this thesis by way of the interviews. In fact, during the interviews, knowledge was shared that shifted my interests and added to the depth of organ transplantation. For example, in efforts to focus on the ways in which medical staff members conceptualize organ transplantation, I had to understand how they conceptualized the human and non-human actors within the world of organ transplantation. Should brain-dead patients be considered valuable objects harboring organs that could be used to restore the health of individuals with a chronic illness by medical staff members, then presumed consent legislation would likely be guiding the practices of medical staff members. Alternatively, if medical staff members do not conceptualize brain-dead patients as potential donors, presumed consent legislation has failed to impact the practices of medical staff members positively. The same proved to be the case when trying to identify how the policies truly play out in medical settings, as they are directly influenced by the human and non-human actors that are part of this realm known as organ transplantation.

I find these questions to be of importance because they focus on the practices of medical staff members in relation to a sensitive topic. In focusing on medical practices at distinct hierarchical levels and in distinct settings, we can witness how the day-to-day practices of individuals function as tools employed by individuals to make sense of complex worlds and interactions of daily life (Garfinkel 1967). The objective herein lies in witnessing through Conversation Analysis and Ethnomethodology how medical staff members' practices serve to make sense of the world of organ transplantation with its many human and non-human actors each conveying meaning to everyday practices.

Ventilators, hospital beds, next of kin, patients, legislation, and procurement organizations all co-exist in the world of organ donation and transplantation – they are actors within a network (Latour 1992). Medical staff members are expected to employ succinct practices in their daily duties in dealing with patients and next of kin, as well as the choosing appropriate treatment for patients; therefore, noting how the practices of individual doctors and nurses maneuver this complex world sheds light on factors that most influence the practices of medical staff members in the process of organ procurement (Dodier 1998). In focusing on the practices of medical staff members in relation to organ procurement, we can understand more about the relevant factors that motivate medical staff members to act a certain way in particular settings.

The legal regulations currently in effect in Austria such as the policy of presumed consent are of importance. In understanding whether legislation motivates medical staff members to procure organs, practices are an important factor in

determining how the medical staff members interpret legislation and their particular role in the world of organ donation and transplantation. Having a stance on the topic dictates the likelihood that a specific course of action will be taken, but the actual practices that one adheres to are more telling than the words we use to convey our opinions.



## 4 Methods

Given that this research project was intended to delve deeper into understanding the organ procurement practices in medical settings, interviews were chosen as the primary data collection method. Interviews, I hoped would allow me to understand how each individual working toward procuring organs places him or herself in this world and manages to mentally cope with the various tasks that are involved in the procurement process. I therefore assumed that interviews would be able to best highlight the subtle ideas and frames that motivate a particular course of action on behalf of medical staff members. I was reassured by Flick et al. that employing qualitative methods would prove fruitful given the vast possibility of questions that qualitative methods can handle (2004). It seemed to fit well with my aims in conducting this research, since a qualitative method “seeks to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features” (ibid., 4).

A primary goal during the interview process was to allow the interviewee the flexibility to speak his or her mind regarding organ transplantation and anything related to the process. In this way, I hoped to compare and contrast topics and themes that arose naturally during the interview and those that did not, but that rather depended on direct questioning. With these aims in mind, the semi-structured interview proved to be of use (ibid.). The questions were not posed in the same manner, or in the same structure for each interview. Rather, the questions were posed rather distinctly for each interviewee and came up at different times during the interview depending on whether the interviewee had mentioned something related to one of the questions formulated prior to the interview or not. The loosely structured interview method allowed each interviewee to speak freely about the topic, thus allowing each individual to share their main thoughts and concerns relating to the varying rates in organ procurement, medical practices and procedures, and ethical aspects relating to the current policy governing post-mortem organ donation within Austria. This approach also allowed the interviewees to share their own particular experiences with organ donor’s next of kin, colleagues, and patients waiting for an organ transplant. These experiences often shared similar characteristics.

This allowed me to analyze the topics and themes that came about in more than one interview, thus suggesting importance given that more than one interviewee shared certain views or experiences. Any common views or experiences could serve as an indicator of systematized practices or procedures. Differing views or experiences

could point to different work practices followed by medical staff members within one hospital or individually that might also impact procurement rates.

I was then tasked with transcribing the data since employing a qualitative method “produces data in the form of texts – for example, transcribed interviews or ethnographic fieldwork notes – and concentrates, in the majority of its (hermeneutic) interpretative procedures, on the textual medium as a basis for its work” (ibid., 8).

#### **4.1 Who and Why: Relevant Actors**

Identifying the relevant actors was crucial for the research process. While I chose to focus on medical staff members within Austria, the procurement process is affected by a variety of relevant actors whose influence varies greatly. Were I to focus on all the actors involved, interviews with policy makers, Eurotransplant representatives, coordinators, doctors, nurses, and representatives from other institutions would have been necessary, not to mention those affected directly, such as organ recipients and the family of deceased donors.

The research focus, being on how the policy of presumed consent shapes and structures the procedures and practices at a particular stage in the procurement process in the Austrian context, resulted in selecting medical doctors and nurses employed at a hospital within Austria for interviews. This allowed me to focus on the individuals who impacted the procurement process in a direct way, but who are also the first to witness the resistance or acceptance of the policy and the biomedical technology from the next of kin of potential organ donors. Medical staff members, are therefore, tasked with ensuring the success of a policy that leaves little room for negotiation, while caring for patients and ultimately reaching an agreement between the policy and the next of kin who might oppose the procedure of organ extraction for donation.

The rest of this thesis will refer to “medical staff members” as those individuals currently or formerly employed in a hospital within Austria and whose function in that hospital is (or was) to care for patients – thus, doctors, intensivists (as defined by Merriam Webster’s Online Dictionary: “a physician who specializes in the care and treatment of patients in intensive care”<sup>14</sup>), nurses, surgeons, specialists, etc., will be referred to as medical staff. Furthermore, I chose not to focus on particular job titles given that organ procurement rests in the hands of individuals who work together for a

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<sup>14</sup> Merriam-Webster Online, <http://www.merriam-webster.com/medical/intensivist> (October 18, 2013)

common cause. Doctors, nurses, coordinators, intensivists, all work jointly, fulfilling a different role in their respective job. Thus, the phrase 'medical staff members' seeks to incorporate those individuals working in the medical field whose job it is to look after the well-being of patients in their care. They do not create the policies that dictate their role within the setting, but they are recipients of information which guides their practices day in and day out.

These individuals must follow guidelines stipulated by such policies, but as Mol and Berg point out in their work, reality interferes (1998). Reality, in this instance, means that individuals lay in hospital wards awaiting transplants, while others become potential donors in a neighboring ward. Doctors, nurses, and coordinators must work to fulfill their duties as representatives of an institution whose role it is to follow policies set forth by another institution. It is their duty to interpret and carry out the task at hand. How do they do it?

Medical staff members were also chosen given that they are generally in contact with the deceased donor's next of kin. According to the policy of presumed consent, medical staff members need not consult with the deceased individual's next of kin for permission to extract organs for transplantation. Their proximity to next of kin suggested that medical staff members had to tactfully handle the situation at hand: inform next of kin of the death of an individual and extract organs from the deceased donor. However, organs extracted from a deceased individual without consent from next of kin would likely result in backlash for the policy or even for organ transplantation as a technology. It also seems reasonable to suppose that some next of kin would oppose to the procedure when informed by medical staff. In these situations, medical staff members are to praise for their success, but how does one accurately measure that success? Is success measured by the acceptance of organ ex-plantation by next of kin, acquiring a viable organ for transplantation, the ability of a doctor to exercise his authority and uphold the policy in place, or the option to succumb to the next of kin in an attempt to avoid controversy that may lead to changes in the policy that has been credited with saving the lives of many?

#### **4.1.1 The Main Characters in This Research Project**

While there are many supporting characters in this research project, there are 3 main characters without whom this story would not exist. My three main characters are my three interviewees who were kind enough to provide their time to an inexperienced, but highly motivated researcher wishing to complete a master's thesis on a fairly



sensitive topic. To maintain the privacy of each interviewee and to retain some consistency, all three characters have been given different names so as not to reveal their true identity. This decision was made in an effort to respect each character's contribution to this work. While two of our characters stated that the researcher – in other words, I – could decide upon how to use the material provided and had no preference over whether or not they were to remain anonymous contributors or not, one character chose not to be identified, thus allowing me to make a final decision. You see, given the power to decide over whether or not these individuals would be anonymous or identified, left me rather confused. My third interviewee put an end to my inability to decide by asking that his identity not be revealed. Thus, the decision was made to maintain each interviewee's identity anonymous. Chapter 4 will introduce all three characters in more depth.

## **4.2 About the Interview**

While I had already decided that the most relevant group to interview would be medical staff, I was unsure whether or not I would be able to gain access into this network of individuals. A main goal was to conduct two interviews in the same hospital and one interview in another hospital. I had hoped that this would allow me to compare any findings and contrast them based on their setting. I had also expected that this would help to highlight whether the practices that medical staff members employ vary on an individual basis or vary depending on the institution to which they belong – for example, Margaret Lock notes that some of the individuals she interviewed had different practices such as anesthetizing organ donors who were brain-dead prior to extracting organs for transplantation (to prevent sporadic movement during organ extraction), while others interviewed at a different hospital chose not to do so given their belief that the brain-dead individual feels no pain given their condition (2002).

All of the interviews were conducted in Vienna. Two of the interviewees are employed at the largest public hospital in the city, a hospital well known for its involvement in organ transplantation. The other interviewee is employed at a smaller, but equally well-known hospital in Vienna. Given that my interest lies in identifying how medical staff members interpret guidelines and allow personal experiences and circumstances to impact procurement rates, interviewing medical staff hailing from distinct medical settings and from different positions within the medical field, would provide a greater opportunity to witness the different conceptualizations and practices employed by these individuals in their day-to-day professional life.

#### 4.2.1 First Contacts

I contacted the first interviewee via email. I had come across a very informative presentation on organ transplantation and procurement, and the individual who gave that presentation happened to be a doctor and professor at the Vienna General Hospital (Allgemeines Krankenhaus). Initially, I thought this individual would know of a medical staff member or two that might be willing and able to meet with me to discuss post-mortem organ procurement in Austria under presumed consent legislation. In an email response, this particular individual stated that I could interview him. I thought it would be interesting to speak to this individual because he seemed very knowledgeable about the subject. I contacted his assistant to set up an appointment, as I had been told to do so in the email. The assistant very kindly informed me how to get to the doctor's office and reassured me that the doctor was very nice and that his English was very good – this was because I asked if he thought it would be possible for me to bring an audio recorder to the interview, given that I wanted to record the interview.

I also emailed quite a few other doctors within Vienna and outside of Vienna. Not many responded. Those who did often took a bit of time to do so. Some responded positively to my request for an interview, a few suggested that I contact their colleague who would likely be able to be of more help. Since my first interviewee mentioned that nurses often play a crucial role in the organ procurement process, I later emailed him to ask if it would be possible for him to recommend a nurse for me to speak to. Dr. Baker, the first interviewee, suggested that I contact the head nurse who responded positively to my request. Thus, another interview was scheduled; this time, with a nurse. Upon my arrival the Vienna General Hospital (Allgemeines Krankenhaus) for the second time and the second interview, I was informed that the head nurse could not conduct the interview, but that she had arranged for another nurse to meet with me. "This might be a problem," I thought to myself, given that this time around I had expectations of the interview and the interviewee. How could this be if I had never met the nurse and I had only preconceived my own notions of what to expect based on the title "head nurse" that was attached to her name?

Fortunately, my interview with Nurse Sam went smoothly. Again, I was armed with more data for my research. Nurse Sam aided my research in many ways by providing candid responses, but also by enlightening me to the fact that personal beliefs and thoughts on a subject don't always lead to specific courses of action. You see, Nurse Sam noted that in a survey that took place in his hospital ward some years ago, medical staff members were polled on their willingness to donate their organs and

many of them responded that they would prefer not to be a donor after death. Yet, these same individuals forwent opting out in light of their beliefs.

#### **4.2.2 English Interviews In A German Speaking Country**

All three interviews were conducted in English. All three interviewees are Austrian, and their native tongue is German. Nonetheless, English is widely spoken throughout Austria and within the medical community. Having the interviews in English did not pose an issue for those interviewed, apart from the occasional word or phrase that escaped them at the time. Each interviewee, even while having a strong command of the English language, sought to ensure that his thoughts were understood as a native English speaker would have done.

Conducting the interviewees in English was important for two main reasons – the first being that my understanding of German would not be sufficient; the second being that the thesis would be written in English, thereby requiring the data to be presented in English. Had I been tasked with conducting an interview in German, transcribing and translating the data, this research project would have fallen short on many more levels.

#### **4.3 After the Interview, Before the Analysis**

Each interview was audio recorded, and later transcribed. Two interviewees initially showed some concern regarding the audio-recording, but their main goal was to “help” and so they acquiesced to the audio recording if it helped me. Transcribing the data took quite some time and quite a bit of effort. In trying to maintain the conversational flow of the interviews, the data was transcribed in such a way that grammar and language corrections were not made. If a word was stated during the interview and it was incorrect, it was transcribed as it was originally used – no corrections. Punctuation was only used to help determine where individuals paused during their speech. In all three cases, I had to listen to the interviews from start to finish more times than I could keep track of. I noticed something new almost every time.

#### **4.4 What I'd Like to Hear: A Few Reflections on Interviewing**

Two interviewees stemming from the same hospital, holding distinct positions, were extremely intent on providing information that would help me in my research; one interviewee summed it up by suggesting that my research may be of benefit to his work and that it was important to help each other. This particular stance was beneficial to me, but also posed a bit of concern for the interviewee given that his intent was to provide answers that would be helpful to my research. At one point during the interview, he asked whether or not his answers were what I was seeking. Nonetheless, his responses were candid and insightful.

Luckily, I wasn't seeking any particular answers, but rather, I hoped that the interviewees and their responses would guide me along the way and provide reasons as to why Austria experiences varying procurement rates across its four transplant regions, how medical staff practices impact procurement rates, and how procedures and guidelines are interpreted and applied (or ignored) by staff members, but also what motivates individual staff members and even next of kin to perform or agree to an extraction of a deceased individual's organs for transplantation.

As stated previously, the interviews were loosely structured to allow for each interviewee to present his views. "No" and "Yes" as responses were not sought after, so it was critical to pose open-ended questions. From there, most of the participants expressed their thoughts on various topics and themes related to organ transplantation. On occasion follow-up questions were posed to maintain the flow of a conversation and to initiate a transition to a topic briefly mentioned by the interviewee. The loose structure of the interviews and the varying responses of each interviewee resulted in three interviews of varying length. The shortest interview was forty-seven minutes long (excluding introductions and good-byes), while the longest interview was slightly over one hour. Since content, as opposed to length, was of primary interest, the duration of each interview posed no threat to the soundness of the data collected.



## **5 Approaching the Data**

Approaching the data proved to be the most critical part in analyzing the data properly. I had conducted semi-structured interviews and then I was to analyze the data with the help of Conversation Analysis. The problem was that there was quite a bit of data and I needed an alternative approach that would also help me view the relevant positions of the medical staff members; for that, I selected Grounded Theory.

### **5.1 On Grounded Theory**

Coding proved to be beneficial because it “distills data, sorts them, and gives us a handle for making comparisons with other segments of data,” which was of key importance given that comparisons were to be made among three distinct sets of data (Charmaz 2006, 3). Consequently, maintaining the authenticity of the data was of importance – this study was concerned with how different individuals may interpret statements (or policies) differently based on their personal and professional experiences – my job, therefore, depends on presenting the data in a way that sheds light on particular issues that may be hampering organ transplantation and not of constructing these issues from the data collected. Charmaz discusses how coding allows researchers to “define ideas that best fit and interpret the data” and so it seemed clear that Grounded Theory would help accomplish the task at hand (2006, 3). Still, Grounded Theory and coding, as discussed by Charmaz, afforded me the flexibility I was seeking in analyzing the data given that the “guidelines” are not limiting one to follow a specific path laid out by predecessors like Barney Glaser and Anselm Strauss.

This qualitative research approach sheds light on distinct factors that influence organ transplantation within Austria, but possibly in countries who share the policy of presumed consent. A quantitative study, such as those conducted by Floden et al. or Sanner et al. yields relevant data, but lack the possibility to delve into the various issues that affect those who are entrusted with successfully maintaining the health of some patients, while procuring the organs of others (Floden et al., 2011; Sanner et al. 2006). These very issues are factors that play a relevant role in the successful procurement of organs throughout Austria. While some may argue that quantitative results tend to provide superior data to that of qualitative results, each methods has pitfalls and advantages that the researcher must be aware of in order to minimize inaccuracy. In choosing to employ Grounded Theory or any other method, for

example, the researcher must be aware that “how you collect data affects which phenomena you will see, how, where, and when you will view them, and what sense you will make of them (Charmaz 2006, 15).

## 5.2 On Conversation Analysis

In conjunction with Grounded Theory, which was employed due to the benefits of coding data, Conversation Analysis made it possible to view and analyze phenomena relating to the interviewees’ professional status.

Paul Drew and John Heritage discuss their interest in employing Conversation Analysis as a method for which to analyze various and distinct transcripts in an attempt to shed light on “ways in which institutional contexts are manifested in, and in turn shape, the particular actions of both professional and lay interactants” (Drew & Heritage 1992, 24). Their work has influenced my thesis in many ways. In particular, I seek to understand how medical staff help “shape the particular actions” of those involved in the process, including next of kin who may be in opposition to the current legislation which dictates that all individuals are organ donors after being declared dead. In discussing the benefits of Conversation Analysis, Drew and Heritage note that it can be applied to institutional talk as well as ordinary conversation, thereby noting that its use on data from media interviews, legal hearings, job interviews, doctor-patient interviews, and health visits can serve to show how interaction and dialogue from various settings can be analyzed. The flexibility largely attracted to me Conversation Analysis because it can be applied to the interviews for my thesis. Furthermore, Conversation Analysis can be done on video or audio recordings (I only did audio). Although a *conversation* took place between myself, as the interviewer, and the medical staff members, my analysis will not focus on my presence in the interviews, but rather, Conversation Analysis will be employed to understand the moments when medical staff members choose to employ certain terms to discuss their role in the procurement process or their particular experiences.

Through their analysis, Heritage and Drew note that the use of particular language in a particular setting can be used to enact one’s profession. Drew and Heritage also note that language use can highlight a variety of different aspects and create meaning within a given context. Thus, I hope to properly employ Conversation Analysis to identify how particular language, interpretations, and actions (practices) affect the practices of medical staff members whose role involves successfully procuring organs from deceased individuals. Drew and Heritage move on to discuss

'institutional' talk and settings noting that in such contexts “participants organize their conduct by reference to general features of the tasks or functions of particular social institutions as they understand them within either a vernacular or technical competence” (ibid., 22). In this case, the hospitals in which these doctors practice, but also the guidelines which they are expected to follow are likely to “organize their conduct.” Drew and Heritage note how individuals choose to use “we” as opposed to “I” thereby noting that the individual seeks to contribute as a representative. The “we” can be used in efforts to diminish or exalt one's authority. The use of a doctor's “we” may serve to show that in the event of a problem, he was only serving as a representative of an organization and the blame would not fall solely on him. In other instances, it may serve to strengthen an individual's authority. Some of the following excerpts will highlight this “phenomena” and while I consider that the use of “we” and “I” in the interview may also be trivial at times, I find this distinction important because it points to instances where the interviewee may seek to lessen his assumed influence as a doctor or enhance his authority.

Employing Conversation Analysis to note how the individuals reference their position as medical staff and how the policies and institutions to which they belong shape their actions. These interviews are also intended to shed light on how the practices of medical staff affect donors and their relatives. While I am choosing not to observe how relatives are informed of the policy of presumed consent or to interview relatives of deceased donors, I am interested in shedding light on how medical staff members' practices evolve – how they inform the family, whether there is often opposition on behalf of the family, and how they deal with the opposition on behalf of family members when a policy dictates that they may proceed without regard for their opinion.

Conversation Analysis will then be employed to understand whether the medical staff members position themselves as representatives without choice but to follow guidelines or if they position themselves as individuals employed by an institution which must follow such guidelines. Focusing on Dodier's use of frames to understand how medical staff members' practices vary in relation to their settings. Much can be gained from such interviews with such key actors in the domain of organ transplants. The work of Drew and Heritage guided me to employ Conversation Analysis in my research. While I hope to use their concepts to identify if, when, and how a medical staff member positions him/herself, I will not be using all of the typical methods outlined. Rather, my main focus in applying Conversation Analysis lied in identifying “professional cautiousness” which will signify how medical practices are shaped by policy guidelines (ibid.).



### 5.3 On Actor-Network Theory

Within the realm of organ transplantation, there are many actors and networks that determine the fate of organ transplantation within Austria, but also worldwide. In efforts to understand more about this organ transplantation, I decided that employing Actor-Network Theory would be of benefit because it could help provide insight on:

- How medical staff members view actors such as donors
- How next of kin view the potential donor as a living or lifeless entity
- How humans conceptualize a given technology and how decisions are made taking into account such considerations

Actor-Network Theory allows for one to view non-human actors, that is, inanimate objects, as having influence over human actors. In this sense, human actors also have influence over non-human actors, but the ways in which they shape each other can be scrutinized under a different light allowing for us to identify how medical technology, such as ventilators, which are so crucial to organ transplantation, help shape the world of medical staff members and patients, our human actors, but also organ transplantation.

I believe Actor-Network Theory to be an important theorizing tool that may impart useful concepts about the relations between human and non-human objects. Often overlooked relations between a technology and humans tend to be of critical importance because they tell us about how humans conceptualize a given technology and how decisions are made taking into account such considerations. Institutions are also actors that influence the development of technology and the ways in which humans interact with such objects. Furthermore, I believe Actor Network Theory may also prove helpful in understanding how medical staff views actors such as donors. Given that individuals are considered suitable for organ donation if declared brain dead, the theory may help illuminate how medical staff and how relatives of the donor in question frame him or her as a living or lifeless entity. In understanding how the donor is defined on behalf of both parties, we may be able to answer more prominent questions about the process of organ procurement and transplantation.

## **6 Empirical Data**

The data and analysis of the data have rendered specific patterns that will be presented in such a way as to aid the understanding of themes that arose throughout the interviews. Similarities and differences stemming from each interview were the primary reasoning for grouping specific data in an effort to showcase the medical practices of staff members in relation to the organ procurement of deceased individuals in hospital settings. Excerpts from interviews are used to highlight the findings, especially when the data presented serves to highlight similar or differing opinions on behalf of the three interviewees.

The data selected intends to showcase how medical staff members from distinct settings, hierarchical levels, and specializations come to have similar thoughts and practices relating to organ transplantation and closely related topics that influence post-mortem organ procurement in hospital settings. The themes that have been identified serve as sections of this chapter, and data and analysis of these sections follows. At times, the data may serve to highlight fairly interesting conceptualizations on behalf of the interviewees. The data should therefore be viewed as an attempt to understand how these conceptualizations shape the practices of medical staff members working toward organ procurement and not as a point of departure for criticizing individual stances.

The data will be analyzed with some tenets of Conversation Analysis and Actor Network Theory in mind, but will also be a reflection of Grounded Theory and therefore seek to address the most prominent themes that came about from each individual interview, but also from the interviews in conjunction with each other.

### **6.1 Setting the stage**

I was pleased with the first interview's outcome. I hadn't expected much from the interview, mostly because I didn't know what to expect. I knew that it was my first real interview and I was content to use it as a test-run if it didn't provide what I was looking for. Yes, that right, although I didn't know what to expect of my interviewee and the interview itself, I knew what I wanted more information on. Specifically, how the medical staff members deal with organ procurement at all stages of the process. How and why were certain approaches taken and what did this mean about medical practices as a whole? Fortunately, the interviewee was very candid in his responses. Relatively little prodding on my behalf was necessary for the interviewee to discuss his

thoughts, concerns, experiences of organ transplantation and everything that goes along with it such as speaking to relatives of the deceased to discuss organ donation.

As I waited for my interviewee in the hospital corridor outside his office, I witnessed nurses and doctors pass me by. I sat quietly waiting for Dr. Baker to arrive. Upon knocking on his assistant's door, I was informed that Dr. Baker was in the intensive care unit and would be back shortly. Shortly after, two men came knocking on the assistant's door just as I had done minutes before; it seemed they were also interested in speaking with Dr. Baker. Like me, they took a seat and waited. Minutes went by and Dr. Baker, unbeknownst to me at the time, walked into the assistant's office and I was called in shortly after. We proceeded into Dr. Baker's office where I promptly took my pen and paper and an audio recording device from my bag.

He seemed confident in his responses and even more so in his opinions which spanned from his thoughts on medical staff members, religion, procurement rates, etc. It was here that I heard Dr. Baker's personal experiences procuring organs at the Vienna General Hospital (Allgemeines Krankenhaus), but also abroad while helping to set up a transplant program. As our senior medical staff member (both in terms of age, when compared to the other two interviewees, and years of experience), Dr. Baker had experiences ranging from positive to negative ends of the scale. I never saw any brain-dead patients who were presumed potential donors at any of my visits to the hospital, and I am not familiar with the typical procedures for removing organs from a deceased donor. The texts I read and the interviews informed me about many of the procedures that would typically occur in a hospital (Lock 2002). Depending on whether there is a coordinator or not, a patient might be identified as a potential donor when the patient has shown no signs of improvement, when the patient's health continues to deteriorate after life-saving efforts have been made on behalf of medical staff members.

Declaring an individual brain-dead tends to bring up questions about the possibilities of life and what death truly looks like – keeping in mind that most brain-dead patients look as though they are still alive. Traditionally, a non-heart beating donor would be considered a potential organ donor. This was not so difficult for next of kin to understand given that we, as a society, have generally accepted death as the demise of the heart. Now, the most common type of donor happens to be the brain-dead patient. “Worldwide, there is a widening gap between the need for organs for terminally ill patients and the supply of necro-organs both because intensive care has become more successful in saving the lives of individuals with severe brain damage and because transplantation surgery is increasingly successful in transplanting organs to new categories of patients” (Sanner 2006, 133).

Depending on the situation, medical tests will determine if the patient is brain-dead. These tests generally require a waiting period to ensure that the diagnosis is not premature (European Commission 2003). If the results are positive and the person has been diagnosed brain-dead, the family will be involved in a discussion regarding organ donation, sometimes a doctor may discuss the possibility of donation prior to the diagnosis. Usually, brain death diagnosis means that the patient will be on a ventilator. On the exterior, this patient *shows no signs of death*. If the family agrees to organ donation, the patient will continue to be cared for until the arrangements have been made to remove his or her organs. Once the time has come, the ventilator will be turned off and the patient will be taken into surgery (Sanner 2007; Lock 2002).

Other individuals suffer cardiac death, in which their heart ceases to beat. If efforts to resuscitate the individual fail, he or she may also be taken into surgery to remove organs for donation. Patients who cease to live due to cardiac death might generally give doctors relatively little time to speak with next of kin. In most cases, cardiac death is sudden and organs must be procured shortly after death to ensure that the quality of the organs is not compromised. This allows little time for medical staff members to engage with next of kin to discuss organ extraction, should the deceased be considered a potential donor. Once a decision has been made, the organs are explanted and transported to the transplant hospital where a recipient awaits. You have just heard the short and simple version. The complex process summed up into a few actions.

In reality, organ procurement involves a number of practices that are dependent upon the medical staff member's notions of brain death, organ transplantation, what constitutes a patient and what constitutes a potential donor, legislation, and the next of kin who are all intrinsically involved in the world of organ transplantation. Since these notions affect all of the actors involved and impinge upon the agency of some, we will begin by focusing on the personal notions of medical staff members.

## **6.2 A Strict Law**

As noted in the first sections, Austria exercises a relatively strict version of presumed consent legislation. The following account from Dr. Baker confirms that although a strict law exists in principle, another approach prevails in practice concerning presumed consent organ donation:

*“There is a strict law, but there is always a, like, human way to go... That’s how it is done at the moment...”* (Dr. Baker)

To begin with this quote is to acknowledge that medical practices, although guided by policies and guidelines, are modified according to the cultural values and conceptualizations of those who enact them. The interview began by discussing presumed consent legislation and the fact that “technically,” organs of the donor can be removed without need for consent from next of kin. Dr. Baker, however, suggests that there is a “human” way to go. Perhaps the use of the term “human” links procurement efforts and practices to the term *humane*. Similarly, the term “human” does a decent job of distinguishing itself from non-human actors who, although influence human emotions, have no emotions themselves.<sup>15</sup>

Dr. Baker thus acknowledges that even if a strict law exists, the opinions of next of kin are generally taken into consideration when organ donation discussions occur. Although medical staff members, in principle, have the authority to override the next of kin’s refusal to post-mortem organ donation, the current practices tend to be less strict in practice than they are on paper. Other factors, for instance, prior experience in dealing with next of kin, cultural values, or even the interpretation of guidelines that stress respect<sup>16</sup> for the deceased individual may be interpreted in such a way as to influence the procurement practices, even when the laws are strict. In this regard, the medical staff members’ practices are influenced by their own particular knowledge of what “human” or “humane” implies.

Practices will vary according to the medical staff member, but they may also vary according to a variety of factors, such as the area or culture in which one practices. Countries establish their own procurement laws and guidelines. These are meant to guide the medical staff members to ensure the safety of the procedure for potential donors and recipients, but also to ensure the effectiveness of the transplantation network. Each system employed, however, depends on the willingness of the actors involved.

*“The Austrian system is different from others. Which one is better? Nobody knows. You have to communicate in a different way in the different systems*

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<sup>15</sup> To be clear, my use of the term “non-human” best reflects non-living entities, so as to exclude animals and other living organisms that, although non-human, do express emotion.

<sup>16</sup> Possibly taken from a law that stresses respect for the body after death, see § 190 StGB Störung der Totenruhe. Federal Law on Hospitals and Health Clinics (Bundesgesetz über Krankenanstalten und Kuranstalten – KAKuG), section 7, §§ 62a to 62c also notes that “the removal of organs or parts of organs shall not disfigure the corpse in any disrespectful way.”

*and the outcome could be the same and the outcome is measured by, like, organ donations by million inhabitants. Could be the same and it depends not so much on the policy or laws that are behind it, but on the activity of the people that are working. In both these systems you can have a donorship of zero. If the intensivist, doesn't find the patient to be reported to transplantation system, nobody would be explanted, and if nobody would be on the list in another country, nobody would be explanted as well. And that's why you have to work in a different way – with the list – you need to motivate the people to go to the list and in other countries you more need to motivate the doctors...” (Dr. Woods)*

Dr. Woods acknowledges the role of medical staff members in the procurement process noting that different practices are necessary according to the policies that exist in each country. A country in which informed consent is practiced may be dependent upon the willingness of citizens to become organ donors after death and on their subsequent enrolling on a donor list. In my opinion, countries with presumed consent legislation may benefit from reducing the agency of individuals because an increase in available organs may follow. This also reduces the possibility that some individuals, although in favor of donating their organs after death, skip registering their names on the donor registry. The successful procurement of organs under presumed consent legislation, however, requires not only increased amounts of agency for medical staff members, but Dr. Baker believes the successful procurement would then be dependent on those who actually choose to pursue organs from deceased individuals for transplantation.

The interview quote also places emphasis on the role of the intensivist or medical staff member involved in the procurement of organs and on the fact that the intensivist be able to report a potential donor. This requires that the intensivist be able conclude that a particular patient may be a potential donor. Thus, under presumed consent legislation, the role of the doctor in identifying a potential donor should be well understood and delineated. Being able to properly identify a donor would therefore suggest that organ shortages are kept at bay, but how can policies and guidelines be enacted in practice to ensure that the stated objectives are met? These are questions that would require more in depth analysis, but that could provide insightful material for Science, Technology, and Society scholars. For now, discussing the practices of medical staff members may help provide some understanding about the shaping of such practices.

### 6.3 Personal Notions

How do personal notions regarding the policy of presumed consent within Austria hinder or benefit the world of organ transplantation, given that to some, the policy of presumed consent may be viewed as diminishing the power of the individual within society to make a choice? Medical staff members, for example, are tasked with carrying out beneficial steps to ensure that the policy accomplishes its stated goal of ensuring more organs for patients in need of transplantation (Kaushik 2009). Thus, it would be of benefit to analyze the ways in which medical staff members carry out the task at hand according to the policy and guidelines, or whether their own personal notions regarding organ transplantation contribute to the success or failure of the procurement process.

*“...so in my conclusion, and this is my conclusion for presumed consent regulation, is that those countries in which there is a presumed consent regulation regardless of whether they observe it like us in a weak way or Spain which doesn't observe it at all, uh, presumed consent is a mirror of the populations attitude towards organ donation... so organ donation in this country is widely recognized and accepted.” (Dr. Baker)*

Dr. Baker addresses his personal thoughts on the policy of presumed consent, yet the last fragment seems to be in contradiction with the belief that many individuals are unaware of how the policy of presumed consent affects them given that Austria is said to exercise a policy of discretion (Felt et al. 2010). As another example, we can also return to the figures showcased by the Special Eurobarometer 333a, which suggest that the policy is not “widely recognized” by the Austrians polled. However, this statement may suggest that most individuals, upon becoming aware of the stated policy, are in agreement with organ transplantation in general and therefore accept the current policy of presumed consent.

Dr. Baker's thoughts also stand out because of the transition from “my” to “us”. Initially, Dr. Baker makes an effort to state his personal opinion by stating “my” and emphasizing that this is his personal opinion by reiterating “my” only to later incorporate “us” to show that he also views himself as part of the population affected by presumed consent. The use of “us” could also suggest that he has an opinion similar to that of the general population. This proves interesting given that Dr. Baker ascertains that this is his personal opinion, yet the use of “us” links him to the Austrian

population in that he belongs to the same group of individuals that are affected by the policy in place.

Similar accounts on behalf of the participating medical staff interviewees strengthen the conclusion that the interviewees view themselves as part of the population and that their beliefs regarding organ transplantation are similar to those of other members residing within Austria. Take, for instance, this excerpt from Nurse Sam:

*“For us here, this is the ideal way. Of course we are thinking it like that because we need the organs to treat our patients, for us that way is the way it should be everywhere on earth. And I guess, here in Austria, it’s a little bit... Austrian peoples are lazy, we, we want the things to be made. Just do it as you have to do it and just don’t ask me and I don’t want have nothing to do with it, just do, so maybe this is working here in Austria quite good because we are like we are...”* (Nurse Sam)

Not that Nurse Sam’s use of “we” shifts through the excerpt. Initially, the use of “we” serves to highlight his membership within the medical community noting that organs from deceased individuals help save the lives of patients. Later in the quote, “we” is used to integrate himself as a member of the Austrian population with whom he shares certain views and characteristics. In this excerpt, Nurse Sam notes that the population shows little opposition to presumed consent legislation because Austrians tend to be indifferent in certain instances.

Yet, all interviewees also responded that many individuals tend to have varying attitudes toward organ extraction when discussions arise in a medical setting such as a hospital and when the individual to be explanted is a family member. Dr. Woods noted that the varying attitudes may arise from the next of kin’s attempts at fulfilling the wishes of the patient, a potential donor, who may have never discussed organ transplantation or their feelings toward the technology while alive. Confronted with making a choice that represents the wishes of the potential donor, next of kin may opt not to go through with the procedure for fear of allowing something that their next of kin may have been opposed to.



### 6.3.1 Presumed Consent

*“...I don’t think that presumed consent is a tool, it’s not a tool to get more organs, it’s rather in my eyes, a reflection on how de we approach organ donation?” (Dr. Baker)*

A concern of mine was to understand how the policy itself was conceptualized by medical staff. Organ transplantation has been conceptualized as a life-saving technology by doctors, patients, policy-makers and many more, that it was surely likely that the policy in place would be regarded as a means to an end by some. This notion proved unfitting when Dr. Baker noted his beliefs regarding the policy in place. Dr. Baker, here emphasized by the use of “I,” suggests that presumed consent is not a tool, or in my words, “a means to an ends.” Rather, Dr. Baker explains the policy as having a beneficial effect on the donation rates as this method proves to be more successful than alternative policies that are presently in use in countries such as Germany where procurement rates have historically been low.

A point of interest stems from Dr. Baker’s use of “we” to signify that he belongs to a group. Here, it remains unclear whether the “we” refers to medical staff and advocates of organ transplantation or whether it refers to his status as a member of the Austrian community. Regardless, the views shared by Dr. Baker are also common among the other two interviewees.

*“I don’t think that people here think about transplants in a bad way...This way for us, for sure, is the ideal way, actually I can say, and, but I think that that problem also the problem with the organ transplant is people do not even know what it’s like in their own country. Transplant is a thing you just have to think about one step before death of some relatives or a friend and you don’t want to think about that” (Nurse Sam)*

Nurse Sam agrees with Dr. Baker as to the current policy benefits and does not view the policy itself as infringing upon some individuals. Both interviewees believe that the policy accurately represents the prevailing attitude of Austrians toward organ transplantation. Nurse Sam also follows in the steps of Dr. Baker by incorporating himself into a group by using “we” to characterize his views and the views of his group. The use of “I,” however, clearly demarcates a boundary between individuals who are not confronted with death and organ transplantation and himself as a nurse who confronts the possibility of death regularly in his professional life. Unfortunately,

attitudes toward organ transplantation and toward the policy of presumed consent may be at odds with individuals who support organ transplantation as a lifesaving technology, and are yet opposed to the current legislation. Philosophers, for example, take concern in challenging legislation and even the notion of brain death on the basis that a patient's rights are often infringed upon when he or she becomes a potential donor.

One might also challenge the notion that the policy is merely representative of Austrians based on the fact that *Austrians* are a diverse group. Many immigrants and second or third generation Austrians are also *Austrian*, but their religious and ethnic views with those that make-up the majority may clash. Secondly, the policy also imposes on tourists visiting the country. Since the policy receives little media attention, many are unaware that they must carry a statement opposing organ donation. Therefore, although the policy may reflect Austrian views, it fails to acknowledge differing opinions on behalf of tourists and the statements made by Dr. Baker and Nurse Sam fail to note that non-Austrians are also affected by the policy and that their opinions may differ to those of *Austrians*.

### **6.3.2 Cultural and Religious Opposition as Perceived by Medical Staff**

When asked about the policy of presumed consent, all three interviewees noted that they felt it best represented the desires and needs of the population, or at least, of most Austrians. All three interviewees believed that most Austrians would want to help other individuals. Fear that a different policy might reduce the number of available organs for transplantation became the sole reason for all three interviewees' support of the current policy. Nonetheless, all three interviewees noted that the situation tends to depend upon a variety of factors: relationship to the potential donor, for example, may result in next of kin refusing to agree to organ donation. Nurse Sam noted that his grandmother would have been strongly opposed to transplantation, but that today's youth tends to be more in favor of helping others. This sense of altruism may then be the reason why many individuals do not oppose transplantation.

While all three interviewees mentioned Austrians as having little opposition to organ transplantation, it might be well noted that there are many individuals from distinct ethnic backgrounds who are also born in Austria or who have acquired Austrian citizenship. Nonetheless, "Austrian" when analyzed in its use by the three interviewees, tends to suggest that it defines members of the population who share common ethnic, cultural, and religious ties. Not all Austrians are Catholic, as are a

majority of Austria's citizens (considered Catholic by practicing the religion or by default), yet the three interviewees seemed to group Austrians in such a way that excluded members of society that had distinct ethnic, cultural, or religious backgrounds because they tended to oppose organ transplantation on the basis of religion. In fact, all interviewees cited religion as one of the primary reasons why the next of kin might oppose organ transplantation.

Religious opposition, however, did apply to "Austrians," as defined by the interviewees, at one point in time. Two interviewees noted that past generations, often viewed as more religious, tended to cite religious views as reasons for opposing organ transplantation. One interviewee suggested that views have shifted because younger generations are not as religious as past generations may have been, while another interviewee noted that when a prominent leader from a given religion accepts organ transplantation, the religious community follows suit, thereby making organ transplantation within the religion more acceptable to the community in general. It is a far stretch to assume that one statement on behalf of a religious leader would significantly alter the opinions of the people, but it may have contributed, along with time, the success of organ transplantation, and changing social values. Pope John Paul II, in this case, may have influenced views of the Catholic community by stating:

*[T]he Gospel of life is to be celebrated above all in daily living, which should be filled with self-giving love for others. . . . Over and above such outstanding moments, there is an everyday heroism, made up of gestures of sharing, big or small, which build up an authentic culture of life. A particularly praiseworthy example of such gestures is the donation of organs, performed in an ethically acceptable manner, with a view to offering a chance of health and even of life itself to the sick who sometimes have no other hope (Evangelium Vitae, no. 86, original emphasis).*

Prior to Pope John Paul II summing up the Catholic Church's view on organ donation, Pope Pius XII had established his support for post-mortem organ donation in the late 1950s, when organ transplantation was still a more controversial procedure due to its lack of success and questionable procurement practices that were highlighted in the media. While both interviewees that happened to be medical doctors were aware of the Catholic Church's stance in stating that organ transplantation was not condemned by the Catholic Church due to its views of charity and donation, the Catholic Church itself may have slightly different views regarding brain death and procurement from brain-dead individuals. This, however, was not mentioned by the

interviewees who were eager to express their concern about individuals who opposed organ transplantation on the basis of religious views when there seemed to be no opposition on behalf of the Church itself.

Like Catholic leaders, Islamic leaders themselves do not oppose organ transplantation; nonetheless, they also tend to have views that differ regarding brain death. Thus, both medical doctors interviewed were knowledgeable in stating that most religious leaders do not oppose organ donation or transplantation, but they failed to mention opposing views to brain death of which, at present, most organ procurements are possible. Some might suggest that other factors may also influence organ procurement. Since Catholic views of charity are highly prominent, practicing Catholics may support organ transplantation based on these practices. Another possibility may be that the term *brain death* itself easily allows individuals to accept the diagnosis as equating to *actual* death. Lock was quick to note that Japanese, for example, do not necessarily find issue with donating organs, but rather, with brain death diagnosis as the end of life (2002). These concerns about brain death might suggest that, if we were to look to religion as a basis for opposing organ transplantation, we might find that the individuals do not oppose organ transplantation on the basis of religious beliefs, as the interviewees so readily noted, but rather, on the next of kin's views on the concept of brain death with which their religion finds issue.

If this happens to be true, medical staff members may benefit from discussing brain death more in depth with next of kin. However, this would ultimately lead to medical staff member's influencing the views of next of kin based on their own views and definitions of brain death. These views and definitions, however, may not serve to convince next of kin that brain death equates to actual death. Not equating brain death with death may occur because of two distinct frames of thought. On one hand, one interviewee noted that although brain death criteria has been formalized to ensure that no doubts exist, one can never know what brain death truly means for the patient. How then, can medical staff members' practices be analyzed in relation to the cultural and religious diversity within a country?

#### **6.4 The Next of Kin**

How does Dr. Baker's relationship to the next of kin change the process of organ procurement? It should be noted that individuals such as next of kin may not view the relationship as reciprocal depending on their views toward the policy of presumed consent, organ transplantation as a technology, and the practices of those

involved in the successful procurement of organs for transplantation. Nonetheless, Dr. Baker suggests that a relationship between medical staff and next of kin develops. This is possibly due to the medical staff members' and next of kin's interaction in the hospital setting.

*“Now, our change was, **these people are our partners in treating the sick people...** and you create a platform of trust... In this case, you, in my feeling, you are obliged to, uh, to exchange all ideas, even including organ donation so in case such a person is going to die, the relatives are informed about the fact that the patient dies and of course at the same side they are also informed that we are planning to do an organ retrieval. If, most people accept this silently, those who do not, who are challenging the decision, will have an interview, a talk, we talk to these people... but if they challenge the idea, okay, then we talk to these people and if we are unable to convince them about the benefits of organ donation we do not do the organ retrieval. So this is a soft kind of, eh, or kind of a soft presumed consent regulation which basically works in most countries.” (Dr. Baker)*

When a doctor or nurse discusses the death of a deceased with next of kin, the topic of organ extraction will come up if the medical staff members feel that the organs are viable for transplantation. In such instances, the families may not be willing to give their consent (which is not legally necessary according to presumed consent legislation) for the procedure, but some instances are different. Dr. Baker discusses his experiences with family members and describes his relationship to them relying on an interesting term: partners. This conceptualization about the individuals who may be viewed as threats to the successful procurement of organs serves as a technique of sorts because it allows the doctor and the next of kin to *work together* toward a common goal as partners typically do, but it also highlights the doctor's willingness to take the next of kin into consideration. This suggests that the policies may often be overlooked in an effort to maintain respect for the wishes of family, but this strategy may also be the reason that the policy of presumed consent avoids jeopardy from next of kin who are in disagreement with the policy over having been dismissed.

The above quote also shows two opposing parties. On one end there is the “we” and on the other there is the “they” or at times, “them.” The statements are important because Dr. Baker discusses a change and he incorporates himself as part of a group and not an individual by using the term “our” to suggest that it was an action adopted by others as well. Note that the use of “we” does not incorporate others as the

notion of partners might suggest. In this case, Dr. Baker's use of we places him as a representative of an institution, but it also places him at the center of a larger group of individuals working toward a common goal. Drew and Heritage note that "we" will often be used by individuals to signify that they are not acting alone, but rather as representatives of an institution, in some ways signifying authority over other individuals, and in some ways showing that the individuals acts only out of commitment to his job (1992). Take for example the following statements made by Dr. Baker:

*"...you know, my personal approach, the reason I am talking to relatives is not because of the deceased person, because **I feel I have to respect these people who are my partners and if there is no one present who should I respect?** I am not taking a telephone and call people in because these people did not communicate with me so why should I have a particular respect for these people, **but if they are my partners** I will certainly because they helped me, so all I feel is respect to the family" (Dr. Baker)*

In this instance, Dr. Baker refers to himself not as "we" thus suggesting he is part of a larger group, but as "I" to show that he can act alone and that his actions are motivated by "respect to the family" (Dr. Baker). In essence, his practices are geared at addressing the procurement of organs, but with an aim to ensure that the family and the deceased are respected. This respect to the family encourages him to act in a particular way, but there is no mention of "we" suggesting that others working alongside him may have different views and practices when dealing next of kin. This respect, it seems, is a personal practice of Dr. Baker's as opposed to a common practice dictated by policy.

Dr. Baker expresses his feelings towards next of kin in this manner as a way of explaining how he feels towards the next of kin, with whom he must work in harmony. As he stated, he must have "respect" for those who are willing to work with him and so he feels obliged to act in accordance with the wishes of family members who were present throughout – mainly in cases where the patient was in the intensive care unit and next of kin had been made aware of the plans for organ retrieval. In instances where family is not present, well, "we just go ahead" and extract the organs (Dr. Baker). Extracting the organs when the family is not present stems from next of kin's necessary presence in order for their opinion to be considered (Rosenbaum et al., 2012), but also from the fact that timing plays a crucial role in the procurement of organs from deceased individuals because the quality of the organs deteriorates

rapidly after death. Calling next of kin and waiting for them to arrive to make a decision would thus be detrimental to the condition of the organs which could be transplanted to a recipient. Thus, next of kin are able to exercise their authority to a certain extent, but the authority of medical staff members seems to always trump that of next of kin who fail to be present for their next of kin. In some instances, the next of kin may not be present because they cannot be reached, but Dr. Baker, in this instance, seems to be concerned with individuals who are not present in the ICU after being informed of the state of their loved one, possibly suggesting their lack of care or interest for the deceased individual.

Such statements are noteworthy because Dr. Baker went from using “I” in discussing his experiences with family members as partners, to “we” when discussing what usually occurs after an individual has been declared dead. The “we” in “we just go ahead” signifies an important shift because in this instance, Dr. Baker does not view the next of kin as “partners” given that they are not present, and so he feels no need to call them at the present time if they were not around for the patient in the first place. The “we” in this instance is of importance because this instance may also be found to be more controversial in that the family was not taken into consideration and they may exhibit anger for not having been informed prior to the harvesting of the deceased’s organs. Yet, this “we” shows that Dr. Baker has the ability to fall back on the authority of his profession as a doctor with the backing of the legal system in place.

A similar account on behalf of Dr. Woods shows that medical staff members are increasingly aware of the next of kin and efforts are made on behalf of medical staff to accommodate the wishes of next of kin.

*“In some cases there is a reason to keep patients longer in intensive care. We do it. If there is an economic discussion, we will have to discuss that, **but sometimes in a situation that, we know there is no signs for intensive care, but we know that the like, sister is coming from United States to see him alive, then we would prolong, maybe for one day the treatment, but this is to be discussed this is not, not really sure what is the right way to do, because the sister could see him when he is dead as well and seeing him alive is a kind of, “Yes, I saw him alive,” but how alive was he really? He was in a deep coma, he didn’t react, but we do not know what is going inside, so that’s always a problem.**” (Dr. Woods)*

Dr. Woods also discusses the fact that the “right” thing to do” is up for discussion. On paper it may be suggested that the individual be removed from

intensive care, but in practice medical staff members might be more willing to consider factors for continuing treatment. The statement proves the medical staff members' interest in respecting next of kin and the deceased shifts the practices of medical staff members.

#### **6.4.1 Experiences**

For example, two of the interviewees, Doctor Woods and Nurse Sam, discussed their experiences with patients waiting for organ transplants, noting that individuals who have worked with such patients may be more willing to be organ donors, but also more willing to actively seek potential organs from brain dead patients thereby initiating discussions with next of kin, rather than passing up a potential organ donor due to issues that may arise from the next of kin's possible unwillingness to allow their deceased family member's organs to be extracted for donation. Thus, experiences with patients depending on organ transplantation for survival may make doctors more likely to actively procure organs because of their personal experiences with these individuals.

These conceptualizations of next of kin influence the practices of medical staff members tasked with enacting policies and guidelines. At times, a medical staff member may take personal past experiences with next of kin to selectively choose which leads to pursue and which to avoid. Although, the medical staff members should discuss organ donation with next of kin whose relative could be a potential donor, certain conceptualizations may influence whether or not a medical staff members perceives the next of kin to be in favor of organ donation.

*"...but from my opinion most relatives are okay, if we step up to them and talk about the probability of an organ transplant, but you can't say it's like this and like that and that's okay for everybody it really depends. It depends on who are, uh, which relative are they losing. It's always a little bit more a fight with children, so I would say mom and dad can't handle the situation that easy, even if the child is already 30, 40 years old. It's always the child, it's always the little one, so that situation sure is a little bit harder. So, I guess, I would say for mom and dad, it's always a little bit harder to agree and to be okay with the situation. It's a little bit easier, I think, from my point of view, if it's not the child, if it's the partner, or the father, the mother, grandfather, friend, whoever..."*  
(Nurse Sam)



Nurse Sam notes that particular members of a family are more likely to be willing the organs of a deceased family member than others. In this case, the next of kin are viewed by some medical staff members as more likely to donate when the deceased individual is not a child. This statement, however, also sheds light on the next of kin and their particular framing of the potential donor. Parents within Austria, it seems, have more trouble acquiescing to the donation of organs if the deceased individual happens to be their child. Thus, one could deduce that the ways in which next of kin frame the potential donor has much more to do with procurement rates of particular individuals. This may also change depending on the age of the potential donor. Parents of infants born with terminal illnesses are at times more likely to donate the organs of their child as a way of giving meaning to their child's short life (Lock 2002).

Dr. Baker also noted that most next of kin take the news about organ donation fairly well; a similar observation was noted by Sanner in her article describing the perspectives of next of kin concerning their personal experiences with organ donation after the death of a loved one (2007). In noting that the next of kin are generally not opposed to organ donation, Dr. Baker shared his belief that this may be because Austrians generally accept such policies and rarely question authority, a notion posed by Felt et al. in their study on Austrian constructions of organ transplantation and genetic testing (2010).

Dr. Baker's own preconceptions relating to organ donation impact how he approaches next of kin, but his notions on the technology also shape how he frames and conceptualizes the technology of organ transplantation.

*"I think they even had a benefit from the idea that at least the kidneys continued to live on in someone else. This is always a bridge that there is something good to the bad side. At least people feel, people like me feel, we have built them a bridge to overcome a great loss. Whether this is true or not?"*  
(Dr. Baker)

The quote shows that Dr. Baker views organ transplantation as a technology which saves lives, but also manages to benefit those surviving a donor. Scholars such as Margaret Lock also discuss the ways in which organ transplantations often soothe surviving family members because it offers them relief given that organ transplantation provides an outlet for the deceased to redeem him or herself. In this sense, the donor has been attributed a new characteristic by those that choose to coproduce a given reality about the deceased individual. Consequently, organ donation allows the next of

kin to “salvage hope from disaster” (Lock 2002, 102). Furthermore, Dr. Baker conceptualizes organ transplantation, his profession, and the institution which he represents as having played an active and crucial role that benefits the deceased and the next of kin.

The use of “people like me” helps to emphasize the fact that Dr. Baker belongs to a group of individuals – perhaps proponents of organ transplantation – that work collaboratively and individually towards a common goal. “People like me” suggests that the doctor is aware of his role in the process of organ procurement, but also that he is not alone in this endeavor. On the other hand, this statement also reflects a lack of awareness for those that oppose organ transplantation. Dr. Baker’s statement is wholly concerned with next of kin who have come to terms with the idea of organ extraction for donation or are unopposed to it from the start. Albeit, Dr. Baker’s sensitivity for next of kin prevails regardless of whether or not the family agrees to donate the organs of their deceased family member (see *Partners in Organ Transplantation*). Furthermore, this statement also reflects that Dr. Baker views himself as having contributed to for the sake of the donors. Rather than discussing the technology of organ transplantation as having the ability to save lives, Dr. Baker discusses the technology as having the ability to help next of kin heal after the death of a loved one. In this view, organ transplantation allows next of kin a mechanism through which to cope for the loss of a loved one and the technology takes on a new meaning as conceptualized by the mourning individuals: that of a technology which provides for the possibility of a ‘good’ outcome from a tragic situation in which a loved one is lost, and also in which the deceased is allowed to retain cynosure-like qualities from having donated organs.

#### **6.4.2 Trust**

The medical staff interviewed all noted that next of kin express uneasiness when discussing organ explantation. According to the medical staff, this uneasiness stems from next of kin’s fear. Instead, I believe that lack of comprehension of the procedures involved in organ transplantation leads to fear amongst next of kin. Some express uncertainty because they fear the patient may undergo pain (as noted above). In other instances, the lack of trust in medical staff may result in uneasiness about the procedure and the consequences for the patient.

*“...some relatives do really have the fear, “is my patient, is my relative really dead? Have you done all that you can do or do you stop the treatment maybe a*

*little bit earlier because he is on the transplant ICU already and we may need some organs for anybody else...” (Nurse Sam)*

Trust also seems to be an important factor in dictating whether next of kin will agree to donate the organs of a loved one once he or she has been pronounced dead. As Dr. Baker noted, a relationship between medical staff members and next of kin must exist in order for the procurement to be successful. Next of kin who do not trust medical staff members or the system may be hesitant to donate the organs of their family member. In areas such as Germany where it was found that fraudulent activity allowed for some individuals to receive an organ without truly needing it at that moment, donation rates suffered. Therefore, the practices of medical staff members in combination with presumed consent legislation may unwittingly be the reason for the successful procurement rates in Austria even when the policy itself is often praised as the strategy that increases available organs from deceased individuals.

#### **6.4.3 On the Role of Medical Staff**

Medical staff members, as stated before, are not only tasked with ensuring that patients in their care are recovering their health, in fact, their job involves a certain amount of juggling between different responsibilities. Medical staff members must care for patients, but they must also inform next of kin about particular procedures and, at times, even suggest organ ex-plantation for a terminal patient whose health is rapidly deteriorating. Boundaries aren't clearly delineated, at times doctors speak to next of kin and at times, a doctor and head nurse might do so together. Who should speak to next of kin and whether results would differ depending on who happens to be speaking to next of kin should be adequately studied as I feel it tends to impact the procurement rates. Dr. Baker noted that although it should be a doctor who approaches next of kin to discuss organ extraction of a potential donor, often, a head nurse might accompany a doctor to help ease tension. Dr. Woods noted that he tends to approach next of kin on his own as it tends to be the doctors' responsibility. Nonetheless, next of kin might still seek the guidance of nurses who are caring for their patient.

*“But, yeah, we do talk to patients, or no not patients, but to relatives about it, because you sure get the feeling that, mm, most of them have to talk about the situation, have to talk about what's going on and how is it gonna go now and... is there a possibility that we are, we are taking the organs too early, or uh, will*

*he still feel pain in that situation or stuff like that, so we are, we do talk to relatives but normally not about the medical procedure, it's more about the how is it all going and its more about how can I say feelings and emotions and stuff like that and not so much the medical procedure, this is, this is part of the doctors on our ward, but the emotion stuff in case of organ transplant and organ donor, we are talking a lot to relatives, I have to say.” (Nurse Sam)*

Nurse Sam discusses the role of nurses, as opposed to doctors, regarding the relationship with next of kin. This extract from the interview suggests that medical staff members, although working together, manage to enact two distinct roles in the procurement process. Nurse Sam suggests that doctors usually discuss procedures with next of kin, but nurses serve to fill the emotional aspects relating to organ procurement and donation. The policy of presumed consent within Austria gives little space for emotion due to its lack of consideration for consent from next of kin who are not always aware of the policy, the medical procedures, and its consequences for their family member.

Also, note how Nurse Sam initially begins by stating “we” to suggest that the process of organ procurement depends on a joint effort amongst medical staff. Nurse Sam continues to use “we” even though a shift occurs when he identifies doctors as fulfilling a different role in the process. The “we” shifts from collectively grouping all medical staff to distinguishing between nurses and doctors – explicitly noting that each group fulfills a different task.

#### **6.4.4 From patient to donor (From Living Person to Lifeless Body)**

Where does the patient transcend the line from living to lifeless entity? When a potential donor initially enters the hospital, he or she is generally viewed as a patient and attempts are made on behalf of medical staff members to restore his or her health – Nurse Sam assured me that this was the case as medical staff members are primarily concerned with restoring the health of each individual in their care. On the other hand, there comes a time when the patient ceases to be a patient in the eyes of some medical staff members and comes to be viewed as a potential donor. For this to occur there must also be a transition from living person to lifeless body. We cannot procure organs from a patient, but they are procured from an individual who no longer has the capacity to live their life without the assistance of medical technology such as a ventilator. At present, post-mortem organ procurement results from non-heart

beating cadavers and brain-dead cadavers – who may, at one point in time, have been referred to as “brain-dead patients.”

In the following excerpt, Dr. Baker discusses his experience with a patient who could not be resuscitated. The medical staff members, it seems, had conceptualized this individual’s likelihood to recover based on certain characteristics: he was young and athletic. Why should he succumb to death when there didn’t seem to be a plausible reason for his belonging to a group of individuals who succumbs to cardiac arrest.

*“...and he came home from his training and suffered a cardiac arrest, we don’t know the basis he was resuscitated and he was resuscitated one and a half hour, you would never do this, but he was strong and no one has an evidence why the heart didn’t work and I said this is a non-heart beating donor...”*

The quote can be viewed as one instance where the medical staff members break with principle and continue to attempt to recover a patient, when principles would dictate that he or she is deceased. The “lack of evidence” for suffering a cardiac arrest also suggests that coming to terms with the death of this individual was difficult for the actors involved. Nonetheless, Dr. Baker realizes that the patient now shows the characteristics of a potential donor. Thus, he chose to engage with the next of kin who were in favor of the procedure.

*“...and I immediately got consent, so I went back with the relatives, with the young lady and his father and showed them you know the, the, the patient after resuscitation, and this is a mess, there’s, there’s fluids spilled over, there’s probably vomit, whatever, you know, it looks ugly. And the nurses wanted to kill me again, but I demonstrated this person is dead, please believe that.”* (Dr. Baker)

These quotes help to highlight how the doctor seeks to fulfill his duty as a doctor, but most importantly, it highlights how the “body” is conceptualized. Dr. Baker begins by discussing a particular experience in which an individual was declared dead and whose organs were subsequently extracted for organ transplantation. However, there is an important shift in which the individual is first viewed as a living entity, later a “non-heart beating donor”. How does Dr. Baker (and his medical staff) make this transition from patient to deceased donor? At which point does the individual become a lifeless entity? Here the body of the donor is also used as evidence of the efforts

made by medical staff members to resuscitate him, while also serving as proof that nothing more can be done for the individual as a patient. In *demonstrating* that the individual is dead, Dr. Baker was then able to extract the organs for transplantation with the permission of next of kin.

Defining the moment at which a patient becomes a potential donor proves to be quite difficult in some cases, especially when the patient is brain-dead. When patients are deemed “non-heart beating” by medical staff members, this usually falls into place with traditional assumptions and definitions of death. On the contrary, brain death poses a conundrum of sorts given that brain-dead patients aren’t dead according to traditional criteria by which death was established when the heart ceased to beat (Lock 2002). Thus, deciding when an individual becomes a donor necessitates the establishment of criteria that can be easily assessed and applied by medical staff members without much variation.

While the interviewees all agreed that a patient is first and foremost a patient in their eyes, they also agreed that there comes a time when “you just know” (Nurse Sam). This knowledge, Nurse Sam says, comes from prior experience. With time, medical staff members become aware of traits that an individual might possess that would make him or her an ideal candidate for organ extraction. Certain physical attributes, it seems, can be indicators of the possible illnesses an individual might encounter in the near future. Viewing patient medical records or current care charts also clue a medical staff member in. The machines, in most cases, function as the transmitter of this knowledge through numbers and lines, but the medical staff members interpret these figures based on prior experience, but most importantly, based on criteria established by the medical community.

*“Well, I can’t really, I can’t really say that it’s if this or that happens, I think of him as a probable donor. Every patient is a patient and is not a probable donor when it comes here. Our first goal is to make him survive and to get him out of here, again, but, sometimes if, if... the situation, that he’s in or she’s in is really hard and you can guess that he just won’t make it. If it comes to a point where you, where you’re thinking that I can’t say that he’s making or there is a chance that he won’t make it, then it comes in handy actually, to think of a probable donor, but that is, maybe it’s just here like that because we are on transplant ICU and maybe somewhere else on another ICU people do not think about it. And this, sure happens because a lot of patients here in this hospital and so I guess in any hospital, do die as probable donor where there was not thinking about the, uh, the-y, um, organ transplant.” (Nurse Sam)*

The quote is also relevant because Nurse Sam acknowledges that his views as to who constitutes a potential donor may be influenced by his personal experiences. During the interview, for instance, he noted that sometimes there are physical characteristics that might point to whether an individual may be a potential donor or not. In the quote above, he notes that his experience on the transplant ICU might make him more likely to identify a potential donor than individuals working in a different ward. In fact, he notes that patients do die as potential donors without being identified as so by medical staff members. Therefore, the practices of staff, even within the same hospital, tend to vary according to these experiences. In principle, the guidelines are meant to standardize the practices of individuals, but the practices are still likely to vary (Mol and Berg 1994; Dodier 1998).

#### **6.4.4.1 Images as Proof**

In the previous section, we noted how Dr. Baker used the body as *proof* to establish death in a certain scenario. Dr. Woods also discussed the role of brain scans as having the ability to help prove a brain death diagnosis. At present, most post-mortem organ donors are patients stemming from brain death. While brain death has been established as an appropriate diagnosis in the medical community, many still question its objectiveness and its validity. Margaret Lock, for example, discusses differences between Japanese individuals who oppose brain death as a proper means for establishing death and subsequently removing organs, but brain death also poses some issues for individuals of various ethnic and cultural backgrounds (2002). In fact, Dr. Woods mentioned that some members of the medical community still question brain death, not as an acceptable diagnosis, but as an effective indication of death as a whole, a notion that resonates with similar thoughts presented by Margaret Lock in *Twice Dead: Organ Transplants and the Reinvention of Death* in which she distinguishes between the “social” death and the “physical” death which often help explain why some individuals may be opposed to organ transplantation (2002).

Nonetheless, Dr. Woods stated that brain scans were often a helpful tool when communicating with next of kin because it allowed him to make the diagnoses clear to the next of kin. The images, in this sense, function as proof of the brain dead patient’s inability to recover, thus suggesting that the time has come to terminate treatment. Furthermore, the images give next of kin a sense of security in that they feel more confident making a decision regarding the termination of life support and the possibility

of organ extraction because the images help next of kin understand that their loved one can no longer make use of his or her brain to be as he or she once was.

*“You have, first, you have to inform the family what really is going on. I normally, I show them the CT scan, because they’re really impressive. Normally if you see a CT scan you have no idea about CT scans, it’s not very, very interesting, or very meaningful, if you see, but if you have a huge bleeding and you see the whole brain is full of blood, that there’s almost no brain left. This is like a picture that patients can understand many times much better... So you have, the first point is to make the family a clear picture what is going on and it’s not the first day when you talk about the donorship.” (Dr. Woods)*

Although Dr. Woods discusses the use of CT scans as having a particular effect on next of kin, little doubts exists about the fact that the CT scan itself serves as tool which helps Dr. Wood’s view of the patient develop into that of a donor. This statement, suggests that although it creates a clear picture for next of kin, CT scans are also employed by medical staff members and these scans create a picture for medical staff members as well, before they manage to create ‘understanding’ for next of kin. On noting the influence of images in particular scenarios, Joseph Dumit notes that images often fail to be objective because they do not speak for themselves, but need the explanation of an expert individual. Thus, the images are a supplement, but not a reality. Showing scans to next of kin, however, may be a practice that the doctor has employed to quicken the acceptance of brain death diagnosis on behalf of next of kin. This practice also highlights that medical staff members themselves also depend on technology such as CT scans to cope with and trust in diagnosis. The fact that Dr. Woods employs CT scans suggests he is confident in help establish the brain death of a patient. For him, these images “provide the capacity to see ‘truths’ that are not available to the human eye (Sturken and Cartwright 2001, 281).

Images serve as tools to defend the practices of medical staff members. Armed with a CT scan, Dr. Woods can suggest that the patient be taken off the ventilator and that the organs be extracted for transplantation. Scholars have warned however, against the use of images in particular setting such as court rooms given that images are not as objective as we often believe them to be. In some instances interpreting images also requires a significant amount of know how. CT scans, for instance, may be telling of a particular phenomenon to the trained eye, but someone without training may not be able to understand what the image itself truly highlights.



Furthermore, I believe that coming to terms with a patient as a donor is a process for next of kin as well as for medical staff members. The difference here lies in the fact that medical staff members are more aware of the process given their experience and knowledge, whereas next of kin may have more difficulty accepting the death of a loved one because they are not exposed to the medical charts, experiences, or criteria that define a patient and a donor. Medical staff members, however, are intrinsically aware of the process and therefore have more time to come to terms with the fact. Next of kin are generally told at a specific moment in time that their loved one no longer lives and even though they were witness to the process, their vantage point is not that of the medical staff members. Thus, I believe that next of kin, are not given the necessary time to come to terms with the idea of the death of their loved one, but are rather shocked by the outcome. Of course, this cannot be proved from the interviews I've conducted and I have not conducted any observations, although personal experiences have led me to realize that even when death was imminent, I was always shocked at the outcome – perhaps because my awareness and my vantage point are not that of the medical staff members – and therefore, believe that the transition from patient to donor arises from a series of events that suggest death will not be avoided in certain instances as opposed to a shift that occurs from one moment to the next based on the establishment of brain death criteria or alternative means.

## **6.5 Policies to Practices**

Nicolas Dodier's study, "Clinical Practices and Procedures in Occupational Medicine," lends itself fairly well to my current work. In his study, Dodier notes that doctors routinely employ two distinct frames to help deal with discrepancies that may arise when struggling to meet with procedural standards and guidelines, as well as effectively meeting the needs of patients under their supervision. Dodier distinguishes between a "clinical frame" and an "administrative frame" (1998). "The framing of medical decisions by legal rules forces doctors to introduce an administrative frame that breaks with certain principles of the clinical frame" which allow for more flexibility in evaluating patients (Dodier 1998, 79).

For example, Dodier notes that "occupational doctors' relationship to rules depends on the way in which they "frame" the people with whom they deal" (1998, 79). This may suggest that medical staff members themselves employ distinct frames in a medical setting when interacting with different individuals and in different settings. This

may, in effect, help and hinder organ procurement. Dr. Woods noted that different language may be employed to discuss patient diagnosis and treatment with next of kin or colleague and subordinates, yet the distinct plan of action according to the individual depends on the medical staff members' awareness of the next of kin's mutual understanding, yet this depends wholly on how a medical staff member conceptualizes the individuals with whom he or she interacts.

*“Yeah, patient language is very different. So if the patient is like the wife of a retired doctor, the language is different than it would be, with a patient from Pakistan or a drug abuser from, from Vienna, the language is every time different. So it's not the technical language and the family language it's the technical language that there's also different languages depending on the department that you are in. if I am talking to my assistant I have a different technical language compared to talking to a surgeon. And that's technical language with different aspects.”* (Dr. Woods)

Then it so happens, that the use of different languages requires Dr. Woods to make an assumption about the abilities of the next of kin to understand. In this sense, medical staff members do not avoid drawing boundaries between lay people and experts. These boundaries, may in effect, be of benefit to lay individuals who are not familiar with the technical language used in medical settings. Nonetheless, the “lay language” used by medical staff members may be more difficult to grasp than they might believe, especially because the time needed to explain a diagnosis or procedure in lay terms may take more time than the medical staff member can allot for next of kin.

### **6.5.1 Necessary and Diminishing Resources: Time**

The issue of time plays a unique role that had previously gone unidentified. Time reduces the likelihood that an available organ will be explanted for transplantation from a viable donor because as a resource, time is limited. Time is a non-human actor that constantly influences the actions of most individuals, including the actions of medical staff members.

Medical staff members are under a certain pressure to perform their tasks under various time constraints. Saving a life, for example, depends on the valuable resource of time. Medical staff members give their time to save the lives of others, but

time itself also decides whether or not an individual will survive a given procedure based on how quickly life-saving measures take place after an emergency or incident that threatens an individual's life. For most individuals, this unique role that time plays in the medical field does not go unnoticed, however, time also influences a variety of other decisions that impact organ transplantation and its life saving capabilities. On paper, however, the policies and guidelines are meant to be followed without acknowledging that in practice, medical staff members are also responsible for a variety of other issues that require their time. Doctors pressed with little time to coordinate discussions with family members regarding organ extraction may view themselves as allotting time for a discussion that may ultimately end in refusal to donate organs. If next of kin agree to the procedure, time for coordinating amongst colleagues such as surgeons and anesthesiologists must be factored in, as well as the time necessary for conducting the necessary medical diagnostics that will determine whether the patient, at this point a potential donor, has organs that are in decent condition for transplantation. Administering the tests are dependent on the available time of medical staff and waiting for the results may lengthen the process by days, during which the patient/ potential donor must continue to receive medical care.

The availability of viable organs for patients in need of transplantation may therefore be lower than expected because medical staff lack the sufficient time necessary to successfully procure organs for transplantation. Given that the process of organ extraction takes time, it also takes more labor efforts from medical staff members because care for the donor must be prolonged until the organ extraction takes place. Identifying a potential donor and beginning discussions about the possibility of organ extraction with next of kin also takes time. Dr. Woods notes that medical staff members need time to transmit the information effectively, but that next of kin also require sufficient time to process the situation at hand and to make a decision that reflects the wishes of the deceased individual as well.

*"If the patient, it depends, yeah, if the patient is like, brain dead or not brain dead you are waiting for the final results and the patient is on intensive care for 1 week just to evaluate if he's brain-dead or not, costs more than the 2500. The workload for doctors doing examinations that would not be necessary if we would not see him as an organ donor, the family discussions for that is a high workload, so I think it's not really, really paid. So, in this, there is no reason for that. The problem is that the security, insurances they do no pay for dead people, that's, like logical. That's why they stop the payment with the brain-dead and if the patient is there for another 24 hours, nobody pays for it, but the*

*patient is there in the bed and needs a lot of activities, nurses, doctors... anesthesiologists, the surgeons. I think that's not a business for the hospital. Not really, no. That there, that's not a motivation. The only motivation for doctors, and for families, and for the patients, could be, that in a situation where you lose your organs anyway, someone else could have a benefit, that's the motivation. And another thing that you must not forget if the patient dies and he goes to pathologist, they remove the kidney as well.” (Dr. Woods)*

Dr. Baker touches upon many of the motivating factors for medical staff members to procure organs for patients in need of a transplant. Yet, these motivating factors may play a different role for different medical staff members. Those who are in close contact with patients on the receiving end may be more willing to actively procure organs because they see a benefit in curing individuals who depend on dialysis treatments to survive when they don't have a functioning kidney.

### **6.5.2 Varying Practices**

The next factor was lack of efforts on behalf of the medical staff members. At times, from those who fail to report a potential donor, at others due to their inability to successfully approach and communicate with next of kin:

*“...it's the doctors' business to talk, of course those who are not gifted in communicating like intensivists mostly are because they always deal with people who have a tube in their mouth and they do not talk and as soon as the patient talks they want to get rid of them. So they are not the masters in communication. And those who are not the masters they never attend a communication course...” (Dr. Baker)*

Variations in a particular hospital or area may occur when an active medical staff member arrives or departs. Dr. Baker gave an example of a particularly active resident who increased the number of donors in a particular hospital during his residency there. The following year, after the resident had left, the donation rates had returned to their norm as it was prior to the arrival of the resident. Although Dr. Baker notes that a population level also impacts the donor rate, he seemed fairly sure that active medical staff can have a beneficial impact on procurement rates while inactive medical staff can have the opposite effect.

Another factor that contributes to the variations could be a combination of the next of kin's ethnic and religious background. Dr. Baker noted that individuals pertaining to particular religions tend to cite their religion as a reason for not consenting to the donation of their deceased family member's organs for transplantation.

Lastly, Nurse Sam and Dr. Woods noted that medical staff members awareness of the importance of organ procurement comes from medical staff members' proximity to individuals who need an organ transplant. Nurse Sam notes that he currently works in the recovery ward<sup>17</sup> and that his views of organ procurement may be different because he has seen individuals pass away while waiting for an organ. The particular setting, therefore, influences his and perhaps his colleagues' views on organ procurement.

*"It should, but if you, if you find a possible donor on a ward that's not yours and you just talk there with the heads why they didn't call or write them down as a donor or whatever... Its, maybe it's a little of a concurrence, uh... well, we often hear that then they say that relatives didn't want it that way, then we find out that there were no relatives at all. So it's, I -c , me, as a nurse, I can't really answer that question, I think it has to be answered in the higher parts, with the higher heads of the medicine, but yeah, they should all work on the same way and the same points, but it's just not working out that way, so, but I don't know why..."* (Nurse Sam)

While the procurement involves the help of medical staff members at all levels, Dr. Woods also notes that their activities often increase when an individual has been identified as a potential donor. At times, it is these extra efforts on behalf of medical staff members that may deter a doctor or intensivist from reporting a brain-dead individual for organ procurement.

*"I mean, working as an intensivist in an intensive care unit, for you, it's the easiest to stop the machines and everything is clear. Family knows what's going on, you know what's going on, and another point, if you need the bed for another person, you don't lose time... So, sometimes it's the easiest for the*

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<sup>17</sup> Nurse Sam explained that the hospital separates patients according to their condition to avoid making next of kin feel as though their patient will be used for the sake of another individual's well-being. Staff members such as nurses are cross-trained so that they may work in the different ICU's throughout the hospital when needed.

*doctors working in intensive care not to think about organ donation, not to call the transplant center because this is a lot of work, a lot of problems, family discussions, you could avoid. So for the doctors it's easiest, just don't think about it and you don't have to act and then you, you lose a lot of troubles.*" (Dr. Woods)

This statement shows Dr. Woods viewing himself as part of a community of individuals. Here, he is referring to his role "as an intensivist" and he is not calling upon his authority as an intensivist, but instead, he is noting that holding a position as such does not only give him a certain level of authority. Similarly, the intensivist can act according to the policy of presumed consent and exercise his authority, but also represent himself as an employee who must follow guidelines, as the use of "we" might sometimes suggest. Instead, Dr. Woods notes that an individual in his position would also gain *troubles* that aren't necessarily part of his job description. Note that Dr. Woods also separates himself from the doctors that might choose not to act by stating "for *the* doctors," as opposed to stating something like, "for *us* doctors." The use of "you" also helps to distance himself from individuals who may choose not to act. Accordingly, Dr. Woods could have stated something along the lines of "we lose a lot of trouble" to signify that he would consider himself part of a group of individuals who feels quite afflicted by the procurement process. Just to make things clear, since I am only providing excerpts from these interviews, Dr. Woods is intent on procuring organs. In fact, Dr. Woods notes that his experience working with dialysis patients may be the reason why his views of organ procurement may be different from those of a doctor who rarely sees individuals in need of an organ transplant, and therefore, doesn't actively procure organs.

A similar view was posed by Nurse Tomas who mentioned medical staff members often experience hardships in the hospital when patients waiting for an organ succumb to death.

*"...we watch people die in here because we don't get an organ by time, and if you saw that 2 or 3 times, if you saw that with children..."*

The emotional experiences with actors affected by the need for an organ for transplantation are thus also shifting the practices of some medical staff members working toward organ procurement. Although, the procurement process may be difficult and time consuming, a motivating factor for identifying and reporting potential donors may be that medical staff members are motivated by the fact that another

individual, whose health can be restored with an organ transplant, will benefit from their efforts to procure organs.

At the end of the day, Dr. Baker notes that doctors may have different views that guide the practices of medical staff day in and day out. These personal and collective views may make the difference between the individuals who actively seek to enhance procurement rates and those that aren't as concerned.

*“And in our country it the same, if the doctor who is active, they report donors. If the active person is not there, they just don't do it” (Dr. Baker)*

Medical staff members who actively procure organs may be more successful in attaining organs for transplantation, but this quote heavily emphasizes that medical practices and approaches regarding organ donation and transplantation. The quote above distinguishes between the actors that are “active” and those that are not, thus suggesting that practices vary quite strongly and that presumed consent legislation alone cannot make the biggest difference in raising the number of available organs for donation. In fact, the practices of medical staff members have the ability to compliment or hinder the effects of the policy.

### **6.5.3 Authority**

Relying on personal convictions to determine a particular course of action suggests that the doctor enjoys the flexibility acquired to him by his job title. However, in some instances, the medical staff member may choose to employ the authority afforded to him by current legislation that presupposes a specific course of action across most organ procurement settings.

*“You have to overcome the fact that your next of kin has died and then you have to make a decision which is not beneficial for you, but it's instead replacing the person who has already died, this is my feeling why I like presumed consent so much. We do not have to impose this additional burden to these people. In addition, I am arguing from a different point, I am not from the same eye level, but I have the law behind me and say well...” (Dr. Baker)*

This quote is relevant for two distinct reasons. The fragment in bold highlights the use of “I” which highlights how the doctor views himself as an individual, yet the “I”

in this instance exercises quite a bit of authority because this particular “I” invokes the “doctor” and his authority over next of kin (granted to him by current legislation) to decide how to proceed with the deceased. The use of “I” helps to distinguish the doctor from the general population. In this case, he no longer views himself as a partner, but rather as the individual with more authority to decide based on his title and role within the procurement process.

According to the legal framework within Austria, next of kin need not give consent for organ retrieval of a deceased individual. Yet one might wonder how medical staff members interpret the policies regarding organ transplantation and whether the policies do influence their practices and actions. How the legal framework manages to impose on a medical staff member’s practices may help better understand the varying procurement rates across Austria. As Dr. Baker pointed out, there are some medical staff members who do not follow the policy accordingly, whether this can be attributed to their understanding and interpretation of the policy may be to note, but in his interview, Dr. Baker gave a slightly different reasoning. In his words, medical staff, in particular doctors, do not pursue opportunities for organ extraction because they perceive the next of kin to be narrow minded when it come to the subject of organ transplantation. Yet, Dr. Baker notes that as a doctor, he has the authority to extract the organs even when the family opposes.

Other reasons for not extracting the organs of a deceased individual may stem from the high workload involved in organ procurement. Dr. Woods discussed how the procurement process, even with presumed consent legislation in effect, involves coordination among many actors. The potential donor still requires care and the costs are no longer covered by the insurance provider given that the individual is considered dead.

### **6.5.3.1 Sanctions to Guide Practices, Enforce Legislation**

When discussing the possibility of sanctions for medical staff members and hospitals that ignore legislative efforts to procure organs as a means by which to possibly increase the donation rate, Dr. Baker states that he feels better without the sanctions as he tends to comply with the procedures based on his “convictions.”

*“No, this is, I know this is a difference from the U.S., in the U.S. you are obliged to report any person who is dead and potential donor and if you don’t you are sanctioned a lot, you can even lose your license regardless what you have to*



*pay. Uh, Germany has introduced a similar law without any sanctions and it doesn't work. Uh, in this country, I personally do not like sanctions, I work in this business for many years, you can see in my gray hair << ha, ha >> but I always relied on conviction and, and, uh..." (Dr. Baker)*

In this case, Austria does not employ the use of sanctions on medical staff who fail to do their part in the procurement of viable organs for transplantation. Although the new law does allow for fines to be issued to those who disregard certain guidelines, such as the commercialization of organs. However, it would be interesting to understand why the doctor believes sanctions not to be effective. This quote may thus reinforce the fact that medical staff members often fail to adhere to the policy of presumed consent, thus allowing potential donors to go undetected and unreported. When asked about the practices of medical staff, Dr. Baker noted that some medical staff members are more likely to identify and report potential donors than others, thus suggesting that individual practices do lead to an increase or decrease in procurement rates and may possibly contribute to the variation among Austria's regions.

Another interesting statement from this excerpt is, "...I always relied on conviction." What does this say about our doctor? Here, one might argue that this individual happens to be a proponent of organ procurement, but also that his personal values help guide his practices and therefore result in a different outcome than individuals who may rely on slight distinct convictions to procure organs – or to fail to do so. When employing the notion of frames discussed by Dodier in his research on *Clinical Practice and Procedures in Occupational Medicine* (1998), it seems as if Dr. Baker relies on himself and the authority and autonomy historically granted to him by his title as a doctor. Dodier contrasts clinical frames to administrative frames to note that occupational doctors might sometimes employ a clinical frame in which their own autonomy as a medical practitioner supersedes the notion that a particular course of action should be taken based on the population with which the patient shares characteristics (1998). Clinical frames allow practitioners to assess the health of patients on an individual basis taking into account that they are individuals within a population and that shared characteristics do not preclude further evaluation. These frames can be expanded to apply to issues on a broader note. Frames, for the most part, function as a tool under which practitioners can engage with patients according to the doctor's own practices, or those established by an institution. Thus, the flexibility to choose a particular course of action conflicts with the overarching approach of legislation.

## **7 Conclusions**

This thesis sought to shed light on the individual and collective organ procurement practices of medical staff members. While these practices are representative of the policies enacted to create uniformity, they are also heterogeneous. While the sample size may not be reflective of the views of a larger population, these interviews illustrate how medical practices in relation to organ procurement are worthy of further exploration because they are not black or white. Instead, medical staff members constantly negotiate the boundaries between a strict policy and more open-minded practices.

Are policies always interpreted in such a way as to allow for flexibility in practice? These are questions that this thesis cannot answer. In light of its inability to answer such questions, the data presented helps highlight how the practices of medical staff are constantly shaped by the world of organ transplantation. Time, fear of ex-plantation, communication between medical staff and next of kin, the culture and values of individuals, the religion of patients and their next of kin are all factors shaping organ donation and subsequently, the practices of medical staff. These factors thus require that medical staff members modify the practices to reflect the actual situations at hand. While the guidelines and principles serve as a point of departure for maneuvering through the procurement of organs, medical staff members often need to adapt these policies and principles in practice to accommodate the varying constructions that exist about organ donation and transplantation.

### **7.1 To Answer the Questions**

How do medical staff members conceptualize actors in relation to organ transplantation and how do these conceptualizations lead to practices in action?

In my attempt to answer the first research question posed in this thesis, I argue that the data presented highlights the fact that medical staff members have their own notions and constructions of organ transplantation, the next of kin, and the potential donor. I believe these notions were guided both by personal experiences, but also by the influence of the actors within the network. For instance, past experiences with next of kin may shape the practices of medical staff members when determining how to approach next of kin in present situations, but constraints from non-human actors such

as the number of available beds for patients in a hospital may also influence whether or not a medical staff member chooses to pursue organs for donation from a brain-dead individual.

These observations help us answer the following question:

Do medical staff pursue organ procurement at all possible times, or do they forego discussing the possibility with some next of kin because they perceive them as being opposed to organ donation?

Given that all three interviewees discussed fear from next of kin as a potential obstacle in organ procurement, one might then assume that some medical staff members may choose to avoid bringing up the potential donation of organs with some individuals. Instead, I would suggest that this alone does not serve as a deterrent for not procuring organs. As Nurse Sam pointed out, some medical staff members might say “that relatives didn’t want it that way,” when it comes to donation, only to later “find out that there were no relatives at all” (Nurse Sam). This statement reinforces that variations in practice are common, but it also points to the fact that next of kin are not always responsible for the lack of available organs on behalf of deceased donors. Rather, other factors could have guided the medical staff member in his or her decision not to procure the organs.

Finally, the second question posed was more in reference to the legislation and policies driving organ transplantation:

Do legal regulations guide the practices of individual medical staff members and if so, how are the practices reflective of these guidelines?

It is my opinion from having analyzed the data that the policies and guidelines are also part of the network. They are non-human actors constantly influencing the practices of medical staff members. The interpretation of policies, for example, may vary depending on the context in which they are framed. Presumed consent legislation exists in a variety of countries, but as some of the interviewees noted, the practices of medical staff members vary from one hospital to another, even within the same country. Therefore, while policies and guidelines are often enacted to promote the safety of organ transplantation, to protect the rights of individuals, and to standardize the practices of medical staff members, they are not the sole actor guiding practices, but are instead one actor in a network shaped by many. The human and non-human actors part of this network help shape and mold the practices of medical

staff members, but these in turn are also susceptible to effects on behalf of such practices. Where the cycle began and where it ends can be difficult to define.

## **7.2 Hard Presumed Consent**

Contrary to the policy and to the many published studies, organ donation in Austria does not represent a strict or hard presumed consent system. Rather, the medical staff interviewed have suggested that Austria exercises a weak or soft presumed consent version given that the medical staff are concerned with respecting the wishes of the deceased individual and also those of the next of kin whose resistance to the policy would likely result in backlash for organ donation itself. The interviewees also noted that the next of kin are often in a difficult position emotionally because of the loss of a loved one and they are not in a position to cause more emotional distress. Thus, Abadie and Gay correctly note that, “in practice, regardless of the type of legislation and of whether a deceased individual is registered as a donor (or as a non-donor), in most countries families are allowed to have the last word on whether organs will be donated” (2006, 600). These practices may also benefit organ transplantation by diminishing the possibility of public discussion resulting in controversy.

## **7.3 Brain Death**

In analyzing the words of medical staff members in relation to the next of kin who oppose organ transplantation based on religious views, I turn to Lock’s defense of the Japanese culture and its issues to brain death and not organ donation (2002). When discussing the opposition to organ ex-plantation on behalf of certain members of Austrian society, religious views of next of kin were often cited as the primary reason for opposition to organ donation. Here, I might suggest that the medical staff members failed to acknowledge that perhaps it is distrust in brain death as the end of life that might cause next of kin to refuse the donation of organs of an individual.

Likewise, the use of CT scans to prove that brain death of the patient is irreversible may also demonstrate that next of kin are somewhat distrustful of brain death diagnosis. In fact, Dr. Woods noted that some next of kin’s experiences with relatives who had recovered from a brain hemorrhage usually made them a bit skeptical about accepting brain death and equating it to actual death. In showing the

next of kin *proof* of death, both doctors employed practices not necessarily guided by principles and policies, but rather by their own experiences in dealing with next of kin.

#### **7.4 In Context**

The ways in which medical staff members conceptualize Austrians as a homogenous group to which they belong also impacts the ways in which they procure organs from deceased individuals. While interviewees acknowledged that some individuals are in favor of organ donation while others are not, their use of “we” often suggested that they viewed themselves as part of a larger population which shared common views. Thus, “we” served as a reflection of the common values of medical staff members, but most importantly, they believed these values were a reflection of *Austrian* values as a whole. Given that the Austrian population is widely diverse, policies and practices must continuously be renegotiated to allow for the views of all individuals to be respected. While the current practices of staff members tend to acknowledge the diverse beliefs of individuals and allow for those beliefs to be respected, efforts to apply hard presumed consent legislation may become an issue that affects all of the actors involved and impacted by organ procurement.

In Austria, little information about organ donation procedures reaches individuals who are not directly impacted by organ transplantation. In fact, Dr. Woods shared his views that the technology itself both suffers and prevails because of this interesting dichotomy. Relatively little information exists in the media, unless it involves a newsworthy procedure (Dr. Woods; Nurse Sam). Although organ transplantation does not suffer from being an “unknown” and “unheard” of medical procedure, little is actually known about the process, the criteria for establishing brain death, the medical procedures involved in the procurement of organs. Nonetheless, being around for many centuries has allowed the technology to gain a certain level of acceptance among societies worldwide. Regardless, this level of acceptance often varies from country to country, culture to culture, and even from person to person (Lock 2002).

Individuals know relatively little about the technology itself and this often leads to fear on behalf of individuals. Nurse Sam stated that often, the next of kin tend to initially oppose organ transplantation because they don’t know much about the technology in terms of how the medical and surgical procedures will affect the potential organ donor. Some individuals fear that their next of kin will be hurt when their organs are surgically removed, even mutilated in the process. Others are fearful that pain will

be felt by the organ donor, even when he or she has been defined as deceased by the medical community and the criteria established by the medical community.



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## **Abstract**

Acknowledging that post-mortem organ donation elicits a variety of beliefs from a variety of individuals, this thesis examines the ways in which medical practices reflect personal and external conceptualizations of various actors in relation to post-mortem organ procurement.

Countries and institutions often work in unison to promote organ donation by implementing policies and guidelines aimed at establishing and protecting the rights of individuals, while increasing the number of available organs for donation. Concerns about the safety of organ transplantation, for example, led to the creation of guidelines to be implemented across borders. Countries approve legislation to carry out the procurement of organs in a secure manner, while keeping in mind the values that best reflect those of their population.

At present, post-mortem organ donation within Austria is regulated under presumed consent legislation. Every individual within Austria is thus considered a potential organ donor after death, save for those who have explicitly stated their opposition prior to death. Upon death, medical staff members are permitted to remove the organs of an individual for donation without need for explicit consent from the deceased or the next of kin. Since medical staff members' practices play an important role in organ procurement, the thesis sets out to present how practices are shaped by policies and guidelines, but also by the various actors involved in organ procurement and transplantation. In analyzing interviews with medical staff members, the thesis seeks to examine the ways in which various actors and conceptualizations manifest themselves in the practices of medical staff members in post-mortem organ procurement.

In utilizing a qualitative approach for data collection, the thesis gave voice to individuals whose role in organ procurement and transplantation helps shape the biomedical technology. To analyze the data, tenets from Actor-Network Theory, Conversation Analysis, and Grounded Theory were applied. These approaches helped highlight the factors that influence the individual and collective practices of medical staff members. Taken together, the interviews suggest that the framings of individuals and their experiences influence practices on a broader scale than the policies and guidelines would suggest. Therefore, while one might assume that policies and guidelines help standardize the practices of medical staff members across borders, a closer analysis of the practices of medical staff members may suggest that uniformity can only exist in writing. In practice, the individual and diverse experiences of medical

staff members, as well as the diversity of the actors involved, shift the ways in which policies and guidelines are applied.

## **Abstrakt**

Unter Berücksichtigung der Tatsache, dass postmortale Organspenden eine Vielzahl an Vorstellungen einer Vielzahl von Individuen hervorrufen, untersucht diese Masterarbeit, auf welche Weise die medizinischen Praktiken die persönlichen und äußeren Konzeptualisierungen von verschiedenen Akteuren in Beziehung zur postmortalen Organbeschaffung widerspiegeln.

Länder und Institutionen arbeiten oft gemeinsam an der Förderung von Organspenden, indem sie Strategien und Leitlinien implementieren, um die Rechte der einzelnen Personen zu etablieren und zu schützen, und gleichzeitig steigt die Anzahl von verfügbaren Spenderorganen. Bedenken, zum Beispiel hinsichtlich der Sicherheit der Organtransplantation, führten zur Schaffung von Leitlinien, die über die Grenzen hinweg realisiert werden. Länder genehmigen die Rechtsvorschriften für die Durchführung der Beschaffung von Organen in einer sicheren Weise, unter Berücksichtigung der Werte, die am besten die Werte ihrer Bevölkerung widerspiegeln.

Derzeit wird die postmortale Organspende durch die mutmaßliche Einwilligung der Gesetzgebung in Österreich geregelt. Jede einzelne Person ist somit ein potenzieller Organspender nach dem Tod, ausgenommen diejenigen, die ausdrücklich während ihres Lebens darauf verzichtet haben. Nach dem Tod sind die Angestellten des Krankenhauses zur Entfernung der Organe einer einzelnen Person befugt ohne die Notwendigkeit, eine ausdrückliche Zustimmung der Angehörigen des Verstorbenen einholen zu müssen. Da die Handlungsweise der Angestellten des Krankenhauses eine wichtige Rolle bei der Beschaffung von Organen spielt, versucht diese Masterarbeit aufzuzeigen, wie die Praktiken sowohl durch Regeln und Richtlinien als auch durch die verschiedenen Akteure geprägt sind, die an der Beschaffung von Organen und Transplantation beteiligt sind. Durch die Analyse der Interviews mit Angestellten von Krankenhäusern untersucht diese Masterarbeit die Arten, in welchen sich die verschiedenen Akteure und Konzeptualisierungen in der Praxis der medizinischen Mitarbeiter in der postmortalen Organbeschaffung manifestieren.

In der Verwendung eines qualitativen Ansatzes der Datensammlung verleiht diese Masterarbeit denen eine Stimme, deren Rolle bei der Organbeschaffung und -transplantation mithilft, die biomedizinische Technology zu entwickeln. Um die Daten zu analysieren, wurden Lehren aus der Actor-Network-Theorie, Conversation Analysis und Grounded Theory angewendet. Diese Ansätze halfen die Faktoren herauszustreichen, die die individuellen und kollektiven Handlungsweisen der Angestellte des Krankenhauses beeinflussen. In der Zusammenschau lassen die

Interviews vermuten, dass die Rahmungen von Individuen und deren Erfahrungen die Handlungsweisen auf einer breiteren Basis mehr beeinflussen, als die Grundsätze und Richtlinien es vermuten lassen. Daher, während man vermuten kann, dass die Grundsätze und Richtlinien die Praktiken der medizinischen Mitarbeiter über die Grenzen hinweg zu standardisieren helfen, lässt eine nähere Analyse der Praktiken des medizinischen Personals vermuten, dass Uniformität nur am Papier existiert. In der Praxis bestimmen die individuellen und unterschiedlichen Erfahrungen des medizinischen Personals, wie auch die Diversität der involvierten Akteure, die Art und Weise, in welcher die Grundsätze und Richtlinien angewendet werden.

## Curriculum Vitae

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