



Orchestrating an Exceptional Death
Donor Family Experiences and Organ Donation in Denmark

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Publication date:
2011

Document version
Early version, also known as pre-print

Citation for published version (APA):
Jensen, A. M. B. (2011). *Orchestrating an Exceptional Death: Donor Family Experiences and Organ Donation in Denmark*. Kbh.: Institut for Antropologi. Ph.D. Series, No. 69

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Ph.D. Series no. 69

Department of Anthropology 2011

Faculty of Social Sciences, University of Copenhagen

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July 31st 2011

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Acknowledgements

Studying the world of organ donation and donor families turned out to be more exciting, more rewarding and more challenging than I could imagine. While I am responsible for the content of this thesis, this study could not have taken place without the help and support from the following.

My deepest gratitude goes to all my informants for their willingness to participate, their sincere interest in my project and their contributions. They provided me with so much knowledge and inspiration that this thesis is only able to reflect a small part of it. It is with pride and joy I look forward to continue my work in this area.

I owe the deepest thanks to the donor family members willing to open their homes and share their story with me. They have my sincere sympathy and respect for what they have been through, and I hope this is reflected in every page of this thesis. Thank you very much.

I sincerely thank the entire staff at the neuro-intensive care units in Odense, Glostrup, Rigshospitalet and Århus for letting a stranger into their world and helping me in my fieldwork. I am overwhelmed by your openness, enthusiasm and professionalism. Thanks to those, also from other departments, who took the time to participate in an interview. Special thanks to Annette Boe, Mette Bruun Mortensen, Michael Kosteljanetz, Karen-Lise Welling, Niels Agerlin, Dorte Jensen, Else Marie Tram, Jens Christian Sørensen and especially Jane Linnet, who have played a crucial part for the outcome of my fieldwork. I also thank the Danish Centre for Organ Donation for their ongoing interest and enthusiasm for my project and for many exciting conversations.

I am grateful to Columbia University, Department of Sociomedical Sciences for having me as Visiting Research Scholar in the fall of 2008, and for their interest in my project. I also sincerely thank the Danish Research Council for Culture and Communication for funding this PhD project and I thank the Danish Heart Foundation for financially supporting a large part of my fieldwork expenses. My deepest gratitude also goes to the Bikuben Foundation for letting me stay in the Bikuben Academic Guest House in New York. In addition, I wish to thank the following scholarships for supporting my stay at Columbia University: the Sasakawa International Fellowship Foundation, the Julie von Müllen foundation the Oticon foundation, the Augustinus foundation, the Knud Højgaard Scholarship, the Hede Nielsen Family foundation, the Frimodt Heineke foundation and the Augustinus foundation. I also thank the Danish Research School of Anthropology and Ethnography for a stipend to go on a

much needed writing refuge in the very last part of the writing process and for all the great social and academic activities they offered PhD students.

I thank my colleagues at the Department of Anthropology for their friendship, generosity and support through the struggles of becoming a PhD. Special thanks to Gry Skrædderdal Jacobsen and Kasper Tang Vangkilde for their friendship and academic insights throughout this process. I also owe thanks to Lotte Buch, Frida Hastrup, Bjarke Oxlund, Ayo Wahlberg, Kirsten Hastrup, Vibeke Steffen, Inger Sjørlev, Birgitte Refslund Sørensen, Morten Axel Pedersen, Henrik Vigh and Karen Fog Olwig who have all generously contributed with inspiring ideas and relevant literature. Also thanks to the students I have taught and supervised, especially Kirstine Birk for insights from her field of organ recipients. I also thank Anne Hambro Alnæs, Frederik Rosén and Klaus Høyer for insightful academic discussions and comments to my research. I thank my student workers Karoline, Ida and especially Sidsel for their dedicated work. Special thanks to Alison Stent for proof reading of this work. I am grateful to Gry Thorsen for commenting on chapters, to Thomas Bornø for helping with references and layout and Helene Hansen for translating appendixes. Also thanks to PhD secretary Kirsten Gelting.

My supervisor Tine Tjørnhøj-Thomsen has been an outstanding help since day one. She is the walking example of why anthropology is the coolest profession and why I continue doing it. She is a supervisor beyond comparison in all phases of the PhD and I sincerely thank her for constant support and loyalty in matters in and outside this thesis.

Since 2005, I have been privileged by the opportunity to learn from Professor Lesley Sharp at Columbia University whose academic skills and insights in the field of organ donation and transplantation are beyond description. I sincerely thank her for her generosity over the years and her willingness to co-supervise this thesis.

I thank my friends and family for their sincere support and interest in my project, for taking my mind of the severity of my research topic when hanging out, for letting me stay with them during fieldwork and for forgiving the cancellations I had to make in the end. Very special thanks to my parents Jutta and Kaj for their constant belief, encouragement and support and, in very different ways, for being so strong.

Most importantly, I thank my husband and soul mate Thomas whom I love and admire personally and professionally more than he will ever understand. I thank him for accepting my crazy working conditions, for supporting me in the many joys and sorrows in and outside this project, and for always making me laugh. I love you very much and I can't wait to experience parenthood with you very soon.

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Thanks to Niels and Dorte for taking pictures for me and to their colleagues for their willingness be photographed. Also thanks to Helle at the Danish Centre for Organ Donation for allowing me to use a picture from their opening symposium in 2008.

Special thanks to Christian and Berit for allowing me to see and to use their private pictures from the time they lost their son. The pictures are beyond words, and having them in my thesis is a rare privilege for which I will always be very grateful.

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Chapter 1: Introduction



Introduction

Holding my breath, I stand at the back of a private ward in the neuro-intensive care unit next to the nurses Lise and Bente. We are watching the woman Dorthe lie in the hospital bed surrounded by her family. Dorthe is attached to a respirator, which is controlling her breathing. She is also hooked up to several monitors measuring her blood pressure and oxygen levels. Dorthe is in her 40s and she just underwent brain surgery for an aneurism. Unfortunately the surgery went wrong and the staff are upset. Lise expressed her sadness to me earlier, emphasizing how rarely this happens. The second brain death exam has just been confirmed by two neurosurgeons in one of the few pauses between the many family members walking in and out Dorthe's room in small groups silently saying goodbye. The test confirmed what was already indicated to the family in an earlier conversation: Dorthe is brain dead. A few hours prior to this, her family was approached about organ donation. After some quarrelling her teenage son remembered watching Rescue 911 with someone talking about organ donation. Then it was settled. They agreed on organ donation. Dorthe's husband sits at the bedside with the 19-year-old daughter, both of them crying. They hug and kiss Dorthe and stroke her cheeks. Bente turns around and looks at me with tears in her eyes and I turn around pretending to read some organ transplantation papers on the desk, feeling simultaneously professionally grateful and personally uncomfortable at witnessing this. Suddenly the anesthesiologist Gerard enters the ward in a hurry and puts on a pair of plastic gloves. Dorthe needs a nose tube to get some saline solution to balance her fluids, which is one of the many necessary medical requirements for a potential organ donor to keep the body functioning. But from the looks exchanged by the nurses, I sense

that they, along with me, are not happy about Gerard's timing and his disturbance of this family moment of goodbye. Lise takes a step forward and is about to say something, but decides to hold it back. She called for Gerard because she could not do it herself and it has to be done now. While preparing to insert the tube, Gerard expresses his sympathy and says how tragic and unbelievable this must be. Dorte's husband looks up from the bedside and replies that this was definitely not the outcome he had expected when walking into the department with Dorte a couple of days earlier. They had so many plans for the future. Approaching Dorte's bedside, Gerard apologizes that he has to put the tube in her nose now, and to my relief the husband expresses his understanding for the intervention with a sad smile. When leaving the ward, the family gives Dorte a last kiss and hugs the nurses and me. We say goodbye and quietly express our sympathy. Suddenly the daughter stops and looks at us with tears running down her face and says: "Make sure somebody will survive from this". Then they walk away and the door closes behind them. I exhale and grab the much-needed pack of tissue in the pocket of my white smock. Turning my eyes to the bedside again, I watch Gerard inserting the nose tube, Lise checking Dorte's blood pressure and Bente preparing the large number of blood samples for the mandatory tests taken on all organ donors to find the best possible recipient match. With the words of Dorte's daughter still printed in my head, I realize that another kind of care has already begun.

This brief description sets the scene for the central issues of this dissertation: Danish donor families and the practice of organ donation. Contrary to widely discussed political issues such as public attitudes, legislation, declining statistics and organ shortage, this study deals with the experiences of Danish families experiencing a sudden loss and dealing

with the question of organ donation. It also focus on the tenacious attempts of the hospital staff to carefully structure and time the flurry of processes related to organ donation, and the fundamental questions regarding life and death that this medical practice brings about. These extraordinary moments are placed within an analytical framework I call ‘the orchestration of death’.

In public campaigns, popular media and most scientific studies, organ donation is often defined or discussed in the vicinity of the concept “the gift of life”. Exchanging organs is framed as a matter of generosity and altruism or as a bodily and symbolic rebirth for sick patients. The positive aspects of organ donation are repeatedly underlined in order to represent a counterpoint to the oppressive and morally degrading organ trade where sick patients in poor countries sell a kidney or, in extreme cases, are even killed and robbed of their organs. While a global perspective of the darker side of organ transplantation is extremely important, this study accentuates an aspect less often revealed. I aim to unfold a story about the emotional and social implications of organ donation, for families as well as for the hospital staff involved.

Donor families in this study often regarded organ donation as “a good thing” and “the only positive in the tragedy” since the notion of solidarity and helping others is deeply embedded in familiar cultural values in Denmark (Jöhncke 2007). This does not mean that the practice of organ donation is unanimously accepted by everybody, but it means that organ donation can be perceived as sense-making for grieving families if it is conceptualized within specific familiar value spheres such as “helping others”. Speaking to families, I did not find many exclusively good stories or bad stories. While the decision to donate organs can be meaningful, the processes surrounding the procedures are often very painful. This has led me to one of my main arguments, namely that the

idea of organ donation sets up complex conflicts of heart and mind, or emotion and intellect; an interplay of tragedy and hopelessness on one hand and logic and meaningfulness on the other. A young man who lost his wife told me that he considered organ donation “a rational choice with emotional consequences”. His statement inspired me to focus on this complex path of making a choice that seems reasonable, while at the same time feeling devastated and confused by all the many social and emotional implications of that decision; some of which do not appear until years and months after. It is this complexity in the experiences of donor families I set out to explore. Following this idea, the starting point of understanding the experiences of donor families is that organ donation is more than a matter of answering yes or no.

Another important point is that as painful and devastating as losing a family member is, most donor families play an active role in shaping and negotiating this exceptional way of ending life. The social interplay between doctors, nurses and families in the clinical context is crucial to understanding the donor family experience. I have chosen the term ‘experience’ to frame what it is donor families and hospital staffs go through in this course of events. Theoretically I lean on the work of Victor Turner and Edward Bruner. They were influenced by the German thinker Wilhelm Dilthey and his ideas about experience as what is “lived through” (Bruner 1986). Inspired by Dilthey’s hermeneutic approach, Bruner states that “the anthropology of experience deals with how individuals actually experience their culture”, how “events are received by consciousness” (page?). Experience encompasses actions, feelings and reflections. In this optic, experience is not only what happens to an individual, but also how human beings “not only engage in, but also shape an action” (Ibid). Considering the things I learned during fieldwork, I embrace the idea that

experience is socially created, and that all actors – in this case staff and families – are active agents in the creation of actions.

In the following pages the experiences, decisions and challenges of Danish donor families will unfold. The discussion is based on exhaustive fieldwork in the day-to-day life of Danish neuro-intensive care units (NICUs) as well as during organ donation cases. Based on multiple interviews with Danish donor families, it also demonstrates how donor family members seek to transform stories and reflections in the time after the death into a narrative recollecting the course of events leading up to the death. Adding another level to the investigation of the donor family situation and the social context in which organ donation is acted out, I also aim to tell a story about the professionals at the Danish hospitals accompanying the family in this situation. Their recollections, experiences and strategies to support the family and execute organ donation are crucial in illuminating what takes place in the social processes of organ donation. This group of informants stands out as an invaluable help in my attempt to grasp this world professionally as well as personally. Together, these interacting empirical perspectives from the field provide an understanding of the practice of organ donation in Denmark from the family perspective and shed light on the many interactions, considerations and social relationships that are played out in this regard.

The pivotal empirical point of this dissertation can be understood as a particular social moment where essential definitions and questions regarding life and death are at stake. The moment starts when the family enters the NICU to find out their loved one is severely injured in the brain and ends when they say the last goodbye at the hospital or in the chapel after the organs have been removed. The empirical object of this dissertation is this particular social moment and all its actions and experiences.

But the study also looks at many reflections and interpretations surrounding this particular moment. First, there are the stories of the families who will spend years and months grieving the loss and contemplating the decision points that led to this particular moment at the hospital. Then there are the experiences of the medical staff. They add each organ donation case, these specific processes and moments in time, to their fundament of professional experience. In order to meet their own ambitions to improve future efforts, their human and medical knowledge of organ donation is constantly created, negotiated and developed.

Adding another level, the educational activities for health care staff all over the country, the political debate, and the medical, secretarial and administrative procedures can all be understood as both reflections of past organ donation cases and preparations for new ones. This work is also crucial for the understanding of the organ donation context in Denmark. Even if this takes place outside the hospital, these social activities implicitly affect the experiences of Danish donor families. Empirical data about this is collected by participating in numerous meetings, conferences, seminars and staff training sessions and by monitoring and participating in organ donation topics in Danish media.

In that sense the particular social moments that are the subject of this study can be understood as an ongoing circle of events all building on each other. The system or the procedure of organ donation is constantly structured and restructured, nuanced and improved by way of the many new organ donation processes happening at Danish hospitals. Theoretically, these social moments in which organ donation takes place can be seen as social rituals repeatedly initiated and performed with the purpose of supporting and guiding families through the processes of losing and deciding, carrying out organ donation and shaping and re-shaping the organ donation community.

This series of what I define as ritualized actions that allows organ donation to take place happens on three levels that are deeply intertwined. They are, first, the hospital staff's careful timing and planning of the processes and procedures of organ donation; second, the families' attempts to understand, decide, and to accept and interpret the experience of donating a beloved family member's organs, and third the medical, political and organizational strategies of Denmark as a welfare state to conduct this medical practice according to the law, staging it as politically correct and socially acceptable, and generally classifying organ donation in the public domain as 'a good thing to do'. It is these complex social processes of ritualization of this exceptional way of ending life that I have defined as 'the orchestration of death'.

Orchestrating Death – Theoretical Framework

While the process of donating organs happens over and over again in Danish hospitals, this dissertation underlines that each case is unique and has its own particular set of complications and conditions. The data collected during fieldwork involves all kinds of destinies, from teenagers involved in traffic accidents to victims of violence or suicide, mothers in their 40s struck by a sudden brain aneurism and lonely alcoholics having a fatal accident on their moped. It is my main argument that the only common thing in these cases is that each family goes through a complex process involving brain death and organ donation. Even if organ donation is a standard medical procedure, I argue that this happens in a multitude of ways depending on the circumstances, premises and social background of every patient and every family. It also depends on the experiences and attitude of the hospital staff and the medical and social conditions of the various hospitals including staff resources, the size of the family rooms,

and the arrangements of the wards. In short, I see the uniqueness of each organ donation case as a premise in this field. It follows, then, that the orchestration of each organ donation demands an extraordinary combination of flexibility and structure, or social staging; it must be constantly adapted to and adjusted by the unique combination of family and staff members, together with the particular configuration of the health care system as their backdrop.

In line with anthropologists Linda Hogle (1999) and Lesley Sharp (2006), I argue that it is advantageous to regard organ donation as something mysterious and wondrous. I classify organ donation as a kind of “strange figure”. Theoretically as well as practically, organ donation balances at the threshold between life and death because of the seductive wonders of medical technology. There is no familiar framework to help us grasp, define or reflect upon this medical practice of removing organs from breathing patients and transplanting them into the bodies of others. It is an unfamiliar way of dying, and of handling dead bodies. At the same time it is strange because it can also be sense making. Remembering the above mentioned words of one of my informants, it is “a rational choice with emotional consequences”.

Even if the medical practice has existed in Denmark for more than 20 years, my fieldwork shows that it still causes many moral, ethical and fundamental discussions for the people involved. Balancing between the need to perform a peaceful, dignified death for the individual patient and the social obligation of helping other sick patients when the health care system offers the opportunity to do so can never be easy. In addition, death in relation to organ donation seems suspicious, mysterious and unnatural to many because the dead patients are breathing and do not look dead, even as the organs are removed. Thus the heart in a body of one of these ‘living dead’ does not stop until the patient is in the middle of

having the organs removed at the operating table. Since life is often popularly associated with a beating heart, this reconfigures ideas about life and death. One might argue that in organ donation the dead are treated as the living and the living are treated as dead; the boundaries are flexible. Returning to the opening case of Dorte, although it seems rather absurd to put a nose tube in a dead patient to give her saline solution, it was necessary to keep the body and the organs functioning.

Organ donation contains an unfamiliarity that somehow must be handled and which needs some kind of “cultural mechanism”, to make it consistent with cultural values, to use the words of Hogle (1999: 42). Investigating the political history of Germany and Northern Europe Hogle argues that due to historical fears of mutilation and apparent death, the practice of organ donation is perceived as fundamentally wrong or unnatural. That is why removing organs have to be translated or transformed into something that is in line with the values and beliefs of the current society. According to Hogle, there has to be clear standards and procedures and there also has to be rhetorical or ideological value statements that can function as a kind of approval of organ donation. The widespread public discursive classification of organ donation as “the gift of life” in many parts of Europe and the US is possibly the clearest example of a rhetorical “translation” of a contested medical practice into something unequivocal positive and charitable. For that reason, the anthropological question to investigate in this regard must be how the procedures of organ donation in a Danish context are translated into something that is socially, culturally and emotionally acceptable and not as fundamentally different from life and death as we know it. I argue that a good way to understand these processes is to focus the various practices performed, how death is orchestrated.

Based on the observation of numerous cases, it is my analytical argument that donor families and hospital staff construct and perform a variety of social and ritual actions and recollections to embrace the overwhelming complexity of the field of organ donation. I argue that death and organ donation are staged and performed in a certain way by all actors involved. I also argue that they do so in order to understand, accept and transform the strange figure of organ donation and the processes they go through in this regard. Put in another way: The actions, routines, statements and interpretations can be seen as performances, carried out in order to transform this unfamiliar figure of organ donation into something socially and culturally acceptable. I examine these complex actions through the lens of 'orchestrating death'.

Etymologically, orchestration comes from the world of music and means the study or practice of writing music. According to the Webster English dictionary, the verb orchestrate means "to compose or arrange (music) for an orchestra". But it can also mean "to arrange or combine so as to achieve a desired or maximum effect". Dictionary.com suggests that orchestrate means "to arrange or manipulate, especially by means of clever or thorough planning or maneuvering". The Oxford dictionary defines the word as follows: "To combine harmoniously, like instruments in an orchestra; to arrange or direct (now often surreptitiously) to produce a desired effect". Adding to this, the Cambridge dictionary defines orchestrate as "to arrange something carefully, and sometimes unfairly, so as to achieve a wanted result". Finally the Chambers dictionary offers the following definition: "(figurative) to organize so as to achieve the best effect". Therefore, the practices of arranging with a purpose, planning and manipulating, and producing and achieving some particular result or effect is essential in the theoretical understanding of 'orchestration' which makes it helpful to understand the social practices of organ donation.

Borrowing terms from the music world to explain the social processes of ritual performance is also done by Levi Strauss in his influential book *The Raw and the Cooked* where he compared South American tribal myth and ritual to “the conductors of an orchestra whose audience becomes the silent performers” (1969:17). In addition, the entire book was organized according to the structure of a symphony. Remaining in the world of music, Alfred Schutz has analyzed the character of social interactions connected with the musical process in the article *Making Music Together* from 1964. He saw music as a meaningful context, but unable to be expressed in conceptual terms. By looking at musical processes, Schutz hoped to illuminate other structures of social interaction. According to him, there is a tendency to regard language as the primary vehicle of communication. Semantic expressions are the fundamental condition of social intercourse, since it is an outstanding tool for the conveying of meaning. But by looking at the musical processes, Schutz suggests that by reciprocal sharing of the other’s flux of experience, a mutual tuning-in relationship is constituted. The system of musical notion is merely a technical device and it is accidental to the social relationship prevailing among the performers. The mutual tuning in fosters the experience of the ‘We’ which is the foundation of all possible communication (Schutz 1964).

Without comparing the very different social situations of making music and losing a family member, I argue that looking analytically at the tuning-in relationship, the experience of the ‘we’, the creation of something going beyond language is very usable when understanding the donor family experiences of organ donation. Language and information has its limitations since donor families do not understand or remember what they are being told. But when the doctors and nurses provide care and support, the experiences of families and staff are shared and a social relationship

between the performers is established. Staff try to tune in to what donor families are going through and thereby create a social relationship where it is possible to communicate in alternative ways. This tuning in is essential to what I define as the social interplay between families and staff and thereby the orchestration of death.

Within anthropology, orchestration is mostly used to describe the processes of ritualizing events and the staging of ritual processes. Theoretically, the analytical concept of orchestration is closely related to Catherine Bell's notion of ritualization, an approach disclosing the strategies by which ritualized activities do what they do (Bell 1992: 4). This means that focus is not on rituals themselves but rather on the ways rituals are created and the intentions or strategies behind them. Pierre Bourdieu has also used the word orchestrate to describe how "the practices of the Kabyles were collectively orchestrated without being the product of the organizing action of a conductor (Bourdieu 1990: 53). Returning to the theory of Hogle, I see orchestration as the cultural mechanism, of social translation to help understand the strangeness and unfamiliarity surrounding the practises of organ donation and the body of the organ donor. In my view, this can happen individually as well as collectively in the social interplay between families and staff. I argue that the term 'orchestrate', or 'orchestration', helps illuminate how families and staff play an active role in performing and creating an alternative environment or reality to make organ donation acceptable and create new truths and frame of interpretations in which their experiences and sensory perceptions are made meaningful.

Corresponding with the title of the dissertation, organ donation can therefore be understood as orchestrating an exceptional death. Based on my field data, I argue that this concept has the potential to embrace what is actually taking place on all levels – from the health care system's

encouragements to sign the donor registry, to the doctors carefully performing the brain death tests on a patient, organ management details such as the timing of inserting a nose tube, and a father's cautiously timed planning of the children's entrance in the hospital room to say goodbye to their mother, as we shall explore in coming chapters. It is ritualization or other purposive practices in order to try to create meaning.

In the hospitals where organ donation takes place, many staff members felt that they lacked what they called "specific rituals" to embrace the moment of closure in the process. While hospital staff could not define exactly what was needed, it was clear that something to accompany the family all the way through the process and give them a dignified and respectful goodbye was much appreciated. This topic was often discussed with me as an anthropologist. They regarded me as somebody with ritual knowledge able to provide them solutions to this problematic. However, I often experienced that the routines and practices performed by hospital staff were carefully timed and structured in order to give the family the best possible experience. The structured and improvised actions were, in fact, much like rituals, although they were flexible and adapted to the individual needs of donor families, and thus constantly being recreated. In this way my study differs significantly from that of Anne Hambro Alnæs, who focuses on donor families in a Norwegian context. While she wonders about the lack of rituals in the intensive care units (Alnæs 2001), my study identifies a number of ritual attempts to accompany and support the family and the hospital staff. The analytical frame of orchestration therefore has the potential to embrace these socially negotiated attempts to classify and define the actions taking place.

Based on my research, I find it suitable to place orchestration in a temporal frame. I argue that orchestration can happen as a plan, a response and a reflection. Elaborating on this, 'plan' means the structure

or preparation of something. Within organ donation that could be the standard procedures of medically determining brain death. 'Plan' embraces orchestration as an intention or a strategic action that is performed or carried out with a purpose. Then there is orchestration as 'response'. By this I mean the immediate spontaneous reaction to something unfamiliar or the instant attempt to control the strangeness. It can be the nurse trying to explain them or to hold down the spinal reflex movements of a brain death patient so they family should not be disturbed by this. It can also be the father making sure his wife looks good in the seconds before the children enter the ward. Therefore orchestration as response is often situational, unique and instinctive. Finally, orchestration can also be reflexive, looking back at what happened and try to make sense of it. Orchestration as reflexive praxis is the attempt to make certain actions and experiences reasonable and meaningful and in accordance with existing values and norms. The process often finds expression in narrative forms as a model of explanation comforting both families and staff. For example, when families say that death was "better than being a vegetable in a nursing home" or "organ donation was the only positive aspect of the tragedy". This might be interpreted as a reflexive orchestration of the traumatic loss of a loved one. Everything in the examples mentioned above can be seen as processes of orchestration with the purpose of understanding the unfamiliar and make it socially and culturally acceptable. This is the main essence of the concept of orchestration.

In the next section of I present an overview of the theoretical and empirical themes that have dominated the research of organ donation, thus locating this dissertation and its contribution to the field.

Anthropology and Organ Donation

Over the past couple of decades a growing body of literature has emerged in the social sciences focusing on organ transplantation. Below I present the most important themes for the purposes of this study and explain how this research relates to or distances itself from the existing scientific work.

In studies of organ donation, gift exchange has been perhaps the most dominant analytical starting point for anthropological studies. (Abrahams 1990; Alnæs 2001a; Ben-David 2005; Fox & Swazey 1992; Fulton et al 1977; Healy 2006; Lock 2002a, 2002b; Sharp 1995, 2000, 2001; Siminoff & Chillag 1999; Sque & Payne 1994; Younger et al 1996). Most authors use the work of Marcel Mauss as a starting point with a particular interest in the obligation to reciprocate, which is generally considered impossible for an organ recipient having received ‘the gift of life’. One of the most significant contributions is the work of sociologists Renee Fox and Judith P Swazey, who introduce the world of organ transplantation in the book *The Courage to Fail: A social view of organ transplants and dialysis* (1974). This was followed in 1992 by *Spare Parts: Organ replacement in American society*, in which they examine living kidney donation and the complexities of reciprocating a human organ using their original framework “the tyranny of the gift”. This notion has since dominated the field. But it has also been critiqued by newer research from the donor family context in the US, which argues that by way of organizational interaction, it is possible to return the gift in alternative ways by providing information, acknowledging the decision and memorializing the dead (Sharp 2006, Jensen 2007). This study will focus on the absence of organizational interaction for donor families in Denmark and discuss alternative ways donor families get something in return. In addition this study turns attention towards the physical and emotional

context of the gift, suggesting its impact of the donor family perception of the exchange of organs.

Whereas physiological aspects of brain death are widely discussed in the medical literature, the religious, social and cultural problems and dilemmas of brain death are subjects for the social sciences. The notion of brain death has sparked a wealth of literature debating its legitimacy as a criterion of death. Anthropological literature has dealt with this in great detail over the years, and we shall return to the many dilemmas of this peculiar death at a later point. In many studies, (Lock 2002, Haddow 2005, Sharp 2000, 2006) there seems to be an explicit critique of the medical notion of brain death questioning whether these organ donor patients are alive or dead. Here, the significant work of the Canadian anthropologist Margaret Lock must be emphasized. During the 1990s Lock investigated the social acceptance of brain death as a criterion for death in Japan and the US, resulting in her award-winning book *Twice Dead* (2002) in which she concludes that patients die twice, and that brain death is a “good as dead” condition invented by the medical world in order to carry out organ transplants. Lock continued to work with the assumption that brain death is a state of ‘betwixt and between’, an ‘invention of death’ constructed to solve the shortage of organs (2002b). The cultural differences in relating to and understanding death have also been explored anthropologically in regard to organ donation. Lock has shown how organ donation has different connotations in Japan because of the habits and rituals surrounding death, where a need to protect the body makes the idea of organ donation very controversial (Lock 1997, 2002a, 2002b). In this study, while I acknowledge the problems of brain death, While this is an important concern, this study does not aim to provide arguments for or against brain death, but rather to look at how the process of brain death is socially practiced and performed by the donor family, patient and hospital

staff, and how it is perceived in the time after the donation. In addition, I suggest that many families have no problem understanding brain death.

An area of interest for many researchers has been the problems that crop up in the mind of an organ recipient after the transplant. (Gutkind 1988; Sharp 1995; Siminoff & Chillag 1999; Lock 2002b). Sharp describes the difficulties of recipients in relating to the organ of a stranger as a “transformative experience”, indicating that the personal identity of the recipient has changed as a result of the transplantation (1995). The identity aspect also unfolds within xeno-transplantation (transfer of organs from animals to humans), where the sense of strangeness in the body is accentuated (Papagaroufali 1996; Lundin 1999).

Several anthropologists have dealt with organ donation in relation to the national and cultural values of the country. In addition to Lock’s abovementioned study in Japan, Linda Hogle studied how contemporary German attitudes to organ donation were impacted by the country’s Nazi history. In *Recovering the Nation's Body: Cultural memory, medicine, and the politics of redemption* (1999), she argues that ideas and values surrounding organ transplantation and the medical practice of removing and using parts from bodies to benefit others are deeply embedded in the history of the country. Hogle also points to the North European history of fear of mutilation of dead bodies, a destiny often associated with criminals and outcasts, to contextualize people’s reluctance to make a commitment to organ donation, as we shall return to later. This study will show how donor families relate to the Welfare state of Denmark and its benefits and obligations when expressing their reasons for donating, some are even feeling extremely proud to be Danish due to the care they received. Simultaneously, other families pose a critique of the Danish health care system when recollecting their experiences. Danes therefore have multiple ways of associating their experiences with donation to being Danish.

Anthropologist Orit Brawer Ben-David's study of organ transplantation in an Israeli context (2005) shows how heroism evident in Israeli society is transcendent in organ donation. For example, is organ donation used to transform an "ordinary" death, for example in a traffic accident, into a heroic death? The link between national or regional heroism and organ donation is also evident in the US, where personal stories of loss are translated into meaningful narratives acknowledging the donor families, celebrating the heroism of organ donors and comparing them to national heroes such as soldiers. Or, in a New York context, to the fire fighters saving other people and sacrificing their own lives during the events of September 11, 2001 (Jensen 2007).

The idea that an organ being moved from one person to another creates some wondrous kind of relationship has also drawn the attention of many anthropological studies. Alnæs has regarded organs as a kind of biomedical death treasure, underlining the mystery and magic these parts contain (Alnæs 2005). This mystery was also unfolded by the American anthropologist Lesley Sharp in her influential book *Strange Harvest* (2006) in which she provided a thorough understanding of the transplant arena in the US and the experiences of families, recipients and hospital staff. Sharp is one of the most significant anthropologists in this field and has worked on organ transplantation as a commodification of the body (2000) from the donor family perspective (2001), and on the technological aspects and potentialities of the field (2007).

The social relations of organ transplantation have also received anthropological attention. Fox and Swazey studied how living kidney donation can affect family relations (1992) because family members might feel an extra connection or sense of obligation to the family member who gives the organ. In relation to donation from a deceased donor, Alnæs argues that organ donation transforms existing kinship categories because

of the new relatedness established between the giver and recipient of an organ, and between the recipients of organs from the same donor, who often classify themselves as siblings or cousins (Alnæs 2001a, 2001b). Sharp introduced the term “fictive kinship” to describe the donor family’s need for contact with the recipient as a way of reciprocating the donation (1995, 2006). Her studies indicate that this fictive kinship can be artificial or unpleasant for the organ recipient, who feels overwhelmed by this contact. New research from the US has nuanced the notions of kinship and relatedness in this medical field. Social relationships can also be established between organ recipients and donor families without having exchanged an organ, but feeling connected because of either the lack of the “real” recipient or donor family, or because of feelings of gratitude and respect. These relationships are classified in “adoption” terms. There are also strong ‘family’ bonds between donor families as a group, and between organ recipients, because of their mutual understandings and shared experiences. While the exchange of an organ constitutes a certain sociality, it is not always only between the giver and the recipient, but can also appear between any giver and any recipient, or between actors with shared experiences, facilitated by the organizational forum in which such relationships are encouraged and promoted (Jensen 2007). This study adds insights to the sociality of organ donation by analyzing not only the social meanings of the organs, but also the dangerous sociality of organ donation, namely the one between donor family and organ recipients. I show how anonymity is practiced in Denma, how it is attempted to be silenced and disguised and how it affects the Danish donor families. In addition this study suggests, that organ donation not only creates social relationships, it is also a way of expressing your social relation to your country.

The commodification and objectification of the body has been explored by several authors (Alnæs 2001a, 2005; Fox & Swazey 1992; Joralemon 1995; Kopytoff 1986, 2004; Lock 2002a; Sharp 1995, 2000). The view of human body parts as 'spare parts' in strong demand as a result of the intense need for organs has initiated discussions about body ownership, embodiment, payment and ethical issues (Brecher 1994; Burrows 2004; DeCastro 2003; Murray 1997). In particular, Nancy Scheper-Hughes has done intensive work on the buying and selling of organs and the exploitation of poor people in underdeveloped countries (Scheper-Hughes 1996, 2004). Her work attempts to expose the crimes and the black market. This study suggest that even those mostly emotionally involved with the deceased donors turn to adapting a objectifying or utilitarian perspective on the body of the patient as a way to make death meaningful through the usability of the body.

There has been a growing body of literature from nurses interested in the problematic of organ donation. Among them, Magi Sque and Sheila Payne, who discuss the dilemmas of organ donation in an English context, stand out as some of the only researchers whose focus is on families who refused donation (2005). In Denmark, nurses and doctors have also published on the topic of organ donation. In the late 80s and beginning of the 90s neuro surgeon Benedikte Dahlerup published two books on the topic of brain death with the intention to carefully explain this new criterion of death (Dahlerup 1986, 1992). Focusing on the donor families, a group of Danish nurses made a comprehensive report in 2001 based on interviews and questionnaires with donor families from their department (Bruun et al 2001). The report was inspired by the difficulties many staff members experienced when supporting families of donors. Five years later, project nurse Lone Bøgh wrote a master thesis based on three interviews with donor families and suggested that organ donation was a "meaningful

burden” to families (2006). Together with the late Melvin Madsen, Bøgh was also the author of a rather controversial report in 2004, investigating the knowledge of and attitudes to organ donation of Danish hospital staff. This report stated that a reason for the low donation rates was that many potential organ donors were never discovered in Denmark.

Besides the body of scientific literature on organ donation, there is also a wealth of personal stories, written mostly by organ recipients but also by donor families. Among the most influential is the book *Nicholas’ Gift* by Reg Green (1999), the father of Nicholas, a young boy who was shot in a drive-by shooting in Italy, and became an organ donor who saved seven Italian lives. From an American context, bereavement specialists have focused on the special needs of donor families and how to support or accompany them in their loss (Holtkamp 2002; Malony & Wolfelt 2001). And the National Donor Family Council in the American Kidney Foundation published a book dedicated to donor families, called *Those Who Give and Grieve* (2003) as a support book in order for families to learn that they were not alone in their sufferings.

After this tour of the theoretical landscape of organ donation, let us zoom in on Denmark as a regional context for this study. In order to understand the ethnography from my fieldwork and the arguments of the dissertation, an overview of the history and context of organ donation and donor families in Denmark must be provided. The actions, discussions, dilemmas and policies of this area are all rooted in complex medical, social, cultural and historical patterns. These patterns shape the way organ donation is performed in Danish hospitals today and consequently also the way organ donation is experienced by donor families and hospital staff.

Organ Donation in Denmark

Medical progress in the world of organ donation is closely attached to scientific developments worldwide. Looking at the world history of organ transplantation, the first kidney transplant in the world was performed in the US in 1950 on a 44-year-old woman and the first successful heart transplant was performed by Christiaan Barnard in South Africa in 1967. Besides the surgical procedure itself, one of the biggest medical challenges in transplanting a human organ from one body to another is the danger of the organ recipient's immune system rejecting the "foreign object". Consequently a growing medical industry has specialized in immunosuppressive drugs which, as the word indicates, suppress the immune system and must be taken by the organ recipient every day.

From a dead human body, it is possible to transplant solid organs such as livers, kidneys, hearts, heart valves, lungs, small intestines, and pancreases. It is also possible to transplant human tissue such as eyes, skin, bones, veins and tendons. When it comes to living donation, it is only possible to donate one kidney or a fragment of the liver, since the liver is the only solid organ that is able to regenerate itself.

Over the past decade surgeons have experimented with face transplants and transplants of wombs and ovaries, all of which have sparked serious ethical discussions and might lead to new standards for transplantation in the future. At the same time, researchers are working on constructing human organs from stem cells and bio-engineers on producing biotechnological versions of organs. While this dissertation does not focus on the technological developments of modern biomedicine, it is an interesting thought that developments in either or both of these fields could lead to ending the need to transplant human organs altogether.

Criteria for the diagnosis of brain death have been discussed in great detail worldwide at medical conferences for years, but in 1968 a paper from the Ad Hoc Committee of the Harvard Medical School called *A Definition Of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death* constituted a landmark in the efforts towards defining brain death. These recommendations shaped national policy and legislation and were the foundation for establishing the brain death criterion (Lock 2002a; Sharp 2006). In 1990, Denmark, as one of the last countries in Europe to do so, applied brain death as a criterion for death and was thereafter able to procure all vital organs from brain-dead patients on respirators. Before that, doctors could only procure kidneys from patients once they had been taken off the respirator. As soon as their heart stopped, the doctor would declare them dead and their heart would be restarted in order to keep the blood flowing so the kidneys stayed healthy enough to be used. This was necessary for the medical progress of kidney transplantation in the 70s and 80s, but according to my interviews, this procedure was frustrating for many doctors, and especially for nurses, who even refused to participate in such a procedure during a conflict near the end of the 1960s. Therefore the brain death criterion, controversial as it might be, was regarded as a much better solution to the problematic of organ procurement. Not only did it become possible to procure all vital organs, but to hospital staff it also served as a much more meaningful way for a life to end.

The beginning of the 90s saw growing acceptance of this new definition of death, though many still found it controversial. Not all doctors were in favor of the idea of organ donation and many nurses found it difficult that a patient on a respirator could be declared dead. As the previous section showed, some anthropologists have argued that brain death is an invented death (Lock 2002a, 2002b). My research in Denmark

in 2009-2010 reveals that this argument is not only a humanistic critique of the ulterior motives of the transplant business posted by social scientists. Rather, it is a medical fact openly talked about by doctors and nurses in the field when reflecting on their own experiences and attitudes to brain death. Brain death is a definition of death that enables organ donation. In fact, in Denmark, the brain death exam is not officially carried out unless consent is given for organ donation, which indicates that it serves no purpose in a declaration of death in itself – only as a medical and legal foundation for removing organs from human bodies. If organ donation is not going to take place, it is called ‘futile treatment’ (*udsigtløs behandling*) and the patient is extubated, meaning taken off the ventilator to die from not being able to breathe on his/her own.

In the early 1990s there was an intense debate in the media regarding the ethical dilemmas of removing organs from patients with a beating heart. In the Danish journal *The Nurse* (*Sygeplejersken*) the tone was confrontational and direct, revealing that some leading nurses found the idea of organ donation very disturbing. They believed that engaging in an organ donation process was incompatible with professional care for a patient and provision of a dignified death. My research reveals that although some nurses, especially the older generation, might still have their reservations towards organ donation, most nurses these days regard organ donation as part of the medical landscape and think it is a challenging and exciting task to take care of an organ donor. Among nurses, it was evident that it is rather prestigious to master the task of taking medical care of the donor as well as giving the family a good closure. Sometimes older nurses familiar with the procedures have a hard time leaving the task to younger colleagues eager for experience. A young nurse even told me that she almost felt there was an “empathy competition” in her department, meaning that her colleagues tried to outdo

each other in doing everything possible for the donor families and almost bragging about it afterwards. Even if hospital managements are all in favor of organ donation nowadays – and my interviews with hospital managements almost invariably showed they are – the area still raises ethical issues that are a part of the daily life at NICUs, though perhaps brought to the foreground during my presence as a social scientist with a special interest in this field. How long staff should wait for a patient to enter the brain death zone? In other words, what is the ‘proper’ length of time before starting donor management, or making “the shift”, as some nurses call it, from taking care of a patient to taking care of a collection of organs? And what should medical staff do if a brain-dead donor goes into cardiac arrest? Should a ‘dead’ patient be brought back to life in order to save strangers? Matters like these will be discussed in forthcoming chapters. However, they are mentioned here to explain that even though organ donation has been taking place and brain death has been a medical fact and a legally approved criterion of death for 20 years and official hospital policies are unambiguous, my research provides strong evidence that in Denmark, an organ donation process never takes place without ethical dilemmas, discussions or comments of some kind or another, no matter how high the level of experience among doctors and nurses.

The ethical debate in the early 1990s was followed up by the Danish Ethical Council, which published a collection of essays in 1998 called *Give me your Heart: The ethical dilemmas of organ donation*. In that book, various experts from a range of disciplines discussed organ transplantation as moral obligation, altruism, business and even a form of cannibalism; humans consuming other humans. This particular chapter, by Lars-Henrik Schmidt, drew a lot of attention; it is still considered very provocative, and is criticized by most Danish organ recipients and medical professionals. In 2008 the Ethical Council published another book on the

subject, where half of the council was in favor of presumed consent and the other half not. The book, also a collection of ethical discussions on organ donation, identified certain recommendations including inventing new rituals and focusing more on the family. Lately, the Ethical Council has done a lot to engage young people in the debate by producing teaching material for the lower secondary school and arranging a seminar on organ donation for Danish school children in January 2011.

In Denmark, there are three transplant centers. In Aarhus they transplant kidneys and hearts, in Odense only kidneys and in Copenhagen kidneys, livers, lungs and hearts. Denmark also has an eye bank in Aarhus for cornea transplants. It is a significant part of transplant history in Denmark that there was a fierce competition for certification to perform transplants between the hospitals in Aarhus and Copenhagen. In the first half of the 1990s liver surgeons fought so hard that this period is referred to as “the liver war”. After being told about this period, I understood better why a country like Denmark, small as it is, was almost cut in two when it came to organ transplantation. The insight helped me understand the insider joking and the ridicule of other parts of the country.

Danes can sign up for the donor registry with full consent to donate all organs, limited consent or no consent. It is possible to donate liver, kidneys, heart, lungs, skin and corneas. The registry is administered by the Copenhagen University Hospital (Rigshospitalet) and around 15% of the Danish population has chosen to register. The public debate on organ donation in Denmark mostly deals with the increasing number of patients on the waiting list to receive a new organ and the number of patients who die on the waiting list. As a consequence of that, Denmark does not differ from other countries in encouraging the public to take an active part in solving this problem and signing the donor registry.

In public, there is no obvious divide between organ donation and organ transplantation. However, it is important to state that the area of organ donation is divided in two. There is the “donation side” – the NICUs, where patients die and become donors (not necessarily perceived in that order, but we shall return to that). And on the “transplant side” are the transplant centers and the surgeons performing the transplants on patients struggling with sick organs. I was not aware of this until I was invited to a transplantation conference in the US in 2006 to talk about my research on donor family aftercare. To my surprise, the conference room was invisibly (to me) but intentionally divided in two. The medical professionals had placed themselves in two sections where one of them, the transplant side, was arguing for the need for more organs, while the other, the donation side, represented by NICU nurses, was more silent and reserved, though their eyes showed they were disturbed by my presentation of the – seen through Danish eyes – rather extraordinary and bombastic world of organ donation in the US. Lesley Sharp experienced the same division of the room signifying the division of the world of organ donation and transplantation during her studies in the US (Sharp 2006: 35). In the discussion afterwards I heard a couple of comments from the NICU nurses that still stand out as groundbreaking for my understanding of the Danish area of organ donation. One of them was “We don’t want more organ donors. To us, an organ donor is a patient in our department we could not save” and the other was “Americans might do too much, but Danes do nothing” followed by a comment on the particular Danish “reluctance to deal with death and grieving people”. In this study, this reluctance became evident on many levels. It is reflected in the myths and horror stories surrounding organ donation, but it also explains the absence of organizational support or network for Danish donor families.

The two sides at that particular meeting very rarely meet in Denmark. The connecting link and the gatekeepers between them are the transplant coordinators. They coordinate the many complex aspects of the organ donation process and make sure that the rules regarding anonymity between donors and recipients are handled. My dissertation deals primarily with the donation side. Denmark has five NICUs, which is where most organ donation cases are admitted, but donations are also done at so-called “normal” intensive care units at smaller hospitals.

Denmark is located at the bottom of the European organ donation rates with only 12.92 ppm in 2010 – meaning that there are 12.92 organ donors per million people in Denmark (www.scandiaintransplant.org). By comparison, a country like Spain is always pointed out as a role model due to their donation rates of over 30 ppm. However, in professional circles in Denmark, the so-called Spanish model is regarded as aggressive, meaning that they have people at the hospitals scanning the halls for potential organ donors and they have specialized personnel working with the family that are said not to accept refusal when it comes to signing for consent to donate.

After political pressure from the rightwing Danish Folk Party (Dansk Folkeparti), the government funded the creation of The Danish Center for Organ Donation in Aarhus in Jutland, which officially opened on June 1, 2008. It took intensive lobby work from large patient organizations such as the Danish Heart Foundation and The Danish Kidney Foundation, which are strong proponents of the “Spanish model” and wish to reorganize the field so that teams of experts go out to hospitals and take care of processes such as the brain death exam, donor management (medical care of the organs) and counseling for the family. This idea came from a documented suspicion that in Denmark, medical professionals had shifting attitudes towards organ donation – they did not

always make sure that organ donation was performed and potential donors were not always discovered and identified in time, especially at smaller hospitals in the more rural areas. By organizing so-called teams of experts to go out automatically, it was believed that more organs would be donated.

In order to protect the autonomy of the ICUs, the Center decided to make the support from a team of experts optional. During the past year, the organization of on-call teams has made it possible for smaller ICUs to call for a neurosurgeon and an NICU nurse to help with donor management or family counseling if they see the need for it. But this opportunity has only been exploited a few times, which could indicate that donors are not discovered, that staff feel they are able to handle it themselves, and/or that most organ donation processes take place at the larger NICUs.

The work of the Danish Centre of Organ Donation has been crucial in the recent development of the organ donation scene in Denmark, especially when it comes to educating and creating social networks among the ICU staff. The Centre has made sure to point out some “key persons” on every intensive care unit who are responsible for educating colleagues and raising awareness at department level. The Centre is also in charge of a wide array of education possibilities, networks and groups of interest, and they organize project days and host the European Donor Hospital Education Programme (EDHEP). This course is a training course from Holland that serves as a model for educating hospital staff in “the difficult conversation on organ donation”. Earlier it was arranged by the transplant coordinators with support from the medical industry, but now the Danish Centre for Organ Donation manages the course and transplant coordinators participate as speakers and observers. As it looks now, it seems as if the Centre is successful in ensuring a good dialogue with

hospitals and medical professionals. However, there are problems, as many doctors and nurses, and some transplant coordinators, feel that the Centre has encroached on their areas of expertise. It is, and will be, an ongoing challenge to ensure smooth cooperation between the different parts of Denmark. Even though the country is very small, it is a long way from Aarhus to Copenhagen, and many of my informants look at the Center as “belonging to the Jutlanders”. This is not entirely wrong, since many of the “innovative” initiatives now performed country-wide were designed in the Jutland regions and implemented there first.

In the past couple of years the debate has been characterized by discussion on whether or not Denmark should move towards presumed consent, as opposed to the informed consent that is currently the juridical background for organ donation. This discussion has been broadcast in the media and also on private websites by people with a special interest in the cause, such as the young Danish heart recipient Casper Palmvig, who is very active in the media telling his story and encouraging people to sign the donor registry. In the spring of 2011, the Danish Parliament decided on two political objectives. One is to make sure that more potential organ donor patients are “discovered” and treated as potential donors, and the other is to bring the percentage of families consenting to organ donation up from 50% to 80%. An annual report from The Danish Centre of Organ Donation published at the end of June 2011, based on monitoring deaths at intensive care units in 2010, shows that the percentage of families consenting is as high as 77%. Even if registrations can be manipulated, this is clearly interpreted as something very positive. The director for the Centre has stated that it reflects that the hospitals are able to maintain the positive attitude of the population shown by opinion polls conducted by the National Board of Health. She also argues it reflects that staff have become more positive towards organ donation, as shown by one of the

Centre's own quantitative investigations over a ten-year period. Thereby she indicates that in the health care system, it is believed that the personal attitudes of the staff clearly affect the decisions of the family.

The category of donor families is only a rhetorical one in Denmark. There are no social forums and no particular meetings devoted to this particular group. It has been one of my main wishes to explore why this group is embedded in social silence, a matter I shall return to in the final chapters. Donor families sometimes appear with their personal stories in newspapers and magazines, and three donor family members are engaged as public speakers in the Danish Transplantation Group, where organ recipients share experiences and inform about organ donation. A few Danish hospitals offer support groups for families who died at their intensive care unit. In such groups all kinds of families meet. So occasionally and coincidentally, Danish donor families meet and share experiences in the support groups of the hospitals. But it is a puzzle why Denmark, the land of organizational activity as described by Anne Knudsen (1996), has no organizations for donor families.

Outline of the Thesis

Chapter 2 is devoted to unfolding the wondrous journey to the strange world of organ donation. I set out to describe the conditions of the field when entering, being in, and leaving it. Chapter 2 starts with the death of a young woman, Molly, who then became an organ donor. This detailed and at times raw ethnographic description, sometimes taken directly from my field notes, exemplifies many of the methodological issues I dealt with, and its rich analytical potential is unpacked in the following chapters. I discuss the methodological and ethical implications of the study of the threshold between life and death, focusing on the emotional distress of my

donor family informants and how it affected my own experiences as an anthropologist. My aim with this chapter is to underline the analytical potential in the methodological and ethical reflections.

The following analytical chapters are all organized in order to support the overall argument that organ donation is orchestrated by means of ongoing social processes of ritualization and other practices in order to grasp and translate the unfamiliarity, the unnaturalness and the ethical challenges this medical procedure poses. It is not my intention to argue that attempts to orchestrate and make sense of the organ donation processes are always a success or a failure. Rather, I investigate the social processes involved in the sense-making attempts, in my own attempt to unravel some of the complexities of donor family experiences. The empirical and analytical focus of each chapter serves to convey how many particular ways death can be orchestrated. While the overall argument of the dissertation stays the same, the sequential analytical discussions take us deeper and deeper into understanding organ donation in a Danish context from various angles through the optic of orchestration.

Chapter 3 deals with donor family experiences of organ donation and brain death. Building on theories of ritualization and performance (Turner 1967, 1974, 1988; Sjørølev 2007; Bell 1992, 2009), I argue that the processes of ending life in that way are embedded in a series of actions that can be seen as attempts to frame and to ritualize death in a certain way. The purpose is to perform 'the good death' in spite of the suddenness of the tragedy, the unfamiliarity of brain death as a criterion for death, the shifting boundaries between life and death and a jolt to traditional ways of handling dead bodies. Chapter 3 aims to give a rich variety of empirical examples from the clinical context of organ donation to illustrate the multifaceted range of family experiences.

Chapter 4 stays in and goes beyond the clinical context. Leaning on Vincent Crapanzano (2003) and Mattingly (2010), I discuss how notions of hope are actualized and practiced in the donor family experiences of organ donation over time. I argue that hope is a transformative practice ranging from the hope of survival to ideas and hopes about the future of organ recipients. The section ends with what I have defined as the donor families' hopes for the improvement of their conditions in the Danish health care system. Here my findings become very concrete and include recommendations. While it is not my intention to write an evaluation report, the families' urge to make suggestions, and the professionals' openness to hearing them, were so strong and bore so much analytical potential that they could not be overlooked.

Chapter 5 deals with the aesthetization of the donor body. It follows the body of the organ donor from being a potential donor, to being a consented donor, to being open on the operation table, and finally returning as an empty corpse. In this chapter I lean on the work of Hogle (1999) and that of Kapferer and Hobart (2005), who point to the importance of the notion of aesthetics in relation to performance. This chapter explores a crucial part of the orchestration, namely the social acts that preserve the dignity of the patient and his or her body.

Chapter 6 looks into the precarious sociality of this field by focusing on the exchange relations of the circulating organs. Here I argue that the context of the exchange – in this case the social surroundings of the hospital – affects the way the body parts are perceived, whether as things or as extensions of personhood (Fontein 2010). This section also underscores an important element of this study, which is that perceptions of the Danish welfare system deeply affect the way organ donation is morally and socially spoken of. Lastly, I unfold the kind of social

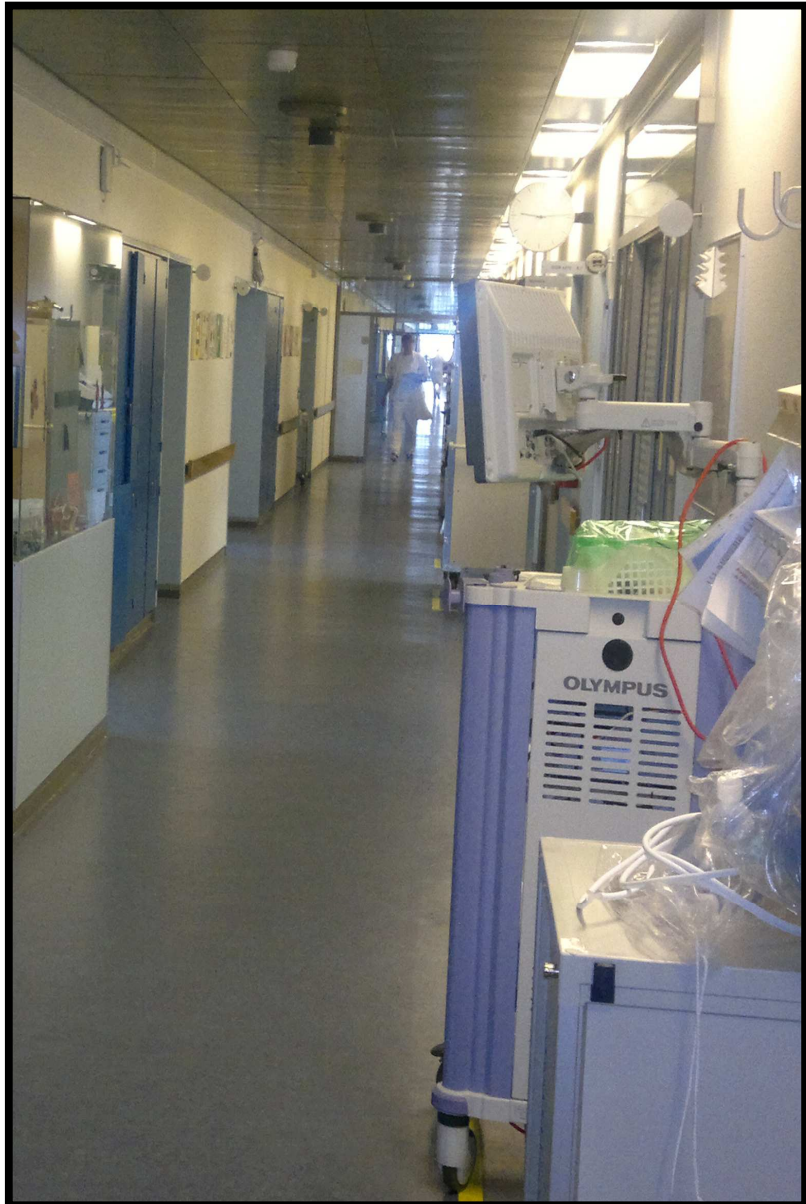
relationships that the system tries to keep hidden, namely the forbidden relations between families and organ recipients.

As a final point I explore the stories of organ donation, meaning the ones being repeated over and over again and the ones that are kept hidden because they can potentially damage the organ donation community. Leaning on Jackson (2002) I explore the purpose of telling stories, and I show how some Danish donor families find comfort in linking their loss to organ donation, while others experience a frustrating lack of vocabulary. Telling stories, I argue, is also an essential part of orchestrating an exceptional death.

Finally, I conclude on my findings and provide concrete suggestions to the context of organ donation and donor families in Denmark.

After this introduction to the field of study and overall argument, an overview of the theoretical landscape and the contextual background of organ donation, I now invite you to join me in a journey to another world. The story of one of my days of fieldwork acts as an ethnographic baseline for understanding the methodological considerations and the nature of this field.

Chapter 2: Journey to Another World



A Day in the Field

It is 7.05 in the morning, as I rush into the long hall at the neuro-intensive care unit where patients are lying unconscious, connected to respirators in paired rooms of two beds each. The nurses are watching their numbers and values on computer screens from an open “control” room between the two rooms and at their bedside. I enter the staff room, where patients are being introduced on the board by the head nurse from the night shift. After their current condition and treatment plan is presented, the nurses (and their many nurse students) are assigned to their individual patients.

Kirsten, the leading nurse of the department, welcomes me and says: “We might have another one for you! A young woman. Isn’t that unbelievable? It is really a good period you have chosen to visit us.” The words make me flinch, but I skip making excuses for my morbid research interest. Instead I smile and say: “It sure is a busy period. Who is she?”

Kirsten explains that the patient, a young woman, came to their department early in the morning after a heart attack due to bleeding in the brain, and they think she has already incarcerated, meaning the blood has stopped running towards her brain and the process of brain death has begun. Kirsten explains that the woman’s boyfriend tried giving her heart massage to bring her back to life, but she never regained consciousness. Kirsten also tells me the woman has three kids, the youngest only six months old. The older kids of six and eight years old have been removed from her care for some time, says Kirsten, concluding that this is a “rather special family”. We briefly discuss that it is different and extraordinarily sad when such young people with small children die.

After this brief introduction, I go to the control room near the patient’s bedside, where the nurse Simone is getting ready to hear “the report” from the nurse on night shift. Simone and her student Anna, who

is training to be an intensive care nurse, greet me and we discuss how unlikely it is that this is the third donor in a week. I glance briefly at the woman, who seems to be asleep, as do all the other patients in the NICU. “It’s terrible,” the nurses say, even though they have seen this over and over in their career – but the suddenness and unpredictability of these bleeds seems to scare all of us. Simone and Anna take me to Molly’s bedside. Simone quickly tests her pupils with a flashlight to watch for any reactions and squeezes her toe and finger nails hard to watch for reflexes. “There is nothing,” Simone says. The patient next to Molly has a tumour in the brain, but is awake, so the nurses quickly decide to move Molly to another room where she can be alone. The decision is rapidly carried out without any questions; the tumour patient should not hear what is about to take place with Molly in the following hours and the family should be able to say goodbye in privacy.

At 7.45am, I start my morning agenda of participating in the morning conferences of the two different groups of doctors at the NICU: first the anaesthesiologists and at 8 am the neurosurgeons. At the 8am conference, the many patients are presented and discussed in a group of doctors and the leading nurses. Everybody is placed in the room according to a hierarchy. The head doctors are around the huge square table with the younger doctors at the back, sitting on chairs placed against the wall, while the nurses sit shoulder to shoulder at the end of the table. The operating schedule for today is presented, the various tasks assigned to doctors and important decisions about the conditions and plans for the patients are rapidly discussed among colleagues while CT scans and X-rays of the sick and injured brains are shown on a large screen. Molly’s case is presented and her picture of a severe intracranial bleed appears on the screen. The doctors quietly sigh and mumble, indicating without further comments that this is the picture of a dead patient. One doctor

talks about approaching the family about organ donation and that the brain death examinations should be made this morning, when one of the younger doctors suddenly yells: “We should call the anthropologist! I forgot her name, but we should call her.” His comment results in the entire room laughing and making jokes, because I am sitting at the end of the table right in front of him. The head doctor jokingly points at me sitting next to him saying “she’s sitting right here Klaus, don’t worry”, and I smilingly raise my arm and say “thank you” to Klaus who is blushing from embarrassment.

Returning from the meetings, I go to the new ward where Molly has been placed. Simone and Anna work hard to monitor all her bodily functions and give her the right amount of medicine. Doris, the anaesthesiologist, is in there too, commenting on how lucky I am to “possibly have another one” and making sure to oversee the medicine. Even though nobody knows if Molly is going to be an organ donor, the processes for maintaining the organs have already started. But the optimism in the room is not high. Doris asks me if I know her story. Two kids removed from the home and a diagnosis of ADHD. Doris cannot promise she is going to be a donor with that social background. “It is going to be a tough conversation.” Simone tells me that she and a doctor already spoke to the family in the family room and told them that I was studying communication and following her today, and asked if it was okay that I was present in the room too. The family had accepted, and I thank Simone for introducing me early. It makes it easier for me to do my observations.

After some time, the nurses are ready to let Molly’s parents come in and rapidly ask me to help them put out chairs for them at the bedside. The nurses are quiet, quickly having made sure she “lies nicely” in the bed, meaning that her hair is combed and there is no blood or body fluids to be seen anywhere. A man and a woman enter, Simone introduces us, we

shake hands and they go to the bedside and hold Molly's hand. They start crying and yell out their pain and fear, choked from the situation. The grief and frustration of the parents is evident and this makes tears come to my eyes. I step back in the room and remember Anna's advice earlier to look up at the ceiling. I see Simone's eyes tearing up and she turns her back to Molly's bed and looks for some tissues to give the family. The nurses watch Molly and quietly speak to the parents. When asking about her condition Simone replies that "it does not look good but we know nothing yet", intentionally leaving the difficult message to the doctors.

Some time after the parents have left the room to call other family members and take care of the parking, the head doctor Olav enters in a rush. He quickly examines the reflexes of Molly and concludes that, as earlier observations predicted, it looks as if she is already brain dead. He asks how long since she took a breath on her own, and is informed that she has not tried to breathe since 4.30am. Olav then walks away to see other patients. After 30 minutes he returns. He approaches me, asking how I think the case will turn out, and if this family will consent to donation. Surprised by his question, I reply that I doubt this, keeping in mind the earlier conversations with the nurses. Olav says that he called the donor registry, and Molly has registered with consent to donate all organs. Olav is very surprised and happy and the nurses smile too. Doris seems almost thrilled that this is going somewhere. Molly is going to save lives. Consent for organs is already given, and the conversation with the family is going to be much easier than expected. Confronted with the *a priori* social stigmatization of the hospital system (and my own) I reply to Olav that "I guess we have to redefine our prejudices" and he agrees. After this, Olav intends to approach the family in the family room outside the hallway of the NICU, and he invites Doris, Simone and me to join him. Olav greets the parents and informs them that, as predicted earlier, it

looks very bad. “We have been observing her for hours. Molly is not going to survive this, and it looks as if she is brain dead.” The speed with which he gives the information makes me feel uncomfortable in the couch opposite the parents, who are devastated but calm. The mother says “life is a bitch” in English and start crying. Olav rapidly continues. “In such specific situations, it is possible to talk about organ donation.” The parents look puzzled and I am sure it is because of the speed of the information. The mother replies: “Oh no. Is it us who is going to decide or her boyfriend?” As if this was timed to perfection, Olav replies. “Don’t you worry. It is none of you. Molly already made this decision for you. I checked the registry and she gave her consent to donate all organs.” The father says thank God, and his shoulders fall down and he starts to cry. The mother also cries, saying “this is typical of Molly. She has always been a special girl, knowing what she wanted.” But the parents say they are very glad Molly decided herself. Olav says that he thinks “it is an admirable decision to make for a person so young”, and the parents nod and express pride in her decision. “Are you keeping her going”, the father asks. Doris replies that they have to do so in order for the organs to be used. Olav then informs them what is going to take place. They will make the first brain death test at 10.30am, six hours after she stopped breathing herself, and one hour after that, the second test will be done, as the law requires. The parents nod their heads and Olav says that they will be kept informed the entire time, that the nurse will help them and that they are allowed to be with Molly at the bedside. Olav uses the next few minutes to express his understanding for their grief and underline how unfair it is for somebody so young to die like this.

Going back to the room, Olav and the nurses agree that this was a good conversation. But five minutes later Simone comes back and looks rather shocked. She went back to the room with some coffee for the

parents and overheard the mother calling a family member. “She just called the number and said Molly is brain dead,” Simone tells me. “And then I could just hear the other person on the phone screaming.” The expressions on the nurses’ faces make me realize that even if the conversation was “by the book”, nurses are constantly reminded that this is a nightmare for families.

Later that day, after the brain death tests, I watch Simone and Anna taking care of Molly in very specific ways as is the case for all organ donors. Simone is going to measure the contents of Molly’s stomach, and draws a lot of dark green fluid from a tube in her nose. Camilla, a new young nurse eager to be a part of this donation process, is holding the content in small plastic cups and constantly emptying them so they can be measured, since the holder normally used to obtain this fluid is nowhere to be found. As she leaves to empty the cups, I choose to step in at the bedside and hold the cups as Simone fills them with the content from Molly’s stomach. It makes me feel sick, so I hold the cups but look away, which make Simone smile. “The expression on your face is so funny. How much would it take to make you drink this?” She giggles, while Anna steps in the room and takes over for me. I also laugh and reply “It’s only a snail, Mulle”, referring to the well known Danish movie *Zappa*, where a young boy is forced to eat a snail if he wants to retrieve his Rokokko Pillow from his friends and be part of the group. Simone and Anna laugh, and I silently feel embarrassed having laughed near Molly’s bedside and having made a joke over something so grotesque. While stepping back, I realize that the attitudes and emotions have shifted back and forth during the day, depending on who was in the room. The nurses had to make a joke with the anthropologist in order to get a few seconds of smiling in spite of the tragedy, even though it reduced Molly to a body with disgusting stomach fluids. In the midst of all the sadness the nurses made a joke

with me. And I, too, felt the need to create some distraction by responding to the joke. On the other hand, the last hours of crying family members entering and leaving the room, the boyfriend saying his goodbye in privacy, letting Molly know how sorry he was that he couldn't save her, and the smiling baby in the hallway was devastating to all. This confirmed Molly's position as an individual with a family we all could identify with and made her situation intolerably sad.

I leave the NICU in the afternoon when Molly is only a few hours away from going to the operation room. As I leave, Maria, who took over after Simone, tells me that the family has said their goodbyes. They want a phone call the next day to be informed about how many of the organs were transplanted. "It seems very important to them," Maria says.

Negotiating Access

Gaining access to observe organ donation at an NICU in a Danish hospital such as the one described above and being part of the world of hospital staff and organ donor families is a complex matter. This section will therefore outline my year-long process of negotiating access and networking.

My entry into the Danish organ donation scene started at the beginning of 2005 when I was preparing for my master thesis fieldwork in the Donor Family Aftercare Department in the New York Organ Donor Network, and I interviewed three Danish donor families. After my research in the US, the field of Danish donor families became even more interesting to me. While American donor families relied on a huge organizational support system after the donation and were invited to a multitude of events honoring and memorializing the dead organ donors, Danish families were alone, unorganized and receiving no public or organizational support

or acknowledgement related to their decision to donate. It was this particular silence or lack of attention in contrast to the American way of speaking about organ donation and commemorating donor families that sparked my curiosity towards the Danish context of organ donation and donor families.

A few of my pilot interviews had revealed what at the time I saw as a shocking lack of compassion in the Danish hospitals. For example, I remember a mother losing her son in a traffic accident and not being allowed to say her goodbyes in peace because the nurse would not stop the loud TV of the patient lying beside the son in the hospital ward. Stories like that made a huge impression on me and inspired me to start a debate in the Danish Medical Journal in the summer of 2006 provocatively questioning whether Danish hospital staff considered the special needs of donor families and were aware that this could affect the decision-making processes (Jensen 2006a). Surprisingly, a leading neurosurgeon immediately wrote an angry reply classifying my arguments as undocumented allegations and emphasizing the educational efforts taking place such as the European Donor Hospital Education Programme (EDHEP course) (Kosteljanetz 2006). After replying and elaborating my arguments (Jensen 2006b), I realized that I obviously did not know everything there was to know, and that something needed to be investigated in the Danish scene of organ donation. Later, when I met that particular doctor, he showed interest in my research from the US and my future project, and in fact became one of my primary gatekeepers and tickets to access the otherwise closed wards of the NICUs.

As a result of the writings in the journal, a kidney surgeon invited me to speak at a scientific meeting in Odense in the fall of 2006, where the staff from the intensive care units met with the transplant coordinators and transplant nurses and discussed organ donation. At that meeting I

presented my findings from New York and made a strong point about the American way of looking at organ donation, specifically the heroic aspects of it such as handing out medals to donor families. My presentation was affected by the fact that while physically being in Denmark, I had not fully returned from the seductive American context of organ donation. Although I underlined the cultural differences, arguing that these practices should not and could not be translated directly to a Danish context, many of the intensive care nurses were very provoked by my presentation. At that meeting I met many people who would later become my informants, among them another important gatekeeper who showed interest in my future project. Eight months later, she opened not only her NICU but also her private home to me and became crucial for my entry, presence and insights in the field.

At the same time, a project nurse working on organ donation, who was later to become employed at the Danish Centre for Organ Donation, had also shown interest in my findings from the US and my plans to investigate Danish donor families. She invited me to speak at other transplant meetings, where I enlarged my network in the field. Thus the process of creating interest and making friends with gatekeepers began several years before the actual project started.

As soon as my project started in January 2008, my dialogue with the newly established Danish Centre for Organ Donation continued, and by way of their advice, I asked for permission to observe the EDHEP courses. I was allowed to do so for three courses/seasons and besides gaining extraordinary data, EDHEP was where I maintained my existing relations in the field and gained new informants. Therefore, when writing a formal letter to the managements of the four NICUs asking for permission to conduct fieldwork (see appendix 1), I already had contacts among doctors and nurses who could pave the way for me.

I chose to focus my research at the NICUs because they represent the largest numbers of organ donors, and I was more likely to be able to follow some cases. They all welcomed me to conduct my fieldwork with them, some of them even appreciating that “studies like this were finally being done”. When arriving at each of the four hospitals, I always started out with making a formal presentation at the morning conference for doctors and during a meeting for nurses. Here I laid out my intentions, interests and methods and emphasized that I was there to learn from them, not evaluate their actions. I made a big deal out of underlining my position as an outsider and thereby it became acceptable for me to ask all kinds of questions. When the Norwegian anthropologist Anne Hambro Alnæs negotiated her way to the NICUs, she underlined that she was married to a doctor and therefore almost an insider (Alnæs 2001a: 46). But I was more comfortable as the strange anthropologist studying organ donation, and it was my clear impression that hospital staff found this exciting and refreshing. I also used these introductory meetings to help find a strategic and decent way to be present in these emotional conversations with the families, an important matter I shall return to in the section on ethics. It was my impression that this dialogue-based entrance approach was appreciated and my presence was quickly accepted. Gaining access to the NICU and the world of hospital staff is all about building relationships of trust (Ibid: 48).

After making all the classic rookie mistakes – wearing jewellery at the NICUs, panicking over alarming sounds from the respirators and not knowing how to open hospital doors – I settled in and became a part of the units. During the course of my stays, I also selected doctors and nurses to participate in semi-structured interviews based on their experiences with organ donation and recent happenings at the department, and nobody ever refused an invitation.

As soon as I entered the unit, I made sure that a several business cards with my phone number and a small poster describing me and my project was always available and visible so staff was reminded to call me if organ donation was about to happen (see appendix 2). This small poster was revised and continued to hang in the NICUS even when my participant observation had ended and I was “only” on call.

But my project also entailed another important element which took a lot of work. I needed to gain access to the homes of donor families and to their experiences. Due to ethical concerns, I did not interview them at the hospital. As a result of the lack of organization and networks of Danish donor families, the group is not easy to find, so I had to lean on many strategies. As done earlier when finding my families for the pilot study in 2005, I put an ad on *www.mindet.dk*, a Danish memorial site for the dead. I also established my own website called *www.donorfamilie.dk* where families could approach me after having read about my study. In addition, I send emails to my personal network and did an intensive search in a media database to find articles and names of Danish families who had donated in the past. I was able to find 15-20 families this way. They welcomed me to visit them and I started doing interviews all over Denmark right away.

But it was also my plan to interview families who had donated recently and perhaps even revisit somebody I had observed at the intensive care units. Therefore, in the last part of my fieldwork, I asked the NICUs for permission to write a letter to families who consented to organ donation within the past two years (see appendix 4). By way of helpful doctors, nurses and secretaries most addresses were found and a total of 63 families were contacted all over Denmark. The detective work surrounding this search for families gave analytical insights into the more administrative obstacles of keeping contact with donor families after they

leave the department. It also showed me that information regarding families is kept in various ways from hospital to hospital. 36 families wrote back wanting to tell their stories to me, some of them including several family members in our interviews. For ethical reasons, I could not refuse any families willing to participate and most importantly, I appreciated this opportunity to learn from donor families. Conducting these interviews turned out to be a logistical and emotional challenge, but at the same time, an incredible source of unique and interesting data. Before the interviews even started, the high number of positive responses was a clear indication that donor families found this matter important and needed some kind of outlet to speak about organ donation.

Going beyond hospitals and homes, the various forums in which hospital staff met and discussed matters of organ donation was another important space for my project. As a result of my good relationship with the Danish Centre for Organ Donation, I was often invited to be a part of their interesting meetings, conferences and symposiums all over Denmark. Often I presented my research at its various stages and thereby bought myself a ticket to the incredibly exciting presentations by doctors, nurses and transplant coordinators, the intense discussions and the social network of the organ donation community. This gave valuable data on how organ donation and donor families were spoken of in professional contexts outside the hospitals. And I got an impression of the sometimes evident dilemma between the political and organizational goal to get more organ donors on the one hand, and the staff objectives to provide emotional support and not pressure or manipulate families on the other. Underlining my own focus on family experiences and not how to increase donor rates was therefore well received. Their response to my ideas and findings also constituted an important source of knowledge. So the strategy of dialogue

was a way of gaining access as well as providing valuable thematic and contextual information.

“The Angel of Death” – Collecting Data about Organ Donation

I get so nervous when I see you (Olav – neurosurgeon)

I started out my fieldwork by following the daily life of various units for a month or so each. By showing up and following the nurses I was attached to at day, evening and night shifts, I quickly became familiar with the routines of the departments and the medical and personal challenges of working in such units. But the strategy was also to have the staff feel confident and safe around me. I had to earn their trust so they would not hesitate to call me whenever a donation case was about to arise. Doctors and nurses also advised me where to strategically place my phone number, so it was accessible to the staff. As the incident with the young doctor in the case of Molly suggests, I dare say that I succeeded in raising awareness towards my project and my special wish to be present during family conversations. Sometimes, I was even called by doctors or nurses I had not personally met. This openness suggested that in matters of organ donation and donor families, Danish hospital staff are very interested in the production of new knowledge from other scientific angles than the ones they usually engage in. The position as a stranger was not an obstacle, but rather an admission card as soon as they realized I could be trusted. Sometimes, the position as stranger enabled collection of completely different data than what I was originally searching for. I was presented with the struggles of being a young doctor trying to fight for the rare option to be educated as a neurosurgical specialist, the physical breakdowns experienced by some doctors and nurses due to the emotional distress of

dealing with critical patients, the internal struggles going on within and between different professional groups, and the crucial mistakes or “unintended events” that should not have taken place. According to anthropologist Tine Gammeltoft studying abortion in Vietnam and Tine Tjørnhøj-Thomsen studying infertility in Denmark, the position as a stranger can create an advantageous position of confidentiality and “social anonymity” resulting in openness even in very personal matters (Gammeltoft 2003). The strangeness provides access to intimate spheres (Tjørnhøj-Thomsen 2003: 108). This turned out to be true for me in my research endeavours, not only when interviewing people who were suffering, like the donor families, but also with doctors and nurses, revealing their personal problems with organ donation, their emotional difficulties in dealing with children as relatives, or the problem of treating patients who reminded them their own family members. While this information could have framed the foundation of many interesting dissertations, it gave depth to the one-dimensional terms “doctor” and “nurse”. It taught me that the medical context in which organ donation takes place is very complex and full of individuals with specific professional, personal and emotional histories and characteristics. Analytically, this means that in relation to organ donation, the donor family experience at the hospital depends heavily on the individuals engaging in the social interaction. It also reminded me, that hospital staff informants also have emotional stories and should be treated with the same sensitivity as families in my study (Høyer et al 2005).

I participated in the doctors’ morning conferences and in their rounds, but by choosing nurses as my primary companions, I was able to stay as close to the patients and families as possible and still maintain the important contact with the doctors going in and out. As many other anthropologists have experienced, the coffee breaks were extremely

valuable for gaining information. During these breaks the staff used me as a discussion partner and many stated that my presence inspired them to discuss matters of organ donation.

Wearing a white coat, I blended in with the staff, and could easily move between wards, conferences, X-ray rooms and staff kitchens, and sit in the “control rooms” where staff monitored the screens and read journals. I did not want to wear white pants, because being mistaken for a nurse and asked questions I could not answer was uncomfortable. I quickly realized that the position as an observant student ready to learn is a common sight in hospital corridors. There were many medical and nursing students, so even if my professional skills were different, my presence did not stand out. Like Alnæs, I did however wear a name tag where it said I was anthropologist to avoid confusion (Alnæs 2001a: 46). Anthropologist Ben David writes that there are often many strangers in hospitals, so medical staff and patients take the presence of strangers for granted (Ben David 2005:3). As the story of Molly shows, families also accepted my presence without question.

I quickly learned that silent observation of the daily life was not a possibility. Because of my “exotic” profession as an anthropologist and my access to the homes of donor families and other hospital wards, I was often used as a discussion partner. Doctors would also ask me for feedback on how I thought they had managed the family conversation or, as we saw in the case of Molly, how I thought the approach for donation would turn out.

From the very beginning, whenever I stepped into the neuro-intensive departments, people associated me with the topic of organ donation. As Olav expresses in the quotation at the beginning of this section, seeing me appear unexpectedly could be scary for a neurosurgeon whose life is devoted to saving patients with sick brains. My sudden presence often meant that one of the patients was not going to make it and

I had been called there to witness the case. I therefore made it a habit to thoroughly inform people about the days I was going to be present to observe or conduct staff interviews. And if plans changed, I would repeat “I am only here to interview” when staff greeted me in the corridors. This methodological strategy of calming down doctors and nurses was to make it clear that I did not view the primary goal of the NICUs as organ donation, but to save the lives of people with brain injuries. While this information is self-explanatory to everybody within the system, the fear of doctors prioritizing functioning organs over saving the life of the potential donor turned out to be an existing prejudice in the public, and a comment I often got when explaining my project to friends and family.

As we saw in the case of Molly, due to staff members’ interest in my project, they were happy that I got to experience many organ donation cases during my fieldwork. In every hospital I visited, there were organ donation cases during the very first days of my observation, and sometimes several within a short time. This was defined by the staff as an incredible coincidence and resulted in the staff teasing me and calling me nicknames such as “jinx”. However, it was easy to see that some staff members were more enthusiastic about potential organ donation cases than others. Everybody let me observe their medical work as well as their family conversations, but it was through the staff’s responses towards my presence that I sensed that organ donation did not mean the same for all hospital staff. As we already heard in the introductory chapter, to a few doctors and nurses, an organ donor was a patient that represented the medical limitations of neurosurgery, a life that could not be saved and nothing to be excited about.

Being called nicknames such as “the angel of death”, “the organ vulture”, and “the brain-dead”, (and perhaps many others that never reached my ears), was part of being accepted at the hospitals. Sometimes

the nurses suggested using me as a guinea pig for students learning to place a rectal tube; jokingly commenting that “I might as well be of some use, just standing there”. I laughed along with them happy to be part of their internal joking. The more troubling part for me was when the nurses and doctors almost excused the fact that none of their patients were potential donors. They were afraid I was getting bored with plain observation of the daily life. At one point, I asked a doctor about the meaning of a brain scan, and while he was kind enough to explain it to me in words understandable to an anthropologist, he ended with saying that “the patient is not interesting for you, you like the dead ones better”. This made me reflect on my morbid-seeming interest in death and the way I appeared to people at the departments. If I only spoke about organ donation, and snuck around searching for death, so to speak, it would be troubling for both me and the staff. Analytically, it gave me insight into the fact that an interest in organ donation could easily be misunderstood. Sometimes the nurses and doctors working as key persons within the area of organ donation were criticized as being “too enthusiastic” by other staff members. Clearly it was okay to be in favor of organ donation, but the performance of the balance between finding potential donors and keeping the focus on care of the patient and family was interesting to observe. This discussion will be elaborated in Chapter 5. As we see in the case of Molly, the hospital staff is very affected by tragic deaths, but simultaneously happy when organ donation is taking place. It is an exciting and medically educating process, it helps potential organ recipients, and most importantly, according to their experience, it is also helpful and comforting for the families. In addition, hospitals are also being monitored for their organ donation statistics.

At one point a nurse who was an organ donation key person asked me how the conversation with the family of an elderly woman had turned

out because she had been involved with another patient. I told her they consented, and she smiled and said “YES” and lifted her hand to give me a high five. Still very emotionally affected by observing the small children saying goodbye to their grandmother, I was appalled by her joy so I exclaimed “I cannot do that!!” and immediately she realized my point of view and gave me a big comforting hug. While my personal reactions should not be the focus of this study, I argue that it is important to take one’s own moral outrage or personal reactions seriously because they carry significant analytical value (Jensen 2009b; Buch 2009). In this case it opened my eyes towards the various roles and agendas of the hospital staff, and to the fact that organ donation has to be handled and spoken of in certain ways in order not to break the general code of conduct at the hospital.

Being allowed to be present in the medical team’s dialogue with donor families is not to be taken for granted for an anthropologist like myself. While studying organ donation in Israel, anthropologist Ben David was denied access to these conversations based on the medical team’s determination to guard the anonymity of the donors and of donating families (Ben David 2005: 4). In contrast, I was surprised by the level of commitment expressed by Danish doctors and nurses. They called me every time they had a potential donor and a conversation with the family was about to take place. Unlike Alnæs who explained that some of the staff was reluctant to her presence (2001a: 46, 56), my study was met with incredible openness and an endless stream of information that was almost exhausting to take in.

Personally, the consequences of being on call for over 14 months were rather hard. If I was sick or out of the country I felt bad for not being able to turn up right away as I usually did. It was as if I was never off duty, and the idea that I was always at risk of staring other people’s tragedy in

the face was exhausting. Still, it made me understand the unpredictability of potential organ donation processes and the working conditions of people on call in the organ donation business, such as doctors and transplant coordinators and the teams of nurses ready to go out to smaller departments if needed. Personally, there was a constant reminder that if the phone rang somebody was dying, which made me aware that the suddenness of death could also take place in my personal life. In the beginning I was reluctant to share this information because I was afraid that I would lose “street cred” at the hospital. However, talking about this fear openly with the nurses and doctors turned out to be a methodological window to understanding how they themselves dealt with the tragic deaths and terrible personal destinies characterizing their working life. Doctors and nurses also kept an eye on me and did what they could to protect me, for example by encouraging me to take a break or leave the department and come back later during cases that lasted for days. They often told me to “hang up my white coat” when leaving the department – a strategy they themselves used to shake off the tragedies in their working lives before returning to their families. When explaining that it was part of the anthropological business to go home and write my field notes and reconstruct the whole day, they found the thought of this almost unbearable. After the first cases I witnessed, I agreed. Many of my field notes are therefore written at the hospital during small breaks or narrated to my dictaphone in bathrooms or bike sheds at the hospitals. I, too, needed to shake off tragedy and exclude it from my personal life.

Visiting donor families in their private homes was also very challenging. Arriving with the agenda of hearing about their worst personal tragedies made me feel as if I was transgressing boundaries. But this was a groundless fear. As soon as families had invited me to their homes, access to their stories was without limit. As a stranger, I was told every

detail of losing a family member and consenting to organ donation. Gammeltoft points to the difficulties of keeping the balance between therapy and interview when interviewing people who are going through pain (Gammeltoft 2003 281). Families expressed feeling comfortable about sharing their stories. Even further, it seemed that the anthropological interview itself – just to have someone listening and daring to ask details about the difficulties of organ donation – sometimes acted as an aid to healing for families. Many claimed that it was “nice finally talking about it” – since for some families, this had never been done before, an insight I will discuss in Chapter 7 on the stories of organ donation.

Such interviews dealing with the death of a close family member were of course very difficult emotionally, but at the same time, the anthropological value was so high that I never considered not continuing. As Ben David says, such interviews take place “in the shadow of death”. And as an anthropologist you feel a tremendous sense of empathy towards these people having lost a close family member. The data is so emotional that it can be a burden listening to the interview again (Ben David 2005: 6).

Sometimes interviews lasted five hours and included tours of the house, especially when the room of a child was left untouched, and viewing pictures from family gatherings and holidays. I was and still am honoured by being shown so much trust. Often I found it hard to leave the homes of families, particularly when the death of a spouse had left my informant living alone, and I could feel they appreciated the visit, not only because of their participation in my project.

Interviewing donor families adds another dimension to the balance of therapy and interview. Some families used me as a resource of medical expertise within the field of organ donation. I was faced with a multitude of questions from the families I interviewed. Even if I have more than the

average person's knowledge from my clinical field experiences, questions such as "if brain dead really is dead" made me feel uncomfortable. At one point, an elderly woman told me about the nightmares she was having, and asked me if I thought her husband had been in pain when they removed his organs. I found myself unable to carry on the interview without reassuring her that he could not feel anything, before advising her to call the hospital and speak to a doctor. Insights such as these, of course, are not only methodologically interesting with regard to the position and the role of an anthropologist studying organ donation. They also serve to show that in Denmark, many donor families are contemplating their decisions to donate. For some families it even causes extra devastation. The lack of important information, or the lowered ability to grasp important information in the course of tragedy, can turn the medical process of removing organs into an act of torture and mutilation rather than a meaningful way of ending life and helping others. This will be further discussed in Chapter 5, which focuses on the organ donor body in the successive stages of organ donation.

Many families wondered if their thoughts and experiences were "normal". "Have you spoken to other families that feel this way?" was a question I often came across. In a way my travels between the homes of Danish donor families put me in a position as the social glue somehow tying this group together by confirming that they were not alone in their considerations. Analytically, this turned my attention to the consequences of the lack of sociality among Danish donor families. But it also suggested the point that even if there are no visible or tangible social organizations or support systems, there is some kind of – following the theory of Benjamin Anderson (1993) – "imagined community" among Danish donor families. Contrary to my earlier research on donor family aftercare efforts in the US (Jensen 2007), Danish donor families have no public or organizational

platform on which their feeling of community can be performed and expressed. But through this curiosity towards fellow sufferers revealed in my interviews, I was able to identify the special kind of donor family fellowship that exists, even within the challenging premises of the Danish structure. These insights will be unfolded in Chapter 4.

Navigating the Ethical Context

As argued in a previous publication (Jensen 2009b), the practice of anthropology is characterized by ethical dilemmas calling for professional and personal standpoints and actions. It is my intention to unfold the dilemmas and their analytical potential, not only in this section devoted to ethics, but throughout this study.

My first ethical concern arose already when choosing the focus of this study. I considered whether to include organ recipients and perhaps also sick patients waiting for organs. But I soon realized that this was impossible to combine with studying organ donor families. Focusing too much on the outcome of the transplants and the usability of organs would somehow blur the perspective on the personal donor family experiences. What mattered to me was not if families said yes or not, it was how they experienced the process. In addition, knowing and caring for informants on the organ waiting lists while at the same time observing families making decisions that could save the lives or take away hope of survival of these patients would constitute an ethical dilemma. It would also cross the already established boundaries between organ donors and organ recipients, constituting an important divide of the Danish organ donation context made out of ethical concerns towards organ recipients. I therefore chose to focus on the donation side, and I made no formal interviews with organ recipients but only spoke to them informally. By coincidence I came

across the dilemma anyway. I was a supervisor to a masters student studying patients on the organ waiting list. One day she entered my office in a rush saying how happy she was that a young girl, who was a very dear informant but also very sick, had just received a new liver and now her health was improving rapidly. I asked when. And when I was told that the liver had arrived Tuesday night, I asked my student not to say anymore. I had followed this particular family throughout the process of making the decision and I knew every detail of the donor providing the liver. Knowing where the liver had ended up was somehow crossing some boundaries that I had adopted from the context of my field. This confirmed that I could not have listened openly to donor families making decisions if I had had social relations with sick patients on the waiting lists.

When doing fieldwork in a medical context like organ donation, ethics are ubiquitous as a methodological concern, as a theoretical point and as a constantly addressed issue in the empirical reality. Ethics cannot be reduced to a set of standards but must be seen as a contextual relation. It is a context and a practice. It is part of preparing, practicing and reflecting upon anthropology, but it also constitutes a reality of its own worthy of anthropological attention (Ibid 151). Put in another way, for me, practicing anthropology in the field of organ donation was a certain way of navigating in an ethical context. But ethics was also an integral part of being, speaking, acting and engaging in social relations. In that sense, ethics is fundamentally embedded in the study of life and death and the people experiencing sudden tragedy. I experienced ethics as an influential part of practicing medicine at the neuro-intensive care units and sometimes it clashed with common anthropological standards.

This was especially evident in the family conversations about organ donation, that I was eager to witness. I did my best to prepare myself ethically for this challenge. I used some of my previous family informants

that I knew very well and asked them how I could be present in these conversations. And they all told me not to worry. As one of the donor mothers told me: “We are losing a child, we do not care about your study.” As explained earlier, I also made sure to negotiate the way this was done best with the individual department and the doctors and nurses involved. As I had already predicted, the anthropological standard to inform your interlocutors on the agenda of the research was impossible in this particular setting. The many conversations with potential donor families often started when families still had hope for the survival of their family member. Presenting me as “an anthropologist studying organ donation and donor families” would therefore mean that families would get sudden and rather harsh information that their loved one was not going to survive. Therefore the doctors and nurses suggested that I was introduced as a student who was studying communication, the dialogue with families or simply, as we saw in the case of Molly, a student following the particular doctor or nurse that day. Anne Hambro Alnæs met the same challenge in her studies of Norwegian donor families. She did however present families with a informed consent document where they could state their willingness to speak to her. But the letter did not contain any information about organ donation since the family did know now at that time that they would be approached about organ donation (Alnæs 2001a, and personal email correspondence).

It was troubling for me not to be able to inform families about my true agenda. On the other hand, I felt I had little choice. I quickly learned that doctors and nurses are extremely aware of the order of the information. As we see in the case of Molly, the course of family conversations and the rhetorical way the information is given are carefully and strategically performed in order to support families the best way, make sure they comprehend the information, and in these cases, give them the

best options for understanding and consenting to organ donation. It was in these ethical negotiations that I realized what was to become the main analytical argument of my work: Organ donation is all about a social interplay of timing, performing and staging this exceptional way of dying. In order for the complex processes of organ donation to take place and to be accepted, it needs to be presented and translated in specific ways. Death is orchestrated.

The strategy of working this way was something I had met before. During my research in the US, I followed a family coordinator from the New York Organ Donor Network when she approached a family about organ donation at the hospital. In the beginning she presented herself as “a family specialist” and me as “her co-worker in training”. It was not until she gained the trust of the family that she revealed her true agenda, namely to ask about organ donation. While being critical of this American way of approaching families, my own anthropological endeavors of observing these cases turned out to work according to the same strategy. But I learned that this was the only way to go if I wanted to be present in these conversations. On the one hand it is extremely problematic because families do not know my true agenda. On the other hand, stories from donor families in the time after donation show that it is important they are given the information carefully in the right order (Alnæs 2001a, Jensen 2007). And this is what the doctors and nurses try to do. Acknowledging that hope is gone is a prerequisite for handling the question of organ donation. In such situations, the anthropologists learn that current ethical standards about presentation and informed participation are and must be secondary to the special ethical premises of the actual field of study (Jensen 2009b: 140). It is a way of navigating the ethical context.

As explained earlier, in the attempt to get donor families to participate in interviews, the hospital sent letters to the families in the

months after the donation (see appendix 3). The letter informed them that I had been there to study organ donation when they were asked about the matter. With the formal letter from the hospital was a letter from me asking them for an interview (see appendix 4). In most incidences, the families I met again did not recognize me and told me that they had met so many people at the hospital. But I never experienced any anger towards my strategy. It was and still is troubling that the families I observed at the hospital who said no to donation were not contacted again due to administrative limitations, as we shall see in the next section. They never had the chance of being told that an anthropologist with a special agenda was observing.

Molly's case teaches us that humor is an important matter in the NICU. While it is rare that jokes are made so close to the patient, the example is important to understand the context and the working conditions. In the beginning I did not quite know what to do when staff members were joking but, as I did in that case, I often chose to participate in the joking even if I was sometimes very embarrassed and afraid to cross ethical boundaries. But searching for this important balance gave me the valuable insight that the meaning of the body of the organ donor shifts back and forth, depending on where it is in the process and who is in the room. Looking at Molly's case, when the parents are there, nurses do all they can to make sure she lies peacefully and neatly, and they can be at her bedside. When it is only nurses and anthropologists, it is okay to make a joke. In fact we all needed to do so, because the circumstances of this particular case were so emotionally disturbing. The ethical conduct of the hospital not only has its own character and context, it also shifts according to the social circumstances of the donor body. And most importantly, the humor is the staff's way of coping with and – to use my theoretical terminology – “orchestrating” the huge number of tragic deaths

they constantly meet. This ethical insight inspired me to focus analytically on the shifting roles of the donor body in Chapter 5 and the strategies of hospital staffs and families in these shifting processes.

In one of my interviews with a donor mother, she commented on how awful it was that there were so many people, students and others, in the wards that had no business being there. She also described how terrible it was that hospital staff were joking and talking about their holidays in the hallways when she was losing her son. Her words made me flinch, because I had been at the hospital observing her case, and I also remembered that at some point I had exchanged tips about New York City with one of the doctors in order to maintain my good relations. After investigating my field notes, it turned out that the New York conversation took place on another day. But it made me realize that when exchanging holiday tips as a way to negotiate trust and good social relations with the doctors and thereby access to family conversations, you risk offend families if the timing is wrong. But at the same time you have to follow the shifts in attitude, also evident in Molly's case, that hospital staff initiate in order to stand their job. Analytically, comments like that confirmed that families are very aware of the physical surroundings and that they have a need to construct a peaceful death and a quiet goodbye in spite of the busy and impersonal surroundings. This matter will be unfolded in the following chapters.

Data material – Potentiality and Limitations

Before starting on the discussions in the following chapters, I will briefly outline the extent of my data material. In total, I have done approximately 20 months of anthropological fieldwork in the Danish world of organ donation. My data consists of field notes from five months of intense

participant observation in the daily life of four Danish NICUs. I was on call to rush to the hospitals whenever there was a potential organ donor for a time period of 14 months. I was a silent participant in over 60 family conversations with the next of kin to 26 potential organ donors (one family can have several conversations) and I observed donor management, the brain death exams and other actions and conversations regarding organ donation I have interviewed 67 members of hospital staff (three anesthesiologists; eleven neurosurgeons, five of them heads of their department; 22 NICU nurses, three of them nurses in charge; two transplant coordinators; one transplant surgeon; one operating nurse; and one hospital chaplain). I have conducted two large group interviews with twelve ICU nurses and fourteen operating nurses and two smaller group interviews with four NICU nurses. In addition to this, some of my most influential staff informants never sat down for formal interviews but instead we had hours of informal conversations on several occasions during night shifts, conferences, car rides, at cafes, or over some red wine in their homes. I have not interviewed any politicians about the topic, but I have interview the person in charge of organ donation in the National Board of Health and on several occasion spend hours discussing organ donation with the staff of the Danish Centre for Organ Donation. In the time after the donation, I conducted 52 interviews with 80 Danish donor family members of 50 organ donors, out of which 77% donated from 2007-2009, the rest donated in the years before 2007. A large majority of the families said yes, only 2.5% of my informants declined donation I have participated in three seasons of the EDHEP course and a multitude of events, seminars, project days, conferences and courses. It was my intention to also interview the families who said no to donation. Hospital records did not at that time register families who said no to donation, and according to hospital regulations, it was not allowed for me to send letters

to “no” families based on my own or the nurses’ memories. Due to the introduction of a national database regarding organ donation and deaths at the intensive care units from the spring of 2010, the Danish Centre for Organ Donation has made it possible to find families who declined donation. This would have been an exciting contribution to my research. However, one “no”-family found me on the internet and offered to participate. And families said no to organ donation in six of the acute cases I observed. So even if the families who said yes constituted the primary part of my data, I do have some information on the experiences and decision-making processes of families who declined organ donation which will also be included in the coming chapters.

As explained earlier I chose to focus on organ donation in the neuro-intensive care units. That means that I have not conducted participant observation in so-called ordinary intensive care units in the smaller Danish cities where organ donation does not happen so frequently. Since these departments are often publicly criticized for their lack of expertise in finding potential donors, they would have been interesting to include in the participant observation. However, I made sure to do interviews with staff from such hospitals, and some of my families also experienced organ donation at these small hospitals.

Some of the hospitals I visited had support group for families that had lost at the NICU. At these sessions, donor families were also present. While these could have constituted valuable information on family interaction and differences between having a family member die the “normal way” and having a family member become an organ donor, I chose not to ask for permission to observe such contexts. I believed such initiatives should take place without audience.

As we shall explore in chapter 5, I was not now allowed to follow organ procurement surgeries at the largest hospital in Denmark. I believe

that could have been avoided if I had made the efforts to follow the daily life at the operating units. When I realized I had to build strong relationships to the transplant surgeons to be allowed inside, it was too late in the process.

Another limitation is that I did not conduct any follow up interviews with donor families. That might have provided extra insights, but since I felt my interviews which often lasted for hours were very thorough, I did not rethink my initial strategy. In few instances, I did email with families or made phone calls.

With that, it is time to start the analytical discussions, starting out with investigating how donor families experience brain death and organ donation, and how they make the decision to donate. The next chapter, “The Death of The Breathing Corpse”, will take us further into this particular process and underline my main arguments concerning the orchestration of death.

Chapter 3: The Death of the Breathing Corpse



The Death of the Breathing Corpse

This chapter deals with the orchestration of death by discussing how the death of the organ donor is ritualized in the neuro-intensive care units. In the following pages, the concept of orchestration serves to unfold how the strange figure of organ donation is introduced, decided upon and practised. I characterize ritualization as the constant performance of trust which is acted out in the social interplay of devastated families; medical staff; and the technological surroundings of this clinical context. As we shall see, trust is essential for handling and understanding this peculiar way of dying called brain death, and for making decisions about organ donation.

Organ donation interferes with familiar ideas, traditions and practices surrounding death. Death in relation to organ donation can be controversial and ambiguous, and can complicate the process of grieving. In order to procure the organs from a patient's body, the brain must be the only body part that is dead. The brain-dead patient is still on a respirator and the body is kept, not "alive" as such, but "circulating" or "functioning" in order to maintain the health of the organs and consequently ensure the most optimal transplant outcome. As one of the intensive care nurses told me in an attempt to classify this special condition: "The patient is dead, but it is not a corpse."

Brain death carries no familiar visual signs that death has occurred. The body has not turned pale and cold, the heart has not stopped beating and the patient is still breathing. As my chapter title suggests, the organ donor patient is a breathing corpse; it is beyond familiar categorization. Linda Hogle argues that brain death has changed the timing, the recognition of cues and the procedures of the dying process

(Hogle 1999: 26). Adding to this, based on my research, I argue that brain death can be defined as a “sensory paradox”. What is seen, heard or felt is not necessarily true. In the face of these ambiguities, families rely on the social interaction with doctors and nurses and with the surrounding technology in order to grasp death. While trying to comfort and support the families, hospital staff try to explain brain death and at the same time ask the central question of organ donation. At a time when families are still in shock, they are asked to let other doctors remove the organs of their loved ones before the heart has stopped beating. Believing in brain death and consenting to organ donation is dependent on the families’ social relationship with and confidence in staff. It is therefore my argument that in the empirical reality, organ donation is a matter of trust. Theoretically speaking, I see the constant performance of trust as attempts to ritualize the peculiar and unfamiliar death and the strange figure of organ donation. I underline that it should be understood as attempts. Depending on the particular configuration of staff and family and the circumstances of death, the orchestration of death is not always successful. However, in the clinical context, attempts to ritualize death through the performance of trust are always made.

As a starting point for understanding the performance of trust in the clinical context, I find it fruitful to use the theoretical concept of social drama to understand the processes surrounding the often sudden and inconceivable death of an organ donor. The British anthropologist Victor Turner defines social dramas as units of aharmonic and disharmonic social process, arising in conflict situations (Turner 1974: 37; 1988: 74). The social drama contains four phases. The first is ‘breach’ of social relations. As I see it, this is when the misfortune happens for a patient and the family; a brain haemorrhage or a fatal traffic accident. The next phase is ‘crisis’: the breach widens and the crisis has liminal characteristics.

Typically this is the time of shock and confusion at the hospital. The patient lingers between life and death and families must understand that brain death has occurred or is about to occur. Sometimes this phase of crisis is also where the question of organ donation is presented, perhaps causing further crisis. The third phase is 'redressive action' or attempts to solve the crisis. In Turner's words, this can range from personal advice to legal machinery or the performance of a public ritual. In other words, it can be performed in any number of ways, from the rational idiom of the judicial process to the metaphorical and symbolic idiom of a ritual process. It is the phase in which brain death is declared according to law and the medical procedures of organ management are begun. But it is also in this phase, I argue, that staff ritualize death through the performance of being trustworthy as they try to support and inform the family. The fourth and final phase is either "reintegration" of the disturbed social group or the "social recognition" and legitimation of irreparable schisms (Turner 1974: 38-40; 1988: 74, 75). I see this process as starting when families leave the hospital, but due to the tragedy of the loss, the social unit of the family remains disturbed and many never experience social recognition. However, even if the crisis of losing a family member cannot be "solved" as such, families might over time find comfort in donating organs.

I do not see the social drama as representing a precise temporality or sequence in which the families experience the event. Also, this chapter is not structured according to the order of Turner's social drama. But seeing organ donation and the death of the donor as a social drama accentuates the performative elements of the social interactions in the NICUs. Leaning on Richard Schechner, Turner argues that actors in a social drama consciously "try to show others what they are doing or have done; actions take on a performed-for-an-audience aspect" (Turner 1988: 74, 76). As I see it, this is exactly what the doctors and nurses do in their

performance of trust. They show and explain to their audiences, the donor families, what they do and what they have done in the process of death. This process entails changing focus from trying to save the life of the patient, to realizing death is about to occur, to starting to think about organ donation. Often the “audience” is not only the family, but other doctors and nurses, themselves attempting to perform, perceive and practice the complex medical and emotional tasks involved in organ donation. And as this chapter shows, families can also be actors trying to solve the crisis and “performing for an audience”, especially when family members try to explain brain death to the young children of an organ donor.

Throughout this chapter, I argue that the performance of trust is a part of the ritualization of death. Theoretically, when talking about ritualization, I lean on anthropologist Catherine Bell. According to Bell ritualization underlines the social practice, the creation of meaning and the dynamic elements of ritual practice. She defines ritualization as the “production of differentiation” or “a way of acting that specifically establishes a privileged contrast” (Bell 1992: 90). While Bell sees these processes as ways of making the ordinary into something extraordinary, ritualization in the clinical context of organ donation also appears as ways of understanding the extraordinary, in this case the breathing corpses. Ritualization attempts to construct something recognizable – a familiar way of dying – and a proper visual appearance of the body of the patient. Following Linda Hogle, there is a need to ‘translate’ the practice of organ donation (1999). Adding to this, my field studies showed the need and the attempt to translate this apparently peculiar way of dying. The body of the patient somehow becomes the scene in, on and around which this translation or ritualization unfolds. That is how death is orchestrated and how the actors involved seek to create meaning. Ritualizing the death of

the organ donor is an attempt to establish a contrast between life and death, since the dead look alive. Brain death is the premise for making decisions about organ donation. That is why trust is so important. As argued earlier, while this exceptional death often cannot be seen or sensed, it can be explained and performed so that families will trust that death has occurred.

As we shall see, for some families, the process of ritualizing helps understanding death and making the decision. Ritualization is not a concept describing a straightforward journey to a point of complete understanding and meaningful closure. Ritualization helps us frame the ongoing attempts to translate and make sense of the events at the hospital through the performance of trust. Due to the severity of the loss and the devastating situation, I argue that meaning cannot ever be found in such situations. But looking at the social practices of attempting to create meaning can teach us important points about donor families' experiences.

Bell focuses not on rituals as such but on ritualization as practice. In the context of organ donation and the performance of trust, what I see as the practice of ritualization takes many forms depending on the individual, social and medical configuration of circumstances of the organ donor and the family. According to Bell, ritualization is also a strategic way of socializing. (Bell 1992, 7,8; Sjørlev 2007: 16,17). "Ritualization produces this ritualized body through the interaction of the body with a structured and structuring environment" (Bell 1992: 98). This idea can be transferred to the field of organ donation. I argue that the body of the organ donor is ritualized as a way of orchestrating this exceptional death. This takes place in the social interaction between the body of the patient and – to stay in Bell's terminology – the environment, meaning the family, the hospital staff and technology (which, I argue, are also mutually

interacting). They are all structured by or trying to structure the individual and ambiguous body of the organ donor.

To sum up my analytical argument, ritualization entails the performance of trust. I argue that trust is a prerequisite for having these complex medical processes take place. The performance of trust is a series of attempted practices performed in the clinical context of brain death and organ donation. They serve to construct a conceptual framework in which death becomes understandable and organ donation becomes meaningful.

In my fieldwork, four moments stood out where the performance of trust was pivotal: locating the moment of death; the social interaction with technology; trying to construct the decision to donate or not; and the attempts to perform 'the good death'. This classification of themes is analytically constructed as a strategic way to unfold my argument and structure the chapter. As my empirical cases will show, in the everyday of the clinical context, these four moments are deeply interconnected, and should not be seen as happening in a linear time sequence.

Locating the Moment of Death

This section serves to provide insights into the paradox of brain death and the difficulties families experience when searching for the moment of death. Locating the moment of death is also a title for one of the chapters in Margaret Lock's book *Twice Dead* (2002a 78). She discusses the historical, medical and political processes towards accepting and establishing the formal brain death criterion. My agenda with using that title is to unfold how the search for a moment of death plays a crucial role for the experiences of Danish donor families and how this moment is performed in the interaction with hospital staff.

Robert Hertz concluded that biological death is experienced as a social event. The corpse has contradictory social meanings and moral significance and must be handled with care and respect. (Hertz 1960, Lock 2002a) Margaret Lock has analyzed Japanese and North American practices of brain death and organ donation. Using van Gennep and Turner, Lock sees death in line with other life cycle transitions: “Death rites are bounded by rituals of separation followed by a liminal period, an ambiguous state carefully orchestrated by society, and completed through rituals of incorporation” (Lock 2002a: 194). Referring to the works of Bloch and Parry (1982) and Leach (1961), Lock continues to argue about death that “This frightening potentially polluting event is controlled through ritual, but the social order is itself in part reconstituted by means of its performance”. Thereby death rituals permit a resolution to the end of individual life and the continuity of the social order. (Lock 2002a: 194). In this work, I also acknowledge the liminal character of the process of dying in the intensive care units. The death of an organ donor can be understood as a transition between life phases. But it is my argument that this ambiguous state of liminality is not only orchestrated by society, it is orchestrated by doctors and nurses in a social interplay with donor families. Adding to the argument of Lock, I see rituals as playing an important role, but it is the social performance of rituals, the practice of creating and shaping rituals that not only attempts to control the event of dying but also tries to reconstitute social order. Therefore, as already argued, when using rituals in this work, I am leaning more towards the theory of ritualization by Catherine Bell (1992)

Organ donation happens at the end of the life of a patient with such severe brain damage that nothing can be done about it. In order for organ donation to take place, the donor patient must be brain-dead. But brain death can turn out to be very complicated due to the complexity of

the human brain and the problems that might occur in predicting the exact moment of brain death. Many families in my study stated that a brain-dead person looked alive, and they had trouble perceiving and defining the actual moment of death. Some found brain death hard to understand because the body looks as if it is sleeping – the hand is warm, there is breathing activity and all in all, death is not at all visible in the sense of someone taking their last breath and beginning the process of becoming pale and stiff.

The picture shown on the front page of this dissertation shows a young woman holding hands with her dead brother after organ removal. This picture not only shows the grief and the emotionality of being a donor family member, it also says something about the moment of death and the construction of death as a social event. When talking to the parents of this young boy, they turned my attention to the number written on the hand of the sister. It said 15.50. That was the time the boy took his last breath. His official time of death was late in the evening after the brain death tests had been conducted. But to the sister and the rest of the family, the boy died when his last spontaneous breath was noted by the nurses. The sister had written it on her hand to remember that this was the one that felt accurate to her. This resonates with what many of my families described. Locating the moment of death is difficult. It can be when the accident happens; it can be the last attempt to breathe; it can be when the brain incarcerates; it can be after the first or the second brain death test; or it can be on the operating table when the heart stops. Like Laurence O'Connell argues: "The moment of death is a social construct, that is, a shared convention among those who move within the same province of meaning" (O'Connell 1996: 27). My study showed that often families and staff do not move within the same province of meaning. Sometimes various members of the same families do not share the same convictions about the

moment of death. By carefully attempting to orchestrate death, this particular moment is located in the social interplay between families and staff.

In order to diagnose brain death in Denmark, two brain death exams one hour apart must be carried out by two doctors; one has to be a specialist in neurological diseases. Some countries have other standards. For example in Norway, all potential donors must undergo a cerebral angiography, which is a test to confirm that there is no blood flow to the brain. This test can also be performed on Danish patients, if for some medical reason the clinical tests cannot be performed. I observed several brain death tests during my fieldwork. The tests are characterized by extreme professional precision and carefulness. They take place when the doctors assume brain death has occurred, which is after the brain has incarcerated. This means that the pressure inside the skull, called the intracranial pressure, has exceeded the blood pressure. This in turn indicates that blood has stopped circulating in the brain and the brain is therefore deteriorating. For a detailed ethnographic description of this process, see the case of Luka in Chapter 5. The doctors work according to a formal outline that is the same all over Denmark. First they double check that the patient has a well-established brain injury and is no longer affected by pain relievers or anaesthetics that could disturb a true clinical impression of the patient's abilities or disguise brain stem reflexes. The temperature of the patient must also be within a certain range (since low temperature can give a false impression of the patient's reflexes) and spontaneous attempts to breathe must have stopped six hours previously. Doctors then check the brain stem reflexes by stimulating the patient in different ways. For example they squeeze the fingernails to look for pain reflexes, provoke the vomit reflex in the throat, touch the pupils with a cotton bud to provoke blinking and pour iced water in the ears to watch for

any reaction to these extremely alarming stimuli. According to the doctors, ice water in the inner ear can cause the heart to stop if the brain is functioning normally. Doctors also make a quick turn of the patients head. If the pupils are stiff and follow the movement like a doll, it is another sign of brain death. All of these tests stimulate the brain stem reflexes in different ways, and in brain-dead patients, there is no reaction to any of these stimuli. The test ends with removing the respirator from the patient in ten minutes. In that period doctors watch the chest of the patient for attempts to breathe. Before and after this apnoea test, the blood gases are tested, and there has to be an increase in the level of carbon dioxide, meaning that the blood is getting no oxygen, and in turn that the patient cannot breathe. Often the brain death tests are observed by younger nurses and doctors wanting to learn about this form of death. Doctors are therefore extra-careful when performing the tests and explain every move in order to make sure that the students (and the anthropologist) know what is going on. All of this usually takes around 20-30 minutes and one hour later, the entire test is repeated all over again. Every aspect of the test is carefully noted on a formal chart and the doctors in charge of the tests sign the paper. This paper follows the patient to the operating table. If it is not properly filled out, the organs will not be procured. One of the senior neurosurgeons told me he was once picked up by the police at his house because he accidentally forgot to sign the paper, and the team of surgeons was waiting in the operating room to start the procedure.

I have also observed tests where the patient failed to qualify for brain death, for example by reacting to the stimulation of the pupils or starting to cough when the vomit reflex is tested. In such incidences, the test is immediately stopped and repeated after one hour. If the same happens, the patient does not meet the standards and cannot be declared

brain-dead and is taken off the respirator. Failing a brain death test is not the same as not dying. But the patient cannot be an organ donor.

These brain death tests are the legal foundation for allowing the removal of organs. They serve to diagnose and confirm that death has occurred. Adopting my analytical perspective of ritualization, they can also be seen to be a performance of the rational, medical and scientific 'trust' or proof that brain death has occurred. Squeezing the fingernails of the patient or pouring iced water in the ears are ritual practices accompanying the patient from life to death. Following Bell, these practices differentiate the brain-dead patients from patients in the ICU who are comatose. They would have reacted to these stimuli; the brain-dead patients do not. By performing or observing these tests, medical staff obtain visual knowledge of this death and have no doubt that technically and according to law, the patient is dead. The brain death exams ritualize the dead body through symbols that are familiar for those with professional knowledge of the human body and the functioning of the brain. But without this knowledge, the brain death tests can be hard to understand.

This study shows that many families, for example Molly's parents in Chapter 2, have no troubles understanding that brain death is death. While acknowledging that brain death is still a controversial topic causing many frustrations and considerations, it is equally important to acknowledge that for a great number of Danish families, the brain death criterion has become an accepted way of dying. That does not mean it is not hard for these families to go through the processes of organ donation, but it does mean that it would be a serious mistake to automatically assume that every family doubts whether brain-dead really is dead. Another important element when families are about to understand brain death is the authority of the doctors. In the case of Molly, Olav delivered the message about brain death and organ donation so quickly that I

started feeling uncomfortable. But he did it with so much authority that the family had not doubts that he was right. Some doctors have the ability to communicate trust and deliver their message with so much professional authority that families cannot avoid trusting them, and that is comforting for families.

Several anthropologists have dealt with the ambiguity of brain death and the challenges it poses to our understanding of the boundaries between life and death (Alnæs 2001a; Ben-David 2005; Haddow 2005; Hogle 1999; Lock 2002a; Sharp 2006; Youngner et al 1996). Anne Hambro Alnæs, who studied organ donation and donor families in Norway, described the ambiguity of the brain death as follows: “An unintended consequence of coupling modern technology to the new death criteria is that the moment of death has become unclear” (Alnæs 2001a: 85). Thereby Alnæs points to an important issue of brain death: When exactly is the moment of death? This question haunts many of my donor family informants as they search for a point in time to fix on where they can say they sensed that death has occurred. That moment is often either before or after the official declaration of brain death. Some even perceive the question of organ donation as the moment when hope of survival has disappeared. Some families even misunderstand the message of death and see a positive response to organ donation as a better alternative than ending life as a ‘vegetable’ in a nursing home. The lack of clarity over brain death means that some families think that they experience deciding not only about the purpose of the body parts, but whether or not to terminate the life. Danish doctors are aware of this risk of confusion, and make explicit efforts to underline that life in any form is not an option. But, as the case below shows, it can be difficult.

Is our son dead? You don't get it. What I want to stress is – by making that decision – and of course it is a really good thing and other lives might be saved – but oh my, it was tough. Because Frederic is kept alive because of that, and at the same time I did not understand what brain death meant. And I said to the doctors, why is he moving his arm? Are you sure? I just felt like: “Are you COMPLETELY sure that he is not alive?” I did not get it. (Signe – mother of Frederic)

This statement from the mother of Frederic was one of many family accounts underlining the difficulties of brain death. The decision to donate means that the body of the organ donor is kept alive. This raises doubts as to whether the patient is alive or not, especially when Frederic is moving his arm. This makes Signe doubt that the doctors are right when they say he is brain-dead.

Meaning cannot be found in familiar or recognizable symbols since they often have different meanings in this hospital setting where, for example, the beating heart does not necessarily symbolize life. When Frederic moves his arm, Signe sees it as a sign of life. She does not understand that death has occurred until a nurse steps in and shows her:

Finally, this nurse – she was probably getting tired of me because I kept running to her and saying that he was moving – she was nice enough to say: ‘If I turn off the respirator he will stop breathing.’ And then she turned it off and shortly after that Frederic stopped breathing. But why couldn't somebody tell me that ‘brain-dead’ means that when they turn off the respirator in the brain death tests the person cannot breathe? Because what I did not get was if it was only in his brain and his body was still alive, wasn't I killing my son? (Signe –mother of Frederic)

The nurse steps in to show Signe that when she turns off the respirator Frederic stops breathing. By leaning on a familiar sign of death, such as

no breathing, Signe understands that he is only being kept alive by the machines. Only then does she understand that brain death also carries the meanings of the death she knows. Here it is important to notice the role of the nurse. Obviously Signe did not trust the doctors, but then the nurses step in and perform actions that create trust. Often the nurses also are the first to talk to families about brain death and organ donation, so even if the important conversations take place in the family room, much important information is exchanged between nurses and families at the patient's bedside.

The Danish anthropologist Inger Sjørnslev argues that, while the classic understanding of rituals emphasizes the sense-making characteristics of symbols, the notion of performance deals with the ongoing creation of meaning in social interaction (Sjørnslev 2007: 11). According to Sjørnslev the concept of performance is developed alongside an increasing attention to practice and to the ongoing construction of reality. Looking at the case above in this light, the nurse constructs a reality for Signe; she shows her that Frederic is dead by turning off the respirator. It was Turner's point that in these social dramas, "participants not only do things, they try to show others what they are doing and have done; actions take on a performed-for-an-audience-aspect" (Turner 1988: 74). Thus by switching off the respirator the nurse performs a trustworthy death for Signe. She performs the message that brain-dead patients cannot breathe, so that for Signe, her audience, brain death is associated with a familiar and understandable criterion of death – cessation of breath. Instances such as these show us how bereaved family members seek to create new meanings about life and death in a constant process and dialogue with the staff, and perhaps also other family members, in order to understand the end of life in this medical context. With this example underlining the social interplay between staff, families and technology, we take another step into

understanding how technology plays a role in the social performance of trust.

Interacting with Technology

Anthropologist Michael Jackson argues that people engage in intersubjective relationships with technology. Technology becomes a subject, an actor to rely on or to fear (Jackson 2005). Jackson takes an existential view of technology and argues that it plays an active part in the shaping of social worlds. Focus must therefore be on how humans experience and interact with technology. I therefore focus on how families and staff interact with technology when orchestrating death. This is indeed also a part of the performance of trust when ritualizing the death of the organ donor.

At the Intensive Care Units, patients are connected to a variety of machines that help them breathe or help the medical staff – anesthesiologists, neurosurgeons and nurses – to monitor and control various aspects of their condition like blood pressure, oxygen levels in the blood and pulse rate. Sometimes patients have a measuring device in the skull showing the intracranial pressure that is crucial to the patient's chances of survival. This also shows as a number on a screen. When the patient is close to death, the technological equipment also helps staff to ensure that the organs of the body are still viable for transplant.

Technology therefore carries a triple meaning. It is necessary for keeping the hope of the patient's survival; it is what helps classify the patient as close to death and it is what keeps the body of the dead patient functioning. But the idea that a person is attached to machines can be troubling. Anthropologist Lesley Sharp has introduced the term "the horror of the technocratic death". She argues that the technocratic death "robs us

of our free will or agency and it dehumanizes us by transforming us rapidly into cyborg creatures, or human bodies devoid of personhood that are nevertheless dependent on machines for survival” (Sharp 2007: 10). Somehow, being attached to a respirator does something for the conception of personhood and, as we shall see, the family’s interaction with their loved one. However, the technological intervention in life and death is not only horrifying. Based on research on organ donation in Japan, Lock argues, that technology is a threat to culture (Lock 2002a: 226). But my research shows that in Denmark, technology can also be an informative and supportive and a very important factor in the processes of ending life as an organ donor. This, however, depends on the social interaction surrounding technology, meaning the dialogue and trust in relation to the staff. As Bryan Pfaffenberger has argued, the social relations of technology must not be overlooked. Technology is a way of controlling and humanizing nature as we see when the respirators make boundaries between life and death blurry. As Pfaffenberger argues, technology is a social phenomenon. To create and use technology is to express social visions and to engage in life. (Pfaffenberger 1988). This underlines that the role of technology is deeply dependent on how families and staff perceive it and interact with it. This can be crucial for attempts to orchestrate death in the NICUs. The case of Signe and Frederic gave a small indication of how important the role of technology in an NICU can be for the experiences of donor families. Brain death can be hard to believe and families therefore interact with technology when trying to understand what happens. Simultaneously, hospital staff use the technology as an important element in their attempts to support families and help them understand that death has occurred. Hence, technology plays a significant role in the performance of trust. By socially interacting with technology and using it to explain the dilemmas of brain death in the performance of

trust, death becomes understandable to Signe, and to other families in her situation.

As Sharp argues from her studies in the US, professionals and families alike claim that the troubling part of brain death is that seeing and believing are not the same thing (Sharp 2007: 18). The technology is what enables a brain-dead patient to breathe artificially and what makes the heart pump and thereby maintain the important blood flow so that organs remain functioning (ibid). There is no visible difference between the patient before and after brain death has been declared. But my fieldwork showed that if families interact with technology, brain death can become visible or understandable by means of reading and interpreting the numbers. This can only happen if doctors and especially the nurses at the patient's bedside deliberately use the potentiality of technology when building and maintaining a trustworthy dialogue with families.

I interviewed Bente and Carsten, the parents of a teenage boy Adam who was in a fatal accident. We shall dig deeper into their story in the following chapter. But Bente and Carsten had a special way of relating to technology that helped me understand that technology is deeply connected to trusting the message of brain death in the social interaction with hospital staff.

Bente: The nurse Thomas made a big deal out of explaining everything to us. You sit looking at that screen. You almost know which buttons Thomas is going to press. I believe that technology shows my son's life. What he cannot tell me, what I cannot see, I can read on the screen. You can see his fever and his pulse. You can see the pressure in his brain, how his respiration is, his inhale, exhale, his oxygen levels. You become an expert in reading it. We trust technology. We trust that we understand technology and we think they are extremely competent, the nurses who

say “bip bip bip” and decide how much to drip from this one and from that one.

Carsten: Trust is when you are told how this apparatus works and how we can read the screens. Thereby you also automatically trust that the guy telling you this is a world champion in doing this. He operates it the best way possible and he acts according to what the situation demands. It was so professional. They were fucking good.

(Bente and Carsten – parents of Adam).

In this example, Bente and Carsten rely on technology to assess the condition of Adam. By learning to read the numbers and what they mean, they see the numbers as representing Adam’s condition and being his way of telling them how he is doing. But through interacting with technology, Bente and Carsten also build a strong trust relationship with Thomas, the nurse. Thomas manages to perform his trustworthiness through his expertise in handling the machines and through explaining how they work. As Turner argues, it is a social drama where actions are performed for an audience. Thomas performs this technological death for the parents. In return, they have full confidence to him and they believe that Adam is dying. Leaning on the theory of Bell, the technology is what helps the staff ritualize the body as dead. Since there are no familiar signs, such as the body turning pale or the heart stopping, families and staff have to rely on technology as the means to understand and communicate that life has ended. Technology is an important element in the orchestration of death for both families and staff because it can create powerful and meaningful symbols through its social characteristics (Pfaffenberger 1988).

As Jackson argued, technology can be an actor to rely on or to fear (Jackson 2005). It was not all families who had the same positive relationship with the technological equipment of the intensive care units as Bente and Carsten. I interviewed Henning and his wife Joan. They lost

their teenage daughter Lilly in a car accident. While Joan spent hours sitting at Lilly's bedside, Henning was very sad that he had not been able to be present at Lilly's bedside because he was disturbed by the technological equipment.

I was only in her ward two minutes. Then I was out again. I felt better sitting outside than by Lilly's bedside. I could not do that. I sat and watched the machines and got stressed out watching all those devices. I followed every curve, pulse, pressure in the brain and all that. And I kept watching it. And I got more and more upset. I felt better standing outside thinking about Lilly than inside next to her. (Henning - father of Lilly)

As this quote shows, Henning does not feel he is able to be close to his daughter while he was sitting next to her. He could not take his eyes off the screens and he was constantly paying attention to the shifting numbers indicating the difference between life and death. He therefore chose to step outside the room in order to be close to her, a paradox often seen at the NICUs. He knew that it was necessary to her survival and treatment that she was on a ventilator, but it kept him from being physically present in her last moments of life. The dual meaning of the technological equipment is evident. It enables the medical experts to control, monitor and treat the body, and for some families it provides comfort and trust, but at the same time, technology is an intruder, keeping family members estranged in the hospital and preventing them from having a private, undisturbed moment to say goodbye. George, an elderly man who lost his wife Gertrud, was also sorry that the technological equipment prevented him from being close to Gertrud when saying goodbye.

I said the last goodbye to my wife at 9.15 the next morning. She was attached to so many goddamn wires. I could almost not come close to her for tubes and shit. And we had spent 36 good years together.

(George – husband of Gertrud)

My observations as well as my donor family interviews often revealed that the medical equipment made it difficult to hug or to touch or simply to be present in the hospital wards of organ donors. While technology can be helpful in understanding that death has occurred, the fact that technology is also necessary for keeping the organs functioning prevents some families from having a peaceful moment of goodbye, as we have just seen. Therefore technology can also disturb the orchestration of death for families trying to create a peaceful death. Following the point of Jackson (2005: 130) technologies are sometimes “extensions of ourselves”, like when Bente argues that it helps her understand what Adam cannot tell. At other times, “technology is alien, invasive forms of not-being” undermining our notion of who and what we are, like when Henning cannot be at Lilly’s bedside, and George is disturbed by the “tubes and shit” when giving his wife a last hug.

Constructing the Right Decision

Now it is time to turn to the decision-making process of donor families. This is the aspect of the donor family experience that has drawn intense public and political attention over the years. The answer to this profound question can give up to six organ recipients the chance to improve their health – or, as it’s phrased in the public discourse, “a new life”. My fieldwork showed that making the decision about organ donation is deeply connected to the ritualization of death. No matter if the answer is yes or

no, deciding about donation is part of the attempt to make death meaningful.

Before we move to the family experiences, it is crucial to know a little bit about the careful preparations and strategies behind the request for organs. This aspect was absent in my mind when producing and publishing my first debate papers on donor families in 2006, but luckily I had the chance to observe them at close hand. It provided me with the valuable knowledge that the decision-making processes of families are dependent on the social interaction with hospital staff. The outcome of this question and the experiences of organ donation are deeply affected by the trust between families and staff. As with the concept of brain death, the question of donating organs can also be characterized as a complex performance of trust. Therefore, if the strange figure of organ donation should be translated or adapted into something familiar and comforting, the question of organ donation must be embedded in a context of trust. This means that doctors constantly perform the information that death has occurred.

Hospital staff participate in EDHEP courses where doctors and nurses receive communication training from experienced neurosurgeons and crisis psychologists in how to give families the serious message that brain death has occurred and ask them about organ donation. The course is a two-day event, with a couple of months between the two days. The course starts with an introductory round, where participants share their experiences and attitudes to organ donation and donor families, followed by presentations and finally role-play of donation conversations with professional actors playing the part of devastated families.

At every course, a neurosurgeon explains how to introduce the subject of brain death and ask about organ donation. In one of the courses I observed, the neurosurgeon John explained that ideally “the best process

consists of three conversations”. According to him, the first was to tell the family that it “looks very serious” and prepare them for the fact that it might go the wrong way but “the doctors are still trying to save his life”. In the second conversation one could say that “the pressure in the brain has unfortunately gone up” and it “looks as if it is taking a wrong turn”. Finally, the third conversation was to explain that the brain had incarcerated and that “we have done everything possible but unfortunately it looks as if the brain is dead”. John underlined that it was important not to say brain dead, but dead. “Brain death is intangible, death is not.” Ideally, the family will ask, “what happens now”. Then the doctor can explain there are “two ways to go – one is to turn off the respirator, the other is to use the organs”. He then suggested that this last sentence could end with: “Is organ donation something you have discussed?” John also underlined the importance of letting the family know that there are only these two options, to turn off the respirator or organ donation. The recovery of the patient is not an option. He emphasized the importance of bringing the family to a conversation room so that they have peace and privacy while the information is being given, and suggested that course participants rehearse some sentences or lines to use. He ended with encouraging them to prepare families for the fact that consenting to organ donation would mean more hours at the hospital. “Even if families do not want to hear it, it is good for them.”

During my participation in numerous conferences and seminars regarding organ donation, the subject was often how and when to ask families about donation. The joking response from the leading doctor and nurses was always: “At the right time in the right way”, with the implication that there is no such thing as the right time and the right way when it comes to organ donation. However, observations from the hospitals

and conversations with families indicate that timing is an essential part of the performance of organ donation.

Many doctors and nurses in my fieldwork also mentioned “timing” as an extremely important factor in the family conversations. Bell also mentions timing as an important element in processes of ritualization (Bell 1992). Timing is not only the order of the information in the request for organ donation. It is also of tremendous importance how long the family has been at the hospital. The staff prefer a family to be there for one or two days, but often the organ donation cases are much faster due to the severity of the brain damage and the condition of the body, making quick decisions about organ donation necessary. Staff prefer to have families there for longer periods because they know it is important to have built some trust or rapport with the family before approaching the subject. Bodil, one of the most experienced neurosurgeons, put it like this:

I always make sure to bring medical students so they can see how I do it. I do nothing by coincidence. It is well thought through and rehearsed for ages. For example entering and talking about something else, whether it is a snow storm or “what is your name my little fellow – what a nice car you have”. That is why I shake hands with everybody and look them in the eyes and ask about their name and relation [to the patient]. That is also good for me to know. Not just say: “I am a neurosurgeon and it does not look good and brain death and organ donation.”

(Bodil – neurosurgeon)

My participant observation at Danish hospitals taught me that even if the course of events is rarely ideal or happening in an exact order, doctors and nurses do everything they can to time and stage the question of organ donation in the best way possible. The structure presented by John and Bodil is developed as a result of many years of accumulated experience,

and doctors and nurses try to work along these lines. Many doctors have their own strategies, but the primary elements – preparing families, not giving all the information in one conversation and making sure families understand death before asking about organs – are fundamental for the conversations about organ donation in Denmark. One of the cases I observed will illuminate the timing and the staging of the information.

One day in September, 17-year-old Sam was admitted to the hospital with severe damage to his head in a traffic accident. In the course of the next week the doctors were operating on him trying to save his life with his family, the Christensens, there 24/7 hoping for his survival. I was called to the scene at noon on Sunday, when Sam's parents Jørgen and Kate, and Sam's three brothers, were about to be approached about organ donation.

Before the conversation, James the neurosurgeon did a short test of Sam's brain reflexes by squeezing Sam's fingers and toes as hard as possible and looking into his eyes with a flashlight to check the size and condition of his pupils. No reaction – James and the anesthesiologist Amy were ready for the conversation and they invited me to join them.

In the family room, the neurosurgeon James explains that Sam has no reaction to pain stimuli at all, which indicates brain death. Sam's father Jørgen says: "We have talked about that. Sam would not have liked to lie there as a vegetable and if that is the case, you should not do any more." And the older brothers agree. James says that the doctors have done everything possible to save Sam's life and the mother silently replies "we know, we know you have done everything to save our boy" and bends her head silently crying. James then introduces what he calls "the other question about organ donation", and the family says yes right away, explaining that "it is in Sam's spirit". The father asks which organs they can use and are told that it is probably kidneys and perhaps also heart

and liver but not lungs since they are too damaged. The dad asks about corneas and after hearing that they, too, are vital organs that other people might benefit from, he breaks down and says that “the ones who get Sam’s eyes will get a great view on life”. After this, there is silence in the room for a while. James and Amy say they are very happy for everything that can be used and explain that there are going to be a lot of tests and blood samples to make sure that everything is okay. “Oh yes,” the father says. “It has to match the recipients.” “It was in Sam’s spirit to help others,” the mother repeats. Amy tells the family that it is okay if there are some organs they are not willing to give. The family is surprised to hear this and Amy explains that sometimes families find especially the heart and the corneas difficult to give. The family says that they don’t feel that way. One brother wants to know how long before it is over, and James answers that it will take some hours but not days. Amy asks if they have had something to eat. The father says “you know how this is – you cannot have anything”. “Only coffee”, the mother replies and looks up with a frozen face and red eyes, “and a whole lot of cigarettes”. The doctors promise that after the x-ray checking if there is blood flow to Sam’s brain, Sam will be put in another ward that is quieter. After the conversation James is content. He thinks it went very well because of the good preparatory work done by him and his colleagues over the last days. “I always try to build it up” he says, “so they are prepared”.

Witnessing the attempts to carry out these strategies and observing family responses to them suggested that the question of organ donation is also a performance of trust. As this case shows, the parents know that everything has been done to save Sam. This has been explained to them in many conversations going beyond this conversation. By way of rhetorical strategies and the use of the right words, doctors communicate that

everything has been done to save the patient. Thereby they establish the trust necessary to say yes to organ donation. The decision to donate organs is not only a decision to end life, but also a decision on how life should end. Such messages should be delivered carefully. Alnæs has argued that Norwegian doctors use certain linguistic tools to handle the family conversation (2001a: 204). This is also true for many Danish doctors.

In her theoretical discussions of ritualization, Bell has also underlined the importance of communicative functions, the gestures and the choice of words. Bell argues that in ritual, words are deeds that accomplish things (Bell 1992: 110-114). While she also points to the importance of seeing the relationships in the ritual, Bell acknowledges the significant role of communication. She argues that ritualization is simultaneously the avoidance of explicit speech and the formation of narrative (*ibid*). In the context of organ donation, it is this very combination of gestures, choice of words, order of speech and what is said and what is not said that constitute the performance of trust in communicating with families.

If we look back at the case of Molly at the beginning of Chapter 2, Olav deliberately uses a strategy to relieve the families that Molly has made the decision herself. It is not his choice of words, rather it is the timing and the order of the information. He creates a context where a difficult decision must be made and then relieves them of the burden of deciding by informing them of Molly's wishes. Doctors always make sure to call the donor registry to find out if the patient has registered. Often this makes the conversations much easier. By performing the wish of the dead, the families can trust that this is the right decision. In that sense organ donation does not differ from other wishes of the dead. If families know the

wishes of the patient, this overshadows everything else, even their own wishes.

During one of the EDHEP courses, a nurse outlined developments over the years when it came to broaching the subject with families. Earlier hospital staff felt they could not dare to ask families about it; now they feel obliged to give families the option to donate. She said it had become easier over the years because many families initiate the question of organ donation themselves. At the same course, a nurse from a smaller intensive care unit, where organ donation rarely happens, described a case where a young man was brain-dead and his family had been very aggressive. In addition they had brought a healer with them who was saying that he could feel the young man was still alive, thereby contradicting the medical message of the doctors. The case was so terrible that the nurses had called in sick because they found it unethical to take care of him. After the case was over, hospital authorities had to run debriefing meetings to help the staff recover. Luckily, the staff received a letter from the family apologizing for their anger. This indicates some of the complexity and the challenges that can arise in the field of organ donation. While asking about organ donation is considered the right thing to do, the process of carrying out organ donation can be extremely difficult, especially in smaller hospitals where organ donation does not take place so often.

I interviewed only one family who said no to organ donation. But their accounts confirm that trust – or the lack of it – can be crucial for the outcome of the donation question. It was the parents of Brian, a young man in his twenties. He had registered as a donor, but the family did not want him to be. They felt very insecure around the doctors, because they felt they got different messages. The mother, Ida, explained it like this: “The first doctor says he is brain-dead, the next doctor says he is not. When can we trust that it has happened? This makes us very uncertain.

We don't want to participate in that when we are given two different messages.”

The parents of Brian also explained that different doctors had been running in and out, and they had missed one person to relate to. This teaches us that if the family is given mixed messages and there is uncertainty about whether brain death has occurred or not, then it becomes difficult to say yes to donation. The creation of trust between staff and families is fundamental for organ donation. But, as we shall see in the case below, whether there is organ donation or not, death and decisions about the end of life cannot be orchestrated in a good way if there is no performance of trust.

It is Friday afternoon and I take the alternative entrance to the NICU so that the family will not see me rushing into the hospital. I am greeted by the nurse Mona. She briefly explains that the potential donor patient is 42-year-old Anna, who suffered a severe bleed in her brain at work earlier today. Her pupils dilated right away and her heart stopped, but she was resuscitated. The doctors assume she is already incarcerated. A senior neurosurgeon has already explained to Anna's boyfriend Per that she is brain-dead and introduced the idea of organ donation. Per said that the decision was up to the girls, meaning Anna's grown daughters and her mother. Anna also has a 12-year-old son, Magnus. Mona ends her briefing: “On top of that, it is her birthday. It is awful.” Mona asks me to make sure the family room is ready, make some coffee and find some cookies for the family and to get some chairs to put in Anna's ward. They are waiting for the last daughter to arrive.

In Anna's ward, Magnus sits close to the window, far away from the bed, biting his nails. Per asks Mona if they have ever seen anybody survive from this, and Mona says no. He asks if she can lie like this for months,

and Mona answers that it is only hours, maybe half a day. “If her heart stops we will not resuscitate her; that is a sign that it has ended.” Mona gives Anna some medicine, checks all her fluids and other observations and offers to move Magnus’ chair closer to the bed. Suddenly Anna’s old mother and one of the daughters arrive. They are devastated and Anna’s mother constantly repeats: “Why is it not me, a weak, old woman, why is it not me?” Per earlier saw the senior neurosurgeon doing some small tests of the reflexes, and he asks Mona if that is a sign that it is over. Mona explains that they need to do more tests, but that depends on their decision; the doctors would like to talk to them about organ donation. Two porters arrive to help Mona turn Anna. The family leaves the ward and I offer them coffee in the small family room. Mona keeps checking Anna’s fluids and pupils, writing every observation down. Suddenly the last daughter arrives. She screams when seeing her mother, and Mona gives me a look indicating I should not be in Anna’s ward right now. A little later I return to the ward and the family sits close to Anna. Suddenly Anna moves her hand, and the daughter jumps up asking Mona if she is trying to tell them something. Mona calms her down and explains that it is probably only a reflex, but they should talk to the neurosurgeon about that. “I am sorry for asking”, the daughter says, but Mona assures her it’s completely fine. Afterwards, Mona told me that it is always bad when this happens while the family is in the room.

Later the family goes out for some fresh air, and Mona explains that one of the daughters has already told her that the family has decided to refuse organ donation. They want her to be removed from the machines and they do not want her to be cut open. Mona calls one of the young neurosurgeons, Martin, to let him know that he needs to have the conversation soon.

When the family returns, we all gather in the small family room. There are not enough chairs for all of us, so I stand behind Mona and Martin. Martin explains that this has looked very bad from the beginning and only 25% of patients survive without serious damage after a hemorrhage like this. The daughter asks about the hand moving and Martin explains that it is a spinal reflex and very normal in brain-dead patients. “Well, I am only clinging to hope, is there anything else to do?” Martin answers no. Martin says that brain death tests have not been made. The daughters then ask if that means she is not brain-dead. Martin explains that the tests are juridical and very formal. Then he rapidly moves to the topic of organ donation. “I understand the neurosurgeon Benny has already mentioned organ donation to you? Do you know Anna’s attitude to this?” Suddenly the mother raises her voice: “She would not have wanted to be cut open, I am sure about that!” The rest of the family confirms that and Martin tells them that of course they respect that answer. And that means that they will turn off the respirator. Magnus then asks Martin if they cannot do the brain death tests anyway, just to be sure. Martin apologizes, but they can’t. “It’s juridical,” he says. Finally the family has some questions about the removal of the respirator. After answering, Martin excuses himself, he has to operate. After he leaves, Mona takes over and explains that they can come and go in the ward as they please, and that they should find out who wants to be there when Anna “dies”. She also explains that they can use the family room, unless another family suddenly arrives. After a while Magnus raises his hand, as if he was sitting in a classroom. “I am sorry if this is a stupid question, but now mom’s brain is ruined, can’t the doctors give her a new one? “ Mona smiles and her voice turns a bit mushy. “I am so sorry my friend, but we cannot do that. And don’t worry, in these situations there is no such thing as a stupid question.”

As this case shows, the process of death is affected by the decision of the family. The official brain death tests are only performed if families say yes to donation. Otherwise they take up too much time and resources from busy neurosurgeons constantly operating and monitoring other patients in the unit. As a result, if families say no to organ donation, the patient is removed from the respirator and, after some time, the heart stops and death is declared. But as this case shows, the family needed to know that Anna was brain-dead in order to feel sure that the respirator could be turned off. If they had consented to organ donation, the official time of death would have been after the second brain death exam. Now death happens when the doctors choose to turn off the respirator. There is insecurity, because brain death cannot be confirmed officially when families say no to donation. Anna was seen moving her hand and that caused doubt that she was really dead. As Mona explained to me, nurses and doctors hate when brain-dead patients move because they are aware it can complicate matters further by causing the family to distrust the medical staff. While the family accepted the doctor's explanations, it was obvious when observing them that they needed a point of time of the death – not to allow organ donation, but to allow the respirator to be removed. Even if this did not turn out as an organ donation case, it shows that the complex interplay of life and death and the strange area between them is what characterizes the clinical experiences of donor families and hospital staff.

This case also illuminates one of the most important reasons for saying no to donation. The family does not like the idea that Anna's body should be cut open. Based on my research and my conversations with staff on their experiences, I argue that the fear of cutting the body has significant impact on the decision-making of families. We return to this in

Chapter 5 when discussing the aesthetization of the body and the nightmare visions of many donor families about the actions and procedures on the operating table. But in relation to the performance of trust, the idea of cutting open also plays a significant role. Families do not trust strange doctors to open the dead body and procure the organs. This is contrary of a peaceful closure and to traditional ways of handling dead bodies. Therefore, if it is not explained to families how things are done in the operating room, they often find it easier to say no in order to keep the integrity of the body and thereby a visual appearance closer to familiar ways of dying. Keeping the body in the intensive care unit, watching the last breath and knowing that the corpse will go to the chapel and not to an operating table can be interpreted as the family's way of ritualizing death in a comforting way. Saying no to organ donation is also an important element in the orchestration of death.

Performing 'the Good Death'

'Performing the good death' is a sentence that makes no sense in this empirical context. There is no such thing as the good death because, as the empirical accounts have already shown so vividly, they are all tragic and devastating and represent our worst nightmares. When using the term 'the good death' anyway, it signifies an analytical attempt to discuss the many ways people seek ritualize death into a more acceptable, traditional or familiar process of ending life. The strange figure of organ donation and the exceptional death must be orchestrated. Performing the good death elucidates the many complex ways the processes of death are practiced, translated and adapted to family needs in the clinical context.

Performing the good death is closely connected to locating the moment of death, since the good death is often connected to the idea of

being surrounded by family when taking the last breath. But trying to perform the good death is also about setting a certain stage or creating peace, so that the death looks as normal and quiet as possible in spite of the stressful surroundings of the NICU.

Many families feel as if the moment of death has been taken away from them, and they cannot decide when the right time to say goodbye is. This is when they jump to the conclusion that the 'real' death has not occurred until after the organs have been removed. During my fieldwork, I discovered that the routines at the hospital actually help support this idea. I spoke to the wife and the sister of a man who became donor. When asking them when they said goodbye, there was the following conversation:

Ruth: We said goodbye to him between the two brain death tests. He was in his ward. Somebody was lying next to him. You can say that it was not like when our mother died. They had prepared her and there were candles and a little hymnal.

Carmen: But don't you think that was because he has to be taken down to have his organs removed? He was not dead at that time.

Ruth: No, he was not really dead.

Classic anthropology has taught us that people use rituals when moving from one period in life to another, especially when moving from life to death (Van Gennep 1960). It is therefore very important, ritually speaking, to mark the time of death and make it social and understandable for the families. As it is now, the second brain death exam is put on a piece of paper, whereas the candles, the Bible, a private room, the opening of the window – all the visible and familiar performances and rituals of death take place only after the organs have been removed. Therefore it is no wonder that some families think that the removal of organs is the actual time of death. In the future, it will be a much-needed challenge for staff to

figure out how to turn the medical time of brain death into a social and ritual marking of death – something understandable and visible to the organ donor families.

Performing the good death can be understood in two different ways. On the one hand it is the combined effect of the strategies and efforts of the hospital staff to make the hospital experience as sense-making and peaceful as possible in their social interaction with families, and on the other it is the performance that happens within the family itself. The donor family's orchestration of death depends on the kind of relationship they have with the deceased and their role and function towards other family members. When losing a husband or a wife, many of the families I interviewed described a two-way position or a double experience: the role as organizer, rising above the tragedy to take care of the kids, and the role as a grieving relative who is in the situation and experiencing the pain. It is not only the doctors and nurses who set the stage and perform the process of brain death and organ donation. Family members themselves orchestrate the good death in order to protect children as much as possible. This performance is staged in order to try to grasp the events that are happening beyond anyone's control and in order to create, if not meaning in death, then a meaningful goodbye despite the unknown and sudden circumstances.

Already when receiving the message that a loved one is badly hurt, caregivers start planning carefully how and when and by whom their children should be given the message, visit the dying parent's bedside and say their final goodbyes. Curt, a man who lost his wife Mette, the mother of their two boys, explained that he considered it as two paths he was walking at the same time. One was being in the hospital world, and the other was the organizing of the events. This dualism represents what Michael Jackson has described as a foundational human reaction to

sudden and catastrophic events – being in the midst of disaster, and at the same time trying to act and structure the surroundings (Jackson 2002). Throughout the interview, it became clear that Curt’s own grief and devastation was secondary compared to accompanying his kids through the loss of their mother.

First we had a conversation with the doctors and my mother-in-law. But that was not my primary focus. It was only a preview to what I was about to go through. I was waiting for my kids to arrive. It has been taken care of that the boys should see her. And it is important that they are not traumatized by what they see. So I try to style her, because her tongue is hanging out, and there are many tubes and something is not good. I speak to the nurse and make sure that something is covering her, and that her mouth is closed. So it looks as if she is resting in peace and sleeping.... Then the kids arrive with my good friend. I sit them down in the family room and say “I am so terribly sorry to say this, but Mom is dead. And they both start screaming.... I have thought it through how to handle this, so when we enter the room we go to the bedside and I tell her that we love her and that we will miss her. And I stroke her so the kids should not be afraid to do so too. Then the youngest points at her and says: “She is not dead, she is breathing.” And I tell him: “I know my friend, but that does not count, because there is a machine breathing for her.” It is good that he asks, and it is really good that he accepts my answer. We are not in there for long. I think we do what we are supposed to do. (Curt – husband of Mette)

This empirical example serves to show that it is not only hospital staff who try to perform a good death and set the scene for a peaceful and meaningful goodbye. Donor families themselves step in to perform a good death for other family members, especially small children. As Curt says, they “do what they are supposed to do”. He tries to establish a situation

resembling that of a normal death. Curt actually carries out many of the roles and actions nurses usually do, such as making sure Mette looks nice and peaceful when the children see her. But he is also the one explaining that a machine is breathing for her when the youngest son cannot make sense of the fact she is dead. Returning to the point of Turner, the children are the audience for whom Curt performs in the social drama of the loss of their mother by creating a setting where the boys can say goodbye. Mette lies quietly, and they believe she is dead even though she is breathing; Curt manages to ritualize death in a way that is as sense-making for the children as possible at that terrible time. This teaches us that the orchestration of death can also take place within the individual family when one member performs trust for other family members. The question then is: Who is performing for Curt? Who is taking care of him and leading him through the process? Curt's interview exposed dissatisfaction with the staff's way of handling him and his kids. Clearly he felt left alone in the process of ritualizing the death of his wife for his children. Therefore special attention must be paid to family members who are also caregivers, since they have an extra task in the ritualization of death. Here we touch upon an area where the orchestration of death becomes extra-sensitive. Staff interviews revealed that they often felt helpless when it came to meeting and supporting families with small children, especially those with special needs. While these cases are extra emotional for staff, they also call for extra resources such as child physiologists, crisis counseling and special follow-up that are far from always a part of the Danish clinical context surrounding organ donation.

Families sometimes have many special wishes and needs in the process of saying goodbye. Staff are aware of these individual needs and try to accommodate them as far as they can. This can be a challenging task, since the dead patients still undergo intense medical treatment in

order to be organ donors, as we see in Chapter 5. Families are often offered the choice of having a chaplain present, either before or after the removal of organs, to perform last rites that may help them say goodbye. In the course of my studies, Danish hospital chaplains formulated a special ritual and text to embrace this special situation of saying goodbye to a brain-dead patient, an important way of orchestrating death that I return to in later chapters. The point I wish to make here is that the ritualization of death is not only religious. When saying goodbye, families turn to their own individual practices. One of the more special ways of performing death was told to me by Iben, who lost her husband Søren during a vacation. She and their grown children performed a rather unusual ritual.

My husband had decided that on the last night of our vacation we should have a rump steak, so he had made a delicious rump steak. And we brought that to the intensive care unit. I don't think the staff had experienced that so many times before. Just the smell of rump steak in the hallways. But now we were in this situation and it was okay. They made us feel it was okay. (Iben – wife of Søren)

For Iben, it was comforting and sense-making to carry out Søren's intention to make a delicious rump steak for the family, and try to achieve the anticipated end to the holiday even though things had changed so drastically. Iben explained how important it was for her and the entire family that nurses accepted this special wish and allowed them to cook the meal in this special situation. This ritualization helped the family to have a socially meaningful end to the process that was in accordance with their own beliefs and traditions. This shows how hard it is to make standards for how to accompany families in a good way during these crucial hours. Performing the good death is extremely individual and implies a lot of acceptance and negotiation between families and staff. According to Bell

(1992), ritualization differentiates the ordinary as extraordinary. The practice of making the rump steak was to try to maintain a sense of something ordinary in extraordinary circumstances. They tried to carry out the meal as they would have normally done, the one thing they could control in a situation that had suddenly sprung out of control. But at the same time, due to the clinical context, it has a new meaning. In line with Bell's argument, ritualization is "a way of acting that establishes a privileged contrast" (Bell 1992: 90). Cooking a nice family meal is indeed in contrast to what is normal. Therefore it acquires significant symbolic meanings.

Ritualization of death for donor families who are trying to say goodbye to a loved one encompasses both the practices carried out to maintain something familiar and the ways of establishing death as something extraordinary. What is familiar to some families is not familiar to others. The same thing goes for the extraordinary. It depends on the individual family. The 'good death' is not a special uniform thing to be desired and achieved; rather it signifies a process acted out in a balance between families and staff.

My fieldwork showed that often the actual decision to donate organs becomes a meaningful performance of death. Trusting that being an organ donor is in accordance with the characteristics and values of the deceased has incredible impact on the perception of death among families. I interviewed Leo, a man in his thirties who lost his father, Erling. Leo was one of the family members who was very clear about organ donation. He had always been in favor of organ donation and had had no doubts when deciding about his father. His sister and his mother, however, found the decision very difficult and were not sure they could allow Erling's body to be cut open. Leo explained that he and his brother then talked to the sister and mother about it, using these words:

Leo: I thought we should see it in relation to how my father lived his life and my father's values. And that can be very hard to apply to such a situation, and it is not something you can redo. But my father was always helping others. He supported us no matter what and always thought of others first. So in relation to how he lived his life, we had no doubts that he should donate his organs. (Leo – son of Erling).

After this, Leo explained that the sister and mother agreed. They could also see that helping others to survive was in accordance with the ways Erling lived his life. Leo gave me the example that Erling had renovated bathrooms for his grown children and prioritized working hard and earning enough money so that his children had the freedom to educate themselves. By looking at the social history, the values and the previous actions of the individual, family members can construct organ donation as a meaningful way of ending life. Deciding to allow the donation is the performance of the good death. For Leo, and many other families in my study, the association between helping others and being an organ donor was essential for ritualizing death in a good way. Leo performs this association for his mother and sister so they become convinced it was the right decision.

This chapter has discussed family experiences when faced with brain death and decisions about organ donation. Leaning on Catherine Bell and Victor Turner, it has argued that the process of deciding about organ donation can be seen as a social drama in which death is ritualized in a variety of ways through the performance of trust. In this particular context, death is hard to understand. Brain death can be understood as a sensory paradox since the familiar visual signs of death do not carry the

same meanings. The dead are kept on respirators that keep the body breathing and the heart beating, even if the patient's brain has died.

Adding to this ambiguity, the decisions regarding organ donation usually take place at a point in time where brain death has perhaps only been assumed by neurosurgeons by testing reflexes and looking at the dilated pupils, and not officially and juridically confirmed by the standard tests. In this time-span, which can last between a few hours and a few days, some families are perhaps still hoping for the survival of the patient, others are denying the messages and trying to contradict the idea of brain death, others are longing for death and the closure of a painful process, and some are overwhelmed by excitement that the organs are going to help other patients. The family experiences are never alike. As a result, the information, the decisions, the medical care and the family conversations must be timed and staged and adapted to the individual needs and wishes of the family. I argue that this can be seen as a performance of trust. And I argue that it is part of a process of ritualization that happens in order to make the complex processes of organ donation and brain death understandable and meaningful to the devastated relatives.

Drawing on empirical examples from organ donation cases, it was argued that the performance of trust happens in a close social interaction with the doctors and nurses in the NICU. Ritualization describes the complex practices of families as they attempt to establish something meaningful in the midst of tragedy and staff as they try to support families in the best way possible. These practices serve as attempts to translate this exceptional way of dying and to time and structure the decision to donate. I argue that these ritual practices are essential for understanding the donor family experiences at the hospital. The ritualization of death is a good way of understanding how death is orchestrated in a clinical context.

Now it is time to take another approach to the ways this exceptional death is orchestrated.

The next chapter will look into the practices of hope, which is another important aspect of the orchestration of death. Empirically, it will give us a deeper insight to the family experiences in the clinical context. Concurrently, it takes us further into the families' complex motives and strategies for deciding to donate, their attitudes to the purpose of the body and their urge to improve conditions and initiatives for donor families through participating in this research project. The transformative practices of hope will help unfold and discuss these matters.

Chapter 4: The Transformative Practices of Hope



The Transformative Practices of Hope

In this chapter the orchestration of death is characterized and discussed as a complex transformative practice of hope initiated during and after the process of losing a loved one. Orchestration encompasses the attempts to transform hope.

When Danish donor families are facing loss and the decision to donate they engage in a complicated process of performing and staging the end of life so that it is as peaceful and meaningful as possible in the social performance of trust, as we saw in the last chapter. As already touched upon in this regard, hope and the loss of hope plays an important role in donor family experiences during the clinical encounter. We now turn our focus to the many ways hope is practiced by staff and donor families in the context of organ donation. This chapter is therefore devoted to an investigation of the many ways hope is perceived, acted out and articulated; in other words, how hope is practiced.

Anthropologist Lesley Sharp argues that organ transplantation is “a personally transformative experience that radically alters an organ recipients’ definition of self” (Sharp 1995: 360). Several studies on organ transplantation have focused on the bodily and emotional transformations when a new organ is received and the problems this can entail (Gutkind 1988, Siminoff & Chillag 1999, Lock 2002a). Some recipients find themselves suddenly craving chocolate or feeling the urge to go rollerblading. The phenomenon is called ‘organ memory’ and suggests that characteristics from the deceased donor are transplanted along with the organ. Such ideas are rejected by medical professionals, who underline the functions of the organs and explain the changes in personality with the

large amount of immunosuppressive medicine organ recipients have to take in order not to reject the organ (Sharp 1995, Jensen 2009a). The transformation of the lives of organ recipients can also be of more spiritual character due to the gratitude for receiving such a precious, life-saving body part. An example is a heart recipient who used to live a hard life with drugs and alcohol and treat his wife badly, and who now lives a healthy life and runs the New York Marathon schools as a way to appreciate the kindness he experienced (Jensen 2007: 66; 2009a). This chapter suggests that donor families also experience a sort of transformation in the process of giving organs. Research from the US context has argued that families of donors undergo an identity transformation from 'family' to 'donor family' in the organizational aftercare interaction, where families are recognized and integrated into a group of fellow sufferers (Jensen 2007). This chapter shows the donor family practices of hope in the clinical context and beyond. I argue that donor families attempt to find meaning and orchestrate death by adapting hope to the changing information and situation.

Theoretically I take a starting point in Vincent Crapanzano notion of hope as a category of both experience and analysis (Crapanzano 2003: 4). In my research, hope is present as a rhetoric and state of mind among donor families and hospital staff, and at the same time I use it as a theoretical frame to illuminate the events taking place at the NICU in that specific time-span of an organ donation process and in the time after. Hope, used as an analytical tool can throw new light on the experiences of organ donor families and hospital staff not only in the clinical encounter but also in the time after the organ donation has taken place. Crapanzano also deals with the complexity of hope and argues that hope can be specific, open ended, lacking final definition, vague, and subject to chance, (ibid 6). In this sense I embrace his notion of hope as "rooted in a

temporality of meaning” (ibid 6) with the argument that hope has a transformative character and changes its focus according to time and context.

Theoretically, I also rely on the American anthropologist Cheryl Mattingly. She has done extensive research on American Afro American families with children suffering from brain tumors or other kinds of chronic diseases. In her work, hope is a central analytical argument explaining the years of suffering of families and children and their engagement with hospital staff. Although this empirical context differs significantly from the abrupt and sudden tragedies of most organ donor deaths, the ways these families engage in processes of hoping with the hospital staff can be compared to the experiences of Danish donor families. The important point to draw from the work of Mattingly is that hope is a practice rather than an emotion or a cultural attitude. She argues that “hope most centrally involves the practice of creation or trying to create lives worth living in the midst of suffering even with no happy ending in sight” (Mattingly 2010: 6). It is these practices and these “creations of lives worth living” in the context of organ donation that is the central to this chapter.

In this chapter hope is therefore presented and discussed as a transformative practice, since hope is subject to change many times in the procedures of organ donation. This became evident when observing the crucial hours at the intensive care unit where families often moved from hoping for survival to hoping for death – and additionally, by way of organ donation, hoping to help other patients. This process was not, of course, linear and smooth, and often the practices of hoping happened simultaneously or shifted back and forth. However, it is my argument that looking at the changeability in the practices of hope can contribute to a

closer understanding of the donor family experience. The transformation of hope is a central element of the orchestration of death.

It was a central feature in my research that hope also entailed that the decision to donate had an outcome – that organ donation would happen and that other people could be helped by receiving the organs. As we shall see, these transformations of hope result in alternative ways of understanding and interacting with the dead body of the patient. When interviewing families in the months and years after the donation, I was met with reflections and observations on the high level of professionalism, empathy and care they had received during their hospital stay. Some commented more critically on what they found was frustrating and could be improved on in the interaction with the health care system. Paying attention to the analytical significance of this explicit wish among families, I have chosen to analytically frame these concrete suggestions as a part of the transformative practices of hope.

Facing Death, Transforming Hope

While I regard hope as a practice, I acknowledge that hope in regards to losing a family member also has a wide array of religious and philosophical aspects in it that I am not able to unfold in this study. I discussed these matters when interviewing Gunnar, a hospital chaplain with great experience in accompanying families when losing a loved one. Gunnar argued that families have two kinds of hope. One is the hope that doctors will save their loved one, the other hope is the spiritual thoughts and ideas after the doctors have given up – hope about after the death. Gunnar argued that hope is there all the time, but is transformed “from this side to the other side”, meaning from this earth to Heaven.

According to my experience, hope is many things. But there is a constant transformation according to the incoming information. Hope is present all the time. It is just moved around. If the doctors cannot do anymore, it somehow turns into a hope [for] after death, in paradise. (Gunnar – hospital chaplain)

When families undergo the crucial hours at the intensive care units, they have to realize that death has occurred. The last chapter showed us that this is attempted in the performance of trust. Thereby the dead body is ritualized and death is orchestrated into something familiar and recognizable. But orchestration of death also entails transformative practices of hope. With this I argue that hope is not only about hoping that death does not occur; it can also be hope that death will occur.

In my study, I therefore met alternative versions of hope. It was not only the hope of a spiritual or religious afterlife as hospital chaplains like Gunnar often encounter in their efforts to support families. When observing organ donation cases and interviewing families, I discovered a hope strongly connected to cultural perceptions of a life with dignity and a death with purpose. Sometimes, this transformation of hope was practiced before the doctors had announced they could do no more. Therefore, the crucial message that life has ended is sometimes met with relief from families, since they consider a life without dignity worse. I am not trying to underestimate the tremendous sorrow of losing a dear family member. The message of death is always devastating. But in order to understand the complexity of donor family experiences and how death is orchestrated in the transformation of hope, it is important to discuss the idea that there can be a destiny worse than death.

The story of Adam will serve as an empirical starting point to understand this complexity in practicing hope in the process of organ donation in a clinical setting. Adam was an 18-year-old boy victim of a

shotgun attack and the following narrative comes from the first part of a long interview with his parents, Bente and Carsten.

Adam was my son. He died two months before he turned 19. I was standing in the garden smoking a cigarette when my telephone rang and a young boy told me that Adam had been shot. We arrived at the trauma centre and a nurse spoke with us and told us it was very serious; they did not think he would survive the night. And then we went upstairs and we saw him. That was not a pretty sight. He was hit in his left eye with a shotgun. Then the next four days we spent hoping. And Adam was going to be scanned three times to find out where the bullets were located in the brain, and we saw those pictures on the Monday. Some of the bullets were in the brain stem and we were told that surgery was out of the question because that would cause further harm. Monday, they put a pressure gauge in his brain to see what the pressure was like and if they could decrease it medically. That was a weird experience. I work in the municipality referring elders to nursing homes and I have read many charts. So I had found out that if he survived this, he would be placed at our nursing home in the section for brain-damaged patients. And I must admit that I did not wish that. His big dream was to become a professional soldier. And I just felt that if he survives this, he would never forgive me for letting him survive. He would have been blind and paralyzed. (...) The doctors tried waking him to see his reactions. It would have been a good sign had he reached for his head but he twisted his arm and that is really bad, that is not the head reacting, only the back. We became very good at understanding the monitors with curves and temperatures and pulse and oxygen levels and everything. The staff in there were incredible and we had the family room to ourselves. We doubted if it was right for Adam's younger sisters to come and see him, but when they came, the nurse sat down and explained to the girls how he looked and that he had bandages and tubes, and that your head swells when it is hurt. She was incredible.

Tuesday they scanned him again and the doctors approached us and told us that the left part of the brain was decaying. There is a certain color that apparently is visible on the pictures. And I have to admit, I was so relieved when he said that. I had feared they would keep him alive just to keep him alive. That would have been the worst for me. And then the doctor said: "There is something I have to ask you." And we said, "you don't have to, because he shall be". So he did not get to say "organ donation". So it was a question of waiting. This was Tuesday morning. It did not happen until Wednesday afternoon that his body gave up, so we had plenty of time to say goodbye. Before we got the message that the left part of the brain was ruined, the hope we had that he would survive had turned around to a hope that the doctors would give us that message. As I was quoted in one of the newspapers, it was a question of vegetable or funeral. So it turned into a hope that it went fast - and a hope that his heart would last the pressure. If his heart stopped he could not be used for organ transplantation and that would be bad! I was very cynical and said of course we are going to do that; we cannot use him for anything else. So we hoped that he would last. The doctor told us on Wednesday morning that it was taking longer than they had expected and that they would respect our wishes if we changed our minds about organ donation. And we were almost offended by that and replied that organ donation was the only reasonable thing in all this, so it had to take its course. It happened on Wednesday afternoon. We were all gathered in his ward. At ten to four in the afternoon, there was no more signal from the brain stem to breathe. We had sensed in the morning that it was the end of breathing. Then he had to lie at least 6 hours and at ten to eleven they officially declared him dead.

There was this amazing thing that somewhere in the background, multiple teams were ready to get Adam into their hands and save as many organs as possible. And that was nice that we did not have to worry about that. Others had thought about that and were making a living out of it. (Bente and Carsten – parents of Adam)

As we see in the case of Adam the practice of hoping for the donor families is a complex and flexible condition whose agenda and meaning changes over time and place. In other words, hope is not a static entity embedded in the same range of meaning; hope and death are strongly intertwined in the complex process of agreeing to organ donation. As illustrated by Adam's story, hope is not only a hope for survival. It is in the beginning, but it changes into a hope that death will finally take place. Hope is subject to change, as Crapanzano argues (2003: 7). Bente and Carsten explain that they fear that the doctors will do more to try to make Adam survive to a life in a nursing home. In a way, that would be more terrible than dying. In this process, hope also turns into a hope that Adam's death will result in something that makes sense to them, namely the survival of unknown others. To Bente and Carsten this is clearly a better alternative than a life without dignity as the fear of the nursing home indicates.

Mattingly argues that hope is about creating a life worth living (Mattingly 2010). I argue that for donor families, hoping for death is better than having the patient survive to a life not worth living. Many donor families told me that in their dialogue with doctors, they had made them promise not to rescue the patient, if the only prospects were life as a vegetable. While many Danes have not decided on organ donation, it seemed as if many had told their families to please let them die if they had no chances to recover to a dignified life. In that sense, hope is not the opposite of death, but rather an interacting factor in the process of performing a meaningful closure to life. The transformation of hope is a way of orchestrating a death that is a more meaningful alternative than a life without dignity.

Torben, the father of Sam, the young boy we met in Chapter 3, explained to me during our interview that most people would like to find meaning, otherwise humanity might as well be an animal. He continued:

Meaning can be hard to find in the midst of tragedy. Meaning for me was that God took Sam to spare him and his family from something worse than death. He was a haunted child. And in order to spare him from being a vegetable or something, “we better get him now to save him and his family from further pain”. And I don’t know if that is how I feel today, but that was how I felt at that time. I needed something to hang my hat on. (Torben – father of Sam)

In this recollection, the religious aspect of hoping, as suggested by Gunnar, is connected to the definition of what constitutes a dignified life. For Torben, God is the one saving Sam from additional pain, from a life that would have been without meaning. Patients in the NICUs have such severe brain damage that families quickly realize that survival does not mean a return to normal life. In Torben’s view, God does not represent the afterlife; he is the one making sure death occurs to spare everyone from further suffering by fetching Sam. Transforming hope in this way becomes a way of orchestrating death into something meaningful, religiously as well as physically.

However, the transformation of hope can be precarious when families have not understood that organ donation is not an alternative to life. Some families in my study claimed to have chosen organ donation because it was better than being comatose for years. They had not comprehended that organ donation can only happen when the patient is dead. For those families, the decision to donate was the same as deciding to end the relative’s life, adding another level to the implications of organ donation. I interviewed the family of Gustav. He was in his 60s and

suffered from a brain hemorrhage. The family discussed that it would not have been good to leave Gustav in the hospital on the respirator. That was not dignified and it would cause his wife, Tove, to have a bad conscience every time she left or if she could not see him one day. When they mentioned some of the media stories about people being comatose for 25 years, and the possibility of brain-dead patients waking up, I sensed that they had an alternative understanding of the fatal severity of Gustav's brain injury, so I asked them whether the doctors had mentioned anything about how long Gustav could lie like this on the respirator. The dialogue following the answer was as follows:

Bitten (daughter): No I don't think they mentioned anything about that.

Tove: Let us say that everybody thinks they should be allowed to... You cannot have all these people lying on respirators all over the hospitals.

Bitten: Imagine if Dad had been a vegetable. Not being able to eat on his own. And not hearing anything. That would have been cruel.

Tove: Let us say we had been so selfish to say that they could not turn him off. They would probably not have kept him at the hospital because of lack of capacity. They would have put him in a nursing home, where we could stop by occasionally. That is no life. I always say, if that was going to happen, it is good it turned out the way it did. He has peace now.

This family, along with others in my study, has clearly chosen to donate Gustav's organs even though they did not understand that he would have died no matter what they decided. In these transformations of hope, the fact that brain death is death is sometimes completely overlooked. Still, the decision to donation is meaningful for them and is considered a better alternative than being comatose or in a nursing home.

Hospital staff have their own way of signaling that there is no hope for the survival of the patient and it might be time to discuss organ donation. This moment is ritually marked by the practice of removing the “organ donation file” from the shelf, where it sits quietly with other files on various procedures such as hygiene, nutrition and stimulation of the patient. The binder is put in a central place on the desk in the “control rooms” where nurses and doctors work monitoring the screens of the patients. When the folder is on the table it is a sign that somebody has thought of this as a potential organ donor and the steps towards how to strategically approach the family and medically prepare the body of the potential donor have already begun. It can also be a way to make sure that the staff remember to discuss organ donations, which is why you will sometimes see more experienced nurses take the file and leave it on the table even though it is not their patient. Most of the time it is to remind the doctors who sit briefly at the desk to fill in the journal that this might be a potential donor and it is important to think about that when deciding the future treatment or end of treatment. In that way it can be argued that physical removal of that particular object represents the transformation of hope. Hope for survival of the patient is out, and the work towards hoping that other patients elsewhere might survive after getting an organ has begun. Sometimes the file comes down too quickly, meaning before doctors have concluded that they presume this patient is brain-dead. Then the organ donation file stays on the table but is visually covered by a piece of paper or by other files, so people will not get the wrong idea. This is partly to avoid the awkward situation where a family still hoping for the survival of the patient goes to the desk to talk to a nurse and finds out that the reality is much worse than expected.

The practices surrounding the organ donation file indicates that in the orchestration of death, the process of hope must be out of sync. It does

not happen within the same rhythm. Staff are often considering organ donation while the family are still hoping for survival. This has something to do with the timing and staging in the family conversations as mentioned in the last chapter. Based on their neurosurgical expertise, doctors and nurses might predict brain death long before it actually happens. But medical professionals try to create a process where family members realize in steps that there is no hope. It is an important element in the performance of trust that doctors want families to maintain hope as long as possible while at the same time being realistic about the severity of the situation. This is also the methodological reason why my organ donation research agenda was not mentioned to families when presenting me, as discussed in Chapter 2. The ethics of maintaining hope in the clinical context of organ donation is a contextual consideration that had to override the anthropology ethic of presenting the research agenda up front.

The practice of hiding the organ donation folder with a piece of paper indicates respect for the family's hope of survival, while putting the file out on the table indicates that the staff's hope has changed hope for an organ donation case. I was often introduced to the "organ donation folder" at an early point in my fieldwork at the NICUs since the file contained all the official protocols and documents and the policies of department regarding organ donation. Besides that, the file was also the place that people suggested I put my business card with my phone number and a short project description. As they said: "If your phone number is in the file, we will definitely see it." Starting to work with the file is therefore a way of signaling that for the staff, hope of saving that patient has transformed into a hope to save other patients, namely the organ recipients. The file was primarily to help the nurses with taking blood samples, making the right phone calls, taking care of the blood pressure of the donor and all the other things needed to go through an organ donation process. Thus the

organ donation file often symbolizes the staff's shift in perception from the body of a patient to the body of a potential organ donor; a process I will describe in detail in the next chapter on aesthetics. However, donor families also undergo a shift in the perception of the body of their loved one, as we shall see in the following pages.

Hoping to Help: Usable Bodies and New Lives

Now we take another step into the transformative practice of hope by taking a look at how the decision to donate organs influences the processes of death in the NICU.

At the end of 2009 and beginning of 2010 a group of Danish hospital chaplains formulated a ritual to accompany donor families when saying goodbye to the brain-dead donor in intensive care units. It was done in an attempt to have something to lean on in these situations and to create a ritual that would embrace the ambiguity often characterizing them. The chaplains made suggestions for an introductory speech, hymns, extracts from the Bible and two different prayers. One of the prayers says:

Our God and Heavenly Father
We are gathered around NN
It is hard to understand he/she has died
The heart is kept going
And at the same time, there is no hope of getting him/her back
Something in us cannot let go of hope
And at the same time, we know that things cannot be changed
We sense that life has changed forever

God, you have given us so much in our lives with NN
Now, we choose to pass on some of what was his/hers

In the hope, that it can be a blessing to others

We cannot make it without your help

So be with us

Help us to say the difficult goodbye to NN before he/she is taken away

Please take care of him/her and of us who are left behind

God, you are with us in life and death

You are our hope

With you, there is future and life for all of us

Amen.

This ritual, or attempt to ritualize, is the first endeavor to put the practice of organ donation into a formal religious frame. Most Danish donor families are given the offer of being accompanied by a chaplain when saying goodbye, but there has never been an official prayer articulating the dilemmas and the emotions of this situation that was designed to this particular way of saying goodbye in the technological surroundings of the NICU. The ritual suggests that it is hard to give up hope in this situation and understand that the patient is dead. At the same time, it turns the hope towards other patients, so donating organs can be “a blessing to others”.

With this new ritual, the hospital chaplains transform the religious hope of a good afterlife into embracing the hope that organ donation will succeed. This is very much in line with the practice of hope I met in my research. Families often cling to the outcome of the organ donation when hope for survival has gone. In one of my interviews, the mother of a young donor said: “Can you even believe there is a God when something like this happens? Yes you can. It was God who made sure that three others could live on with his organs.” God therefore plays a role not only in the hope

that the patient will die and not survive as a vegetable, but also as the one making sure organ donation is able to take place.

For donor families, the notion that the body had transformed into something that could benefit others resulted in changed practices of hope to ones that could be comforting and reassuring for families. Sharp describes how American doctors tend to objectify organs and talk about them from their functional and not their emotional meaning. This is mostly done to protect the organ recipients, who should not feel guilty about receiving a body part from a dead stranger (1995). Thereby the body is objectified and the symbolic and emotional meaning of the body parts of the dead is strategically forgotten. My research shows that this strategy of objectifying body parts is also initiated by Danish donor families in their attempts to orchestrate a meaningful death. By transforming the hope for survival into a hope that the organs can be of good use, some families find meaning. Some families even use very objectifying language when talking about the body parts of their loved ones.

I interviewed Poul, who lost his 27-year-old son in a traffic accident. He compared the body of his son to a washing machine where the control system was broken, but the spare parts were still in good shape. Poul was an electrician and in his transformative practice of hope he therefore turned to a language and a model of explanation that was in line with his own profession. By applying metaphors and situations from his working life, he was able to see the usability of the body parts of his son and transform his hope into hoping for the survival of the organ recipients. The transformative practice of hoping can therefore be a way of orchestrating a peculiar death into familiar values close to everyday life.

The shifting understanding about the usability and the purpose of the body is an important element in the transformative practices of hope for donor families. Adam's parents, Bente and Carsten, were extremely

keen that Adam would be an organ donor. The interview, which has far more detail than space allows for here, shows how much they appreciated the efforts and the support of the hospital staff. But as we saw in the case, they were almost offended when the neurosurgeon told them out of concern that it was okay to withdraw their consent as time dragged on. Making sure that Adam's organs were used was their way of orchestrating death into something meaningful.

During a follow-up interview with the family of young Sam from Chapter 3, six months after his death, the family explained that Sam's death also lasted several days. But they chose to keep him on a respirator and wait it out because it was important to them that Sam became an organ donor. Sam's oldest brother Jeppe explained that "everything else would have been a total waste of good organs". Jeppe had been a soldier and knew about the need to save young lives. So the idea that his brother's organs could potentially help others was, based on his personal experience, very sense-making. While mourning the loss of his younger brother, he could also view his body as a resource to repair other bodies.

Anthropologist Margaret Lock argues that technology has permitted us to manipulate death to meet the utilitarian interests of the transplant world (1995: 596). By way of my studies from the Danish context of organ donor families, I feel a need to revise this statement and say that technology enables us to perform a death that meets the utilitarian interests of donor families. For the families of Adam and Sam, as well as the father Poul and many other families in my study, the usability of the organs is incredibly important because it becomes a way of transforming hope or, in other words, of overcoming the hopelessness that such situations of loss are characterized by. Making sure that the body is kept going by way of technological equipment so that the organs can be as healthy as possible is not only to accommodate the wishes of "greedy"

transplant surgeons, as the past few decades of critical literature has suggested. Families, too, can be utilitarian in their view of the organ donor body while of course at the same time still mourning the loss of their loved one. Carsten, the father of Adam, told me that when saying goodbye to Adam he had thought: “You’d better keep going; this must not be in vain. Something good has to come out of this.” It was not my son lying there, he told me. “He was just a shell for keeping the organs alive.”

While technology played a significant role in the performance of trust, as we saw in Chapter 3, I argue that it also has a significant role to play in the transformation of hope. The technology of respirators and other devices helps patients to survive in the NICUs. And it helps establish a trustworthy death. Additionally, it helps keep the bodies of the dead alive. Compared to traditional ways of handling dead bodies, this might seem ambiguous and confusing. But as these examples have shown, it is exactly this ambiguity in the relation between patient and technology that helps donor families to transform hope and find some kind of solace in helping others through the usable parts of their loved ones.

To Bente and Carsten it would have been a disaster if Adam’s heart had not lasted the pressure. Thereby they touch upon an ethical dilemma often discussed in the organ donation context. What if a patient goes into cardiac arrest before the organs are procured? This medical problem is woven into the experiences and hope of this family.

Getting information on the logistics of the procedures also affects the practice of hope for donor families. Detailed information helps families imagine the recipients and make them feel good about their decision. The parents of Lilly, the young girl we met in Chapter 3, put it like this:

The only positive thing the weekend she died is the lady who was removing her organs who told us what would happen. She told us about

the big machinery that is started and that all Nordic countries are involved and messages are sent to those receiving the different organs. Doctors are flown in and everybody is ready. They are removed and given to them and in the airplane and home. When we drove home Saturday afternoon after having said goodbye they flew flags at half-mast. We could claim it was the worst weekend we ever experienced. And somewhere there were five or six families having their best weekend in many years. This is the only fucking reconciling thing about this. And then that it caused a tremendous debate at school. Because we told them that she was a donor and that it was her decision and we think that is great. We are proud of her. (Joan and Henning – parents of Lilly)

Sometimes hospital staff are reluctant to inform families about the technicalities of the procedure because they are not sure how it will affect them. But for families finding comfort in the decision to donate, the complex and fascinating logistics behind an organ donation makes hoping for a positive outcome more tangible. When driving home, Joan and Henning even imagined the families of the recipients and understood that while they were in the middle of a nightmare, these families were regaining hope. Imagining other lives saved and feeling happy about other families getting hope is an important aspect of the family's orchestration of death. By transforming hope all the way into the hope for other unknown families, organ donation somehow becomes meaningful. This story also teaches us that the transformative practice of hope reaches not only to the potential recipients. The fact that Lilly's decision resulted in a debate at school was also a comfort to Joan and Henning. Lilly's decision made them proud and, as other statements from our interview showed, they hoped that she would be an inspiration to other young kids, so they would sign the donor registry as well and thereby make a potential decision easier for their families. Therefore, the transformation of hope is about not only the

usability of the donor's body, but also that other bodies can become usable by way of the donor registry.

Hoping to Improve: Sharing Experiences

Interacting with donor families taught me that they had many intentions and expectations towards telling their story. I have decided to frame them analytically as a practice of hope, and thereby a way of orchestrating death in the months and years after the donation.

Deciding to participate in my study was thoroughly thought through by the donor families. Most of the times, families shared their attitudes and feelings about agreeing to an interview; information that helped me to move closer to an understanding of not only their story but the personal costs of telling it and my role as an anthropologist. It was my clear impression from their feedback that even while participating was emotional and carried personal costs, at the same time they felt it was a personal privilege to tell the story.

Most families have never had the "organ donation" approach to their story. Besides two women and one man having met with journalists, every one of my 82 donor family informants was interviewed for the first time about the organ donation experience when I came to their house to talk to them. The stories they share in their personal networks are often about trying to live without a close family member and the process of grieving. They have a lot of thoughts about organ donation but it is the anthropological research focus that brings that particular subject in the foreground, because the fact that organs were donated is not always important compared to other emotional and social consequences regarding the death.

But I found out that some families had an additional agenda when agreeing to participate. An important part of the story was the way families were treated by the hospital system. Many of the families regarded me as a person who by way of my research could report back to the hospitals and pass on their voices. Families could be very concrete in their suggestions as to how the conditions for organ donor families could be improved. This made me realize that practices of hope stretch beyond the clinical context and the hope that organs are used. It is also about passing on experiences others can learn from. This matter is highly prioritized by families and in strong demand among the hospital staff working with families.

It is important to realize that the practice of this kind of hope has no stage upon which to be performed. Unlike, for example, the American organizational context for organ donation, where donor families are regarded as 'experts' and asked to participate in advisory councils to give feedback on organizational initiatives, Danish donor families are not officially regarded and used as a resource of knowledge regarding organ donation. My fieldwork showed that both hospital staff and policy makers were extremely interested in feedback from families in order to improve their efforts. But there was not always the time or resources to make a phone-call or to have families return to the hospital to speak to doctors and nurses. Therefore my position as researcher of donor family experiences somehow puts me in the position of communicating messages and suggestions for improvement. Somehow that was hard to do without jeopardizing the anonymity of my informants.

The important question to ask is: Why do families care about passing on their experiences? In an attempt to answer this, I see the practice of hoping for future improvements as a way to imagine and establish a community of fellow sufferers. It is a way to orchestrate a collectively experienced death somehow, to stay in the analytical

framework of this study. In this I follow the arguments of Mattingly, who also sees the practice of hoping as a way to create new communities of care (Mattingly 2010: 6).

In the organizational system of organ donation in Denmark, donor families are not structured as a group with special needs who might want to meet and share experiences, as is the case in the American context (Jensen 2007). There is no social interaction among donor families, and we shall return to this matter in Chapter 6, which deals with sociality. But I argue that this sociality is somehow performed through the practice of hoping for future improvements. Based on the statements of my family informants, I argue that implicitly, some families think about potential families who are about to go through the same processes of brain death, the same devastation and the same negotiations and contemplations regarding the question of whether a loved one should leave life as an organ donor. Therefore as a way to construct this social group, families articulate the hope that by speaking to an anthropologist moving back and forth between hospitals and the private homes of families, their knowledge can be transferred to others in the same situation. I shall therefore devote the following pages to outlining some of these suggestions for future improvements. Thereby we gain insights on how Danish donor families would have preferred the death to be orchestrated.

Before moving to the critical suggestions, I find it important to mention the gratitude and admiration some families feel towards the hospital staff. The efforts made by doctors and nurses to accompany families in these tragic times were crucial for the family experiences. But equally, negative attitudes to organ donation were often based on bad interaction with staff and the other way around.

In many of my interviews, it was clear that the quality of the waiting facilities for donor families, and other families at the NICUs, was critical. As my informant Curt explained:

My wife is put in a ward and I am offered a waiting facility resembling a train station, with dirty cups and dirty plates and people going in and out. It is an extremely stressful situation. There is another family there arguing and I have to throw them out. "Please go now, my wife is dying and my kids are on their way." And I am not the one supposed to do that.
(Curt – husband of Mette)

Statements like this indicate the importance of the physical surroundings of the intensive care units. Families need a peaceful place where they can be alone without being disturbed by other families. In addition, the fact that rooms were sometimes not cleaned created distrust towards the level of perfection in the units. While the ability to clean in principle has nothing to do with the expertise of neurosurgeons, it does have an impact. The last chapter opened our eyes to the importance of performing trust in the dialogue between families and staff. My fieldwork showed that if families are disappointed in the physical surroundings, they have a negative starting point in the dialogue with staff. The peculiar logic behind this is: "If they can't even keep their hospital clean, how can we trust that they are certain about brain death?" Therefore, for families insecure about brain death and the decision to donate, the physical surroundings can affect the performance of trust, and thereby the decision to donate.

Another point about the physical surroundings was also often mentioned by families. It was the need to have a private room for the patient so that it was possible to have moments of peace when saying goodbye. A woman I interviewed mentioned this lack of privacy as one of the worst elements in the clinical encounter. She was losing her mother

and she felt like screaming. But she felt she could not do that because she had to be considerate to the other patients in the ward. Another donor mother was so angry about the same lack of privacy that she started an angry debate in a leading Danish newspaper. She had been bothered by the patient lying next to her son, whose TV was playing loud music while she and her husband were trying to say goodbye to their son.

Donor families often mentioned the experiences at the chapel as crucial for the experiences of losing. One father of a donor said he felt as if the chapel was the warehouse of a nice furniture store. Inside you got a nice service but when it was time to go home with the products (meaning the dead body of his son) then you were left alone without any service. Many other families explained about practical problems when the body should leave the hospital. One mother told how her son was suddenly dressed in a paper shirt when leaving the chapel after she had made sure he was wearing his favorite clothes after the organ procurement. It is therefore important to recognize that the experiences of donor families are also affected by what happens outside the NICUs. This can easily influence the whole perception of the donation experience.

Other families mentioned that there was no contact or dialogue in the time after the donation. A mother told me that she needed some kind of “hinterland” or “organization” in order not to be left alone. She based that on her experiences that the notion of organ donation comes on top of losing a child, and therefore families need extra support and information. She believed that Denmark shouldn’t even practice organ donation without having the proper psychological and emotional follow-up for donor families.

An important point to mention is that many of my informants are very much in favor of organ donation. Participating in my study was therefore their way of communicating a positive message about organ

donation. When I thanked a donor father for letting me perform such a painful interview, he said:

If your product results in just two people – no, that is not enough, but then ten people – signing the donor registry, and one of us, or one in our families, suddenly needs an organ, then it is all worth it.

Therefore, when talking about donor families' hopes in relation to future improvements, it is a significant hope for many families that organ donation rates will increase and Danes will be better at signing the donor registry.

This chapter has suggested that an important element in the donor family orchestration of death is the transformative practice of hope. Donor families hope for the survival of their loved one. But if the damage to the brain is so severe that what they define as a dignified life cannot take place, then hope is transformed into hoping for closure, hoping for death. In the NICUs where families decide about organ donation, we have seen that some families adopt utilitarian perspectives on the bodies of their loved ones in order to transform death into something meaningful. Finally, families participating in interviews on this topic express hope for future improvement in the health care system by sharing their experiences. This can be seen as a way of practicing not only hope but also practicing the imagined sociality of donor families in Denmark.

Now it is time to discuss another aspect of the orchestration of death. While keeping focus on the experiences of donor families, we shall also focus on the actions of the hospital staff in their personal and professional ambitions to treat the body with respect and dignity. I have classified this analytically as the aesthetization of the body of the organ donor. By focusing on aesthetic performances, the next chapter

investigates the social meanings of the body of the organ donor in all its phases: from being classified as a potential donor, to becoming a donor, to having the organs removed and, finally, returning as an empty corpse. In this process the orchestration of death is performed and negotiated in a multitude of ways.

Chapter 5: The Aesthetization of Ambiguous Bodies



The Aesthetization of Ambiguous Bodies

This chapter will show how death is orchestrated by making the body of the organ donor “look nice” in all the phases of becoming an organ donor. Analytically this is seen as a process of aesthetization.

Organ donor patients exhibit an astounding paradox: They are simultaneously dead and alive because the brain is dead but the body is kept alive on a respirator. The heart is beating, the body is breathing, the hand is warm to hold and, to use the words of donor families, they “look as if they are sleeping”. They are also simultaneously an individual person dying suddenly and tragically, leaving behind grieving family members and friends and a collection of usable body parts that may be of benefit to critically ill patients. The body of the organ donor therefore possesses a number of ambiguous meanings. The apparent contradictions in the appearance, perception and experience of a dead body make it hard for families to figure out when, and even if, death has occurred, and how to interact with their relative. And the staff find it challenging to engage in the medical process of preparing the body for organ donation. Is it right to consider removing the heart from a person that is breathing? Can you let your child’s body be cut open by surgeons to help strangers? And is organ donation in accordance with traditions and ideals about dying peacefully? Engaging in organ donation raises such fundamental questions regarding the body and regarding life and death.

Hence, the central issue to explore is whether and when, and especially how it becomes socially acceptable to remove the organs from the body of a patient and to medically prepare, conduct and terminate that intervention. Anthropologist Linda Hogle studied organ transplantation in Germany and linked the history of the nation to its perceptions of the

body. She argues that in order for a nation or a health care system to accept these apparently inhuman procedures of handling dead bodies, a “cultural mechanism” to translate the concept must be initiated (Hogle 1999: 42). I set out to explore how this translation is attempted in the clinical context by way of the aesthetization of the donor body.

Referring to Donna Haraway’s political cyborg, Marilyn Strathern talks about aesthetic convictions and argues that aesthetics can persuade through form (Strathern 2004: 38). My main point of reference in my analytical work with aesthetics is the theory of anthropologists Bruce Kapferer and Angela Hobart, who understand aesthetics in relation to performance. They argue that aesthetics can be understood as a “created symbolic genre” that can construct, shape and perform a reality in a certain way that is related to human experience but, most importantly, is meaningful and takes on a certain value. From this point of view, aesthetics plays an important role not only as form but in the shaping of human experience. Following this thought, Kapferer and Hobart claim that aesthetics can be understood as a kind of agency since symbolic forms are not only representative of ritual acts, they create a reality. The aesthetic processes have the “potency to act upon their environment”. Kapferer and Hobart argue that:

Symbolic forms are active in the creation of their realities and have effect or bring about changes in the circumstances of existence through the aesthetic dynamic of their composition. (Kapferer & Hobart 2005: 9)

Leaning on Kapferer and Hobart in my analysis of the practices surrounding the organ donor body, I argue that aesthetics is not only a question of convincing through form. It also persuades through social performance, in the power it has to shape and construct a reality. When dealing with the body of the organ donor, making the body appear in

certain ways constructs a reality in which this medical procedure becomes visually and socially acceptable. This is a way of orchestrating death.

During my fieldwork it became clear that Danish doctors and nurses are very aware of the ways the donor body is handled. Hospital staff have a sincere wish that the bodies of their patients look nice and are treated with respect. Making sure that the patient is well taken care of, not only medically but also regarding personal hygiene and physical appearance, was highly prioritized among nurses. One time during my fieldwork I was following Else, an older nurse, on an evening shift. She invited me to participate in the personal hygiene of a patient, a comatose man in his 50s who was possibly nearing brain death. While combing his hair and brushing his teeth, Else gave me some lotion and asked me to rub it on his feet, so they would not be dry. Feeling uncomfortable at performing this personal task on a strange man who was dying, I tried to figure out why it was important to perform these actions. Rubbing the dry, unkempt feet of the man indicated that it had been a while since these feet had seen any lotion. This revealed to me that this act of nursing was not only a matter of making him look as he used to. It was Else's goal to have him look better than he used to. To nurses the matter of creating a visual appearance of the patient that is dignified and "beautiful" is extremely important. Thereby they not only showed respect to him and his family, they also underlined that they performed a good job of nursing. Caring that patients live up to certain aesthetic standards is very important for nurses. There are certain rules and directions that are deeply grounded in their professional ethics and rules of conduct. This was evident in all organ donation cases. The aesthetics of the body was performed in order to comfort and support the family in the best way possible. Aesthetic practices are challenged in regard to the organ donor patient, where the body changes status, purpose and visual appearance according to the

phases of the organ donation. Having the body “look nice” is sense-making to both families and staff, but sometimes the process of brain death and the medical procedures of maintaining the functions of the organs are an obstacle to this. When it comes to organ donor patients, the aesthetic practices surrounding the care of the body become more important than ever. The way to understand my use of aesthetics in this section is therefore more in line with Kapferer’s concept of *aesthetization*, meaning the actions of “making things and processes into art” (Kapferer & Hobart 2005: 10). Aesthetization is another word for using aesthetic processes and directs us to think about aesthetics as something that not only is, but something that is socially practised and performed and actively shaped, constructed, negotiated and contested.

Aesthetization is strongly connected to the ethics and values of the medical profession, since there is a strong code of best practice among doctors and nurses. Anthropologist Janelle Taylor has proposed the term ‘moral aesthetics’ in a recent article on standardized patient performances, which are the staged clinical encounters where health care students and actors engage in role-playing (2011). Taylor uses the term ‘moral aesthetics’ to propose a connection between what is morally right and what is aesthetically compelling. This connection was also evident, I argue, in the practices surrounding the donor body. Making the body look good, or aesthetically compelling, was a way to make the processes of organ donation morally right. Other actions could happen or be intentionally performed as a way to make organ donation look morally bad, as this chapter also explores. Therefore, aesthetization can be used to show “the right way to do things” but also to underline and perform the ugliness of, or controversial or amoral aspects of organ donation. I argue that aesthetization can be used intentionally or strategically in order to clarify, visualize, translate or emphasise the dilemmas involved in interacting

socially with the human body at the limits of life and death and, in line with Taylor, to show what is morally right and wrong. Aesthetization is a tool to orchestrate death with a certain purpose.

In line with this, it is the argument of Kapferer and Hobart that aesthetic processes contain both a *function*, meaning a purpose, and an *intention*, or an organization of symbolic form that is based in and directed toward the senses. (Kapferer & Hobart 2005: 11). While function is the purpose or the rationale of the aesthetic process, the intention is closely connected to ascribing meaning and cognition to the feeling, which can be done both consciously and unconsciously. In this sense, aesthetic processes are not only representative; they also have the ability to constitute the realities they present (Ibid: 13).

Based on this, I use aesthetization as an analytical frame to investigate how certain practices, forms, languages and visual and emotional actions are played out at specific times in the process of organ donation and with a specific function and intention: To make the body of the organ donor “look nice” and thereby to orchestrate this exceptional death according to current aesthetic standards.

Adding to the argument of Kapferer and Hobart, in my analysis of the interaction with the body of the organ donor patient, I find it suitable to place the process of aesthetization in a temporal frame. I argue that aesthetization can happen as a plan, a response and a reflection. Elaborating on this, ‘plan’ means the structure or preparation of something. Within organ donation that could be the standard procedures of medically determining brain death as shown in previous chapters. As we have seen, there are protocols, law and procedures for the process of determining the death of a patient that is still breathing in a suitable and culturally acceptable way. ‘Plan’ embraces aesthetization as an intention or a strategic action that is performed or carried out with a purpose.

Then there is aesthetization as ‘response’. By this I mean the immediate, spontaneous reaction to something unfamiliar; that is, the instant attempt to control the strangeness. Thinking back to the spinal reflexes of the brain-dead patient, as discussed in earlier chapters, an immediate attempt to aesthetize could be the nurse trying to explain them or to hold down the arm of a brain-dead patient. Another example would be the father making sure his wife looks good in the seconds before the children enter the ward. Therefore aesthetization as response is often situational, unique and instinctive.

Finally, aesthetization can also be reflexive, looking back at what happened and trying to aesthetize it. Aesthetization as reflexive praxis is the attempt to make certain actions and experiences reasonable and meaningful and in accordance with existing values and norms. The process often finds expression in narrative forms as a model of explanation comforting both families and staff. For example, when families say that death was “better than being a vegetable in a nursing home” or “organ donation was the only positive aspect of the tragedy”. This might be interpreted as a reflexive aesthetization of the traumatic loss of a loved one.

This level of reflection can again lead to plan or structure. For example, as is the case in some Danish hospitals, the disturbing experience of spinal reflexes has been used to introduce the standard that brain death patients can be given relaxing medicine after the brain death tests have been carried out. This action is done in order not to disturb the family’s process of understanding death and to prevent the operating theatre staff from having the traumatic experience of the dead patient moving an arm or leg when opening the chest.

Everything in the examples mentioned above can be seen as processes of aesthetization with the purpose of understanding the

unfamiliar and make it socially and culturally acceptable. It is a way of orchestrating death. Donor families and medical professionals all participate in all aspects of the process of aesthetization, as we shall see. My main point is that aesthetization is not only strategic or intentional. Everything cannot be structured and planned in the world of organ donation; therefore aesthetization also takes place as an immediate response and a subsequent model of rationalization, explanation or reflection. And most importantly, as with the other elements of the orchestration of death, aesthetization is about attempting to make the body look nice. As we shall see in this chapter, it is not always successful.

With an analytical point of departure in the concept of aesthetization this chapter therefore discusses the actions and practices that are initiated, negotiated and performed by the hospital staff and by the family in order to handle and to socially interact with the organ donor body on its way through the processes of organ donation: From the patient as a potential donor not having entered brain death yet, to a brain-dead patient becoming an organ donor after the family consent, to being the open body on the operating table and finally, returning as an empty body after the organs have been removed.

The first apparent point of investigation is when and how a patient is regarded as a potential organ donor, and the dilemmas that arise as a result. The case of Luka provides an empirical foundation for understanding this controversy so often played out in the Danish organ donation scene, as well as an introduction to the clinical context in which, I argue, the aesthetization of ambiguous bodies is played out.

The Potential Donor Body

“There might be an organ donor for you.” While silently flinching at the choice of words and simultaneously appreciating the doctor’s cooperation

with and interest in my project, I walk to the two-bed ward in the NICU and see a young girl lying in the bed. Luka, a 19-year-old exchange student visiting Denmark from Japan, was hit by a car while crossing the street and is now lying in a bed attached to the respirator and surrounded by doctors. The nurse Robert pulls her blanket to the side and shows me the damage to her body: the right side is completely blue and her head is swollen and deeply injured. Robert explains that the pressure in her brain is 90, which is about ten times more than a severe headache. The doctors can do nothing to save her life. “Those beautiful black eyes,” Simon, the young doctor, says with a sad tone in his voice while using his flashlight to check for pupil responses and brain reflexes. Robert watches the monitors, checks her urine levels and expresses his sadness that such a young life should end this way.

Suddenly a discussion arises among the staff. What to do? Deborah, the head neurosurgeon and an enthusiastic figure in the area of organ donation, argues that the medical care of Luka’s body should continue so that the family, who are arriving on a plane tomorrow, “can have the opportunity to say goodbye before she dies”. This makes Robert angry: “But we are not taking care of Luka, we are taking care of her organs. I think she should be allowed to die in peace. But I would not be saying anything if Anja was not here.” He is pointing at me, and I am standing in the circle of arguing doctors and nurses mumbling “it’s hard, it’s hard”, every time Deborah asks for my opinion. I am trying my best not to get actively involved in the discussion while simultaneously appreciating Robert’s courage to openly raise his voice to the dilemma evident in the faces of the hospital staff: What are they fighting for? Since survival is out of the question, it is only prolonging the breathing and heartbeat. But what is the real purpose of that? So the family can see her “alive”, or to keep alive the possibility of organ donation? Deborah replies that “it might

be good for the family to get the chance to decide about organ donation". And Robert says: "That is your opinion. Not mine. It's like religion. I don't believe in that either." Finally, Deborah concludes the rather intense discussion. Luka should be monitored closely and kept stable on the respirator as long as possible. It is okay to give her blood but not okay to give heart massage if she goes into cardiac arrest.

After Deborah leaves, Robert explains that he is missing consistent messages. He has been given three different orders since he came this morning. "Are we taking care of her medically or not," he asks, and repeats that he is not against organ donation but he does not agree with the decision to continue the care and wait for the possibility for organ donation. "Sometimes Deborah is too keen on organ donation," he concludes while checking Luka's respirator and checking her airways with a tube. To my shock and surprise this makes Luka cough. "She is not dead yet," he concludes.

A few hours later, Robert calls me over to look carefully at the screens and says: "It's happening now." Luka's blood pressure and intracranial pressure suddenly increase rapidly, which is a clear sign that she is incarcerating, meaning the pressure in the brain is so high that the blood flow stops and the blood desperately tries running to the brain as a last survival mechanism. To doctors, this is a clear sign that brain death has occurred. We watch the screens and the numbers are running higher and higher. The pressure in the brain goes to 100, 150, 200. I am terrified to see this but can't take my eyes off the numbers. According to Robert, who carefully notes all the changes of numbers in the journal every five minutes, the process is "by the book, but the numbers are extreme". Suddenly the young doctor Simon enters and yells: "No no, don't keep those numbers running, why do we have to watch this, shut them off!" clearly indicating that this is too brutal to witness. "This is for education

purposes,” Robert replies, glancing at me and a young nurse in training. Simon stops and I freeze, realizing that Luka has just died alone with no family members, no friends, just a curious audience watching the screens. While struggling with my disgust, my embarrassment over observing this and my urge to leave the room immediately and go home, I realize that Robert has succeeded in his attempt to make visible the cold brutality of the brain death process with his use of the technology.

After the numbers have peaked and rapidly fallen, something is changed. There is no hope of saving her brain. According to the neurosurgeons, Luka is dead. Her brain has closed down, but her body looks the same. While watching this apparently dead patient, the monotonous whistling of the respirator is a rhythmic reminder that Luka is still breathing and her body is still pumping blood to the organs. Robert checks Luka’s respirator and cough reflexes again by pushing a long oxygen tube down her throat. There is no cough. “Now she is gone,” he says, and while retracting the tube, which is now filled with dark red blood, he quietly notes: “And nobody can use these lungs.”

The next day, Luka is still on the respirator and has been moved to a private ward. The medical monitoring of her body continues, meaning that the body is being given extra blood and she is receiving intravenous medicine to keep the blood pressure up. While carefully controlling and medically adjusting the functions of Luka’s body and her organs, the nurse Liza struggles to find time to prepare the bed, making sure the sheets are clean and everything is in order. Liza explains that she often invites families to lie in the bed with the brain-dead patient and that she hopes they will welcome this opportunity when they arrive. Lifting Luka’s hand on top of the extremely straight blanket so the family can hold it, Liza notices some blood on Luka’s forehead and gently removes it before combing her black hair. Another nurse opens the door and announces that

the family is on their way and Liza quickly puts some chairs at Luka's bedside. Suddenly the mother, father, and boyfriend arrive and rush to Luka. The father grabs her arm and tries to wake Luka by calling her name: "Luka! Luka! Luka! Luka!" over and over again. He yells at her and cries, and then lets the mother step in and try to wake her. "Luka! Luka! Luka!" The father lifts her blanket to see the injuries. He touches her arms and hands again and I notice that they sense she is still warm. The mother sits down and hides her face in her hands and the father desperately continues calling Luka's name louder and louder for the next ten minutes without any interference from Liza. Every time he yells "Luka" it is an increasingly nerve-racking, painful sound, burning through my flesh and bones and underlining the fact that Luka is a beloved individual and this family will never be the same after losing her. The contrast to yesterday's "teaching session" watching Luka's brain deteriorate is devastating to me. The boyfriend sits down close to Luka, speaking to her in Japanese while constantly squeezing and caressing her hand. The parents leave the room briefly and the boyfriend asks with sign language and in broken English if he can play some music for Luka that she might remember, because it is "their music". Liza allows this but has to help the boyfriend force the earphones in Luka's ears because her face and her ears are extremely swollen due to the damage in her head. The boyfriend rapidly searches the iPod to find their song and expectantly watches Luka for several minutes for any signs that she might recognize the song and react. I look away and, noticing tears running down Liza's face, I am selfishly relieved to see that I am not the only one crying.

When it is time for the conversation, the staff taking care of Luka, the family, her Danish contact person, a translator and I gather in the small conversation room in the hallway. The family is informed about the accident and that Luka is brain-dead. The neurosurgeon Monir makes an

effort to communicate slowly and clearly so the translator from the embassy can give the right message. He tells them that the brain is so deeply injured that it is dead and the only thing that keeps Luka's heart beating is the respirator. The mother sits next to me crying and I feel an urge to put my hand on her shoulder but decide to remain as quiet as possible. Monir explains that he is obliged by Danish law to ask about organ donation but that is declined by the father straight away, and there are no additional questions trying to convince the family. The relatives silently nod to the explanations and are informed that they are allowed to spend some time in Luka's room saying goodbye to her, after which the respirator will be turned off, her heart will stop beating and she will be moved to the hospital chapel. During the entire conversation, they sit quietly without any questions, paralyzed by the doctor's message but seemingly accepting his authority to define life and death.

After the conversation they silently enter Luka's room and go to her bedside. I choose to allow them their private goodbyes without the presence of an anthropologist. Before the door closes behind me, I notice a much-too-evident quietness in the room, and that the boyfriend is rolling the earphones around his iPod and putting it in his pocket.

When walking slowly down the hallway on my way to the staff kitchen, a couple of nurses come towards me: "So did they say yes?" Unable to speak, I look at them and shake my head, suddenly realizing that regarding organ donor patients, something else is at stake than the outcome of this particular question.

Lukas's story represents the emotional aspects, professional dilemmas and medical practices in dealing with the body of a potential organ donor hovering on the threshold of life and death. In this case, it never came to organ donation due to the family's refusal. Their refusal was no surprise,

since Margaret Lock have showed that the Japanese are often very reluctant to the idea of organ donation, because they do not believe in the brain death criterion and they prioritize the care and intactness of the body (Lock 2002a).

Luka was put off the respirator the next morning and her heart stopped beating while the family was holding her hands. This course of events is an example of how patients who are either not brain-dead but classified as “not possible for treatment” or are brain-dead but are not going to be organ donors end their life. If she was going to be an organ donor, the official brain death tests would have been performed, two tests with one hour in between as described in the previous chapter. The official time of death would then have been after the second brain death test. Now it was the time her heart stopped. As earlier chapters have shown, the time of death in the NICU is a complex process depending on the family’s decision about organ donation or the decision of the doctors to end treatment. Luka was then taken to the chapel before the family brought her body back to Japan a few days later. But even if Luka never became an organ donor, her story shows us that the processes of organ donation and the contemplations over her body start as soon as a doctor or nurse raises the question whether it is reasonable to consider this patient a potential donor. The interesting observation in this is the fact that this particular moment where Luka is treated and defined as a potential organ donor is contested and not unanimously agreed upon, as we see in the discussion between Robert and Deborah. While families can have trouble locating the moment of death, as we saw in Chapter 3, hospital staff can sometimes have difficulty locating the moment of potential organ donation.

When a patient is admitted to the NICU with severe brain damage, difficult decisions have to be made. Sometimes, the medical interventions of controlling the blood pressure and the oxygen levels must start to

happen before it is certain whether or not the patient is brain-dead, in order to be able to medically realize the possible process of organ donation. Interfering with the boundaries between living and dead is a precarious activity. Luka did not die before the process of medically preparing her organs for donation was started. Even if there was no way the doctors could treat her injuries, starting to consider the outcome of the body so early caused heated debate regarding the purpose of the patient care.

The quarrel in this particular case exemplifies the often rather intense dialogue between different positions and attitudes regarding organ donation. The argument on one side would be that Luka's life could not be saved, so is it not reasonable to start considering organ donation? The "other side" would claim that it is better to consider the individual state of each patient and consider what classifies as dignified treatment. The tension in these matters is often the purpose or the intention behind the medical intervention on dying patients. Is it a matter of saving the patient, giving the family an opportunity to say goodbye, or keeping the body going so it can be used for organ donation?

Deborah, the neurosurgeon, deliberately mentions that Luka's body should be treated so the family can get to say their goodbyes while she is still breathing and make the decision about organ donation. When repeatedly discussing this dilemma with Deborah, it became clear to me that this concern was not only because she wanted another organ donor in the book. Indeed she wanted that and she was always honest about her enthusiasm for organ donation. But she explained that her decisions was also based on her years of experience that some families appreciate the option to donate, and making sure that the family is provided that opportunity was in accordance with her ethical standards as neurosurgeon. Deborah and many other neurosurgeons often mentioned that if they could not save the life of a neurosurgical patient, they had to

shift the focus towards other patients outside their unit that could be saved by organ donation. But the exact time to start these considerations and actions was always contested. This teaches us that when dealing with potential organ donors, it is often a matter of intense social negotiation since there are conflicting ideals about what to do with the body of the patient and especially when to do it. This negotiation can be regarded as a way to aestheticize death but with a double agenda. Some doctors will make death meaningful by going for organ donation; others will aestheticize death by giving the patient peace and sparing the body from medical intervention. Giving the family the option of donation and continuing the medical care can be seen as a way to try to translate a tragic death into something meaningful for the family while at the same time turning the neurosurgical failure to save Luka's life into another organ donor in the department statistics.

An important point to note from the Luka case is that Deborah orders that it is okay to give blood but not to give heart massage if the heart suddenly stops. The dilemma of heart failure of potential organ donors is an ongoing ethical dilemma and a topic of discussion at conferences on the Danish organ donation scene. When interacting with the potential donor body, there seems to be a difference between discreetly giving medicine that keeps the body alive and performing cardio-pulmonary resuscitation, or CPR. When a potential donor's heart stops it is interpreted as "the body's way of saying stop". So hospital standards determine that a donor should not be resuscitated. The logic behind this is that one shouldn't resurrect the dead. Pumping the patient's chest is a visual sign that you are bringing him or her back to life. But since an organ donor is strictly defined as dead, in order to justify the medical focus on the organs, bringing the dead back to life is a complicated matter. However, my fieldwork at the NICUs showed that this problematic is

always discussed since it is professionally unnatural for doctors and nurses not to perform CPR when a patient goes into cardiac arrest. Looking at this through the optic of aesthetization shows that the decision not to give heart massage to a donor is a way to classify a visual logic surrounding the body of the potential organ donor that leaves no confusion as to whether this patient is dead or not. Having a team of doctors and nurses restarting the heart will disturb perceptions and understandings of the body of the potential organ donor – not only for the family, who might be present to watch this intervention that contradicts all earlier messages, but also for the staff, who need clarity about whether the patient is considered alive or dead and what the purpose of this breathing corpse is.

What is at stake in Luka's case is the shift from regarding her as a person to regarding her body as a potential collection of organs. Starting the donor management process before the patient is legally brain dead raises serious ethical concerns and seems to interfere with the professional 'moral aesthetics' of the nursing profession. Keeping in mind that the official brain death exams are not performed unless there is consent to organ donation, the medical monitoring of potential donors will always raise this issue: When is it okay to care for the organs and not, as Robert pointed out, for the patient? It is all about the symbolic marking of the shift in attention.

Returning to the case of Luka, the family is not present in the beginning, so this "awkwardness" of when to start considering her a potential donor should supposedly have been "easy" compared to the cases where the family is in the room hoping for survival while medicine is almost secretly given to foster the option of organ donation. But instead, a nurse stepped in and defended Luka's autonomy. His questioning of the shift in medical attention almost represented the emotional perspective of

the family. Clearly the decision to keep Luka's body going is controversial due to the time conditions in this particular case. Having the parents come all the way from Japan adds hours to the process and keeping Luka on the threshold between life and death is considered not only a challenging medical task but also unethical by some of the staff. Some days after Luka's death Robert commented on the process and pointed out that he was not against the idea of organ donation but he had considered it very problematic to continue the care for so long in order to keep the possibility of the family consenting to organ donation. This teaches us that aesthetization is deeply rooted in temporality. It is the length of time that the body was kept going that disturbed Robert.

The personal attitudes of the staff dealing with the particular case is a determining factor and often crucial for the process and the outcome of an organ donation process. Some nurses and doctors are considered "key persons" or "fiery souls" when it comes to organ donation. Another way to determine them more negatively or humorously is "hawks" or "vultures". They are very positive towards the idea of organ donation and they spend time educating others and promoting the cause. Often they play a significant role in identifying potential organ donors. Another group is the doctors and nurses that are not eager to engage in the processes of organ donation. They realize it is part of their job description and they are willing to perform the procedures, but they do not go to extremes or push any boundaries to engage in the matter. It is important to realize that the attitude of the individual staff member has a deep effect on how the body of the potential organ donor patient is regarded and treated.

Adding to this, it is not only a matter of personal conviction. In the past decade, political pressure to identify organ donors in Denmark has intensified since medical reports were published identifying the country as having one of the lowest proportions of donors in Europe at 13,9 organ

donors per million inhabitants. In August 2010, The Danish Folk Party (*Dansk Folkeparti*) suggested making it a political goal to have 25 organ donors per million. This was welcomed, not only by patient organizations awaiting organs, but also by the leader of the Danish Centre for Organ Donation, who stated that “a political focus is crucial for strengthening the effort”. This political and organizational urge to identify donors has affected the policies and practices of the NICUs and caused them to be more aware of patients with the potential to meet the brain death criteria and therefore become a potential donor. The current state of affairs in Denmark indicates that in the future, this will be even more significant.

However, as we see in the case of Luka, the urge to keep the option open seems very provocative to some of the staff, who feel it would have been more appropriate to let her die in peace. On the other hand, my research shows that taking care of the organs is a completely different, yet still contradictory, task when there is family consent for donation. Knowing that a family has a wish to donate and is focused on the actual donation outcome makes these paradoxical procedures more meaningful. In the case of Sam in Chapter 3, the staff informed the family that they were doing all kinds of tests. The family accepted this because they were eager to donate and knew the tests had to be done in order to match the recipients. But giving blood to a dead or dying person without knowing the decision of the family and for a longer time than usual is disturbing. Luka therefore exemplifies the fine line between ethical patient care and meeting the political demand for struggling to identify and medically optimize every possible donor. One can argue that the foundational ideals of nursing are challenged and that nurses therefore do what they can to reinterpret the events and turn the focus back on the patient and the family.

In dealing with the potential donor it is a matter of shifting between keeping the option for organ donation open and still making sure that the

family is allowed to spend time at the bedside and be with their loved one in the last hours. Looking at the actions of Liza in dealing with Luka shows us that Liza tries to shape a scene for the family goodbye where Luka is looking peaceful and her bed is nice and clean. The Danish anthropologist Britt Boesen has studied how dead bodies are handled until they are placed in the coffin, by conducting fieldwork at Danish hospitals and nursing homes. In her analysis of the work of the professionals, Boesen identifies “aesthetic guidelines”, such as the folding of hands and the closing of eyes and mouth, which help make “death appear like a time of rest” (Boesen 2008)

I argue that Liza is strategically using the aesthetics of a peaceful death to disguise the fact that Luka’s body has been artificially kept going in order to await the possibility of organ donation. You can say that Liza is visually performing the aesthetics of the body of a dead patient, not the body of a potential donor. She makes sure that Luka’s body functions because she has been told to do so, but all her focus goes towards creating a context for the family to understand the death of their daughter and girlfriend, and to say goodbye. She uses her professional experience to shape the experience for the family and to clarify that this patient is not going to survive.

Some of her ways of doing that were rather hard to observe. Standing in the room listening to the constant calling of Luka’s name, I was very frustrated at Liza for not stopping the family in their attempts to wake Luka and to play music for her. To me that seemed heartless. But in a later interview, Liza told me she wanted to allow them the time to sense the body and that Luka was dead, to feel it, to realize it. By not interfering with their attempts to sense that death had in fact occurred, Liza visually and tangibly performs the oral message of the neurosurgeon and perhaps helps the family to understand the message. She knows that a brain death

patient does not look or feel dead to a family hoping for survival. What the family senses goes against the severe message; it is a sensory paradox. But letting the family experience that Luka would not react to anything was a way of communicating the occurrence of death. But later it occurred to me that it could also have been her way of strategically illustrating the sensory paradoxes of brain death to me as a student trying to learn about these matters. Like Robert did when he forced me to look at the numbers, Liza was showing the ugliness of the brain death criterion by allowing the family to keep calling her name. In that sense Liza's aesthetic actions are both an "ugly" performance of personal attitudes and beliefs and a sensory translation of an unknown death trying to orchestrate it so it becomes understandable for the family.

When meeting Monir a couple of days after the death of Luka, he told me how affected he had been by this patient and how he had struggled not to cry when looking at the mother. Monir asked the family about organ donation because he was supposed to do so, but his task was to orally communicate the message of a complex death and use his authority as a neurosurgeon to do so. To Monir, entering the process at the time when the difficult official message of death had to be given to the family, Luka was primarily a young girl dying tragically, not a potential donor, which is why he did not push the family into reconsidering their initial refusal. Monir was not interested in using his power as a doctor to try to convince the family to try to transform the death of their daughter into an altruistic donation of life, as another doctor might have done. His way of making this conversation as acceptable as possible was to immediately accept the father's refusal of organ donation. Other doctors might have done this differently. What is the right thing to do, or in other words what is best practice, is a matter of personal conviction.

The story of Luka teaches us that there are other issues at stake than the actual outcome of the decision. The body of the potential donor is not only to be understood as a possible resource for others. In a more general sense, it becomes a locus for a multitude of contradicting views and ethical standards regarding the purpose of the breathing corpses. The ambiguity of the body thereby becomes a way to obtain a deeper understanding of the sensory paradoxes and the different opinions and practices played out at the NICUs when taking care of the patients who might or might not end up as organ donors. The potentiality of these patients challenges the justifiability of the organ donation process, since the bodies that are neither dead nor alive lack a categorization, and that is disturbing. Are they alive or dead? Are they organ donors or not? Are we taking care of the patient or the organs?

It is this lack of categorization of the potential donor that raises a multitude of responses and strategic attempts to outline the meaning of the body. By interacting with the body in certain ways at certain times, the staff and the family try to determine the status of Luka and create a certain frame in space and time to understand and, just as important, to express the ambiguity of the body of the potential donor. So in that sense, the aesthetization of the potential organ donor body has many functions: It can be a way to attempt classifying the unknown, to translate the disturbing ambiguity of the body into something that is closer to being socially acceptable and to underline and express personal attitudes towards controversial bodies and the idea of possible organ donation. The potential organ donor body becomes a locus of orchestrating death and organ donation.

With these points in mind, let us move to exploring the social interactions with the body of the patient that is going to be an organ donor after a family has consented.

The Consented Donor Body

When the brain death exam is done, the patient is gone. We stop talking to him and telling him what we do. It is just a body lying there and we have to take care of some organs that will make other people happy. It is clearly a shift. But the family does not shift. They are still the family.

(Kelly, NICU nurse)

As we saw in the case of Luka, there are difficulties in moving back and forth between treating the patient as a person and as a potential organ donor with body parts others might benefit from. This section will look into the processes of perceiving and handling the body that is going to be an organ donor and discuss how the aesthetization of the donor body is played out in this situation. At this particular moment, the family must be able to say goodbye while at the same time the doctors and nurses have to perform the brain death exams and give medicine to monitor the organs and their functions. Basically, the foundational human dilemma is that in order to fulfill the emotional and medical tasks surrounding the organ donor body, the dead must be treated as living, and the living must be treated as if they are dead. The social implications of this paradox will be the focus of investigation in this section.

After the patient is declared brain-dead I do not speak to the patient. And I explain to the family why not. That is a way of making them understand that it has ended. It is a very bad signal to inform a brain-dead patient what you are doing in front of the family. That is a stupid mistake. But it happens. A stupid mistake. You can easily understand why some families will start wondering and questioning. It is very important to make that switch, that change in care. (Hanne – NICU nurse)

When the decision to donate has been made, the notion of the body undergoes a shift regarding the medical care. The family has to say goodbye to the patient and at the same time, the nurses and doctors have to monitor the organs to make sure that they can be used for transplantation. The dilemmas are similar to those in the case of Luka, the potential organ donor. It is not an easy task for the nurses to try to accommodate the needs of the family while at the same time taking care of the organs. What is troubling is that these tasks are taking place at the same time and in the same room. In her studies of the managing of the dead in Denmark, Boesen emphasizes the importance of separating the rooms where the dead are handled from the room where the next-of-kin are allowed to be. There is a strong boundary that must not be crossed in order not to extend the suffering of the family. She writes that the family must always regard the dead as a subject and treating the dead as an object is disturbing (Boesen 2008). Adding more to this dilemma is the fact that the body of the organ donor is often perceived as being in transition between life and death. There is a lack of categorization and a lack of understanding of the status of the body that is extremely problematic. Therefore staff tries to make it easier for families by not talking to the donor and treating him or her as a living patient.

In order for organ donation to take place, the organs must undergo thorough intensive care and meet certain standards regarding blood pressure, urine, oxygen saturation and so on. This is called “donor management” and is a medically challenging task that needs full attention and expertise from anaesthesiologists and intensive care nurses. This is also the case for so-called ordinary intensive care patients that have to be carefully monitored 24 hours a day in order to have the best chances to recover from severe brain injury. A majority of the patients are in a coma or unconscious and on the respirator, but still the nurses talk to them and

touch them as if they were awake because time has shown that many patients can recall episodes from their time in a coma at the hospital and can be deeply traumatized because they were able to hear but not to react. When it comes to taking care of a patient's medical condition, taking care of the body of an organ donor is more or less like taking care of a patient in a coma. But the crucial difference is that the organ donor patient is dead, and that is what makes it rather paradoxical for many. It is considered rather contradictory to treat the body of a dead patient. During my fieldwork, it was clear to me that an organ donation process also has an emotional impact on the staff, and the planning and orchestration of events as discussed in earlier chapters is also in order to help staff through these bodily interventions, which are still a significant deviation from normal patient care no matter how much experience and routine the department has in organ donation procedures. The medical practices of controlling blood pressure and urine levels, meeting the right values and keeping respiration steady is the same, but the provocative variation is the purpose or the intention of the treatment. The medical care for an organ donor is about the organs, not the patient, and must therefore not be (officially) initiated before the patient has died.

Earlier we were quite reluctant, even if families considered organ donation, to give medicine to control the blood pressure or regulating medicine and so on. We considered whether it was suitable. You did it discreetly while the families were out for a conversation with the doctors. That was a big issue; talking about the idea that now it is no longer a human lying there, it is a body who used to be a human. Looking at it that way made it easier for us. (Kelly, NICU nurse)

Almost all nurses classified the transition from patient to organ donor patient, or from human to body, as a shift in their professional way of

handling a patient. They explained that they had to move their attention from the wellbeing of the patient to the wellbeing of the organs in order to be able to save other patients in other parts of the hospital or the country. Taking care of a patient in a holistic way, where you take care of the body while at the same time respecting the person, is essential to Danish nurses and the fact that the patient still looks the same way, still is in the bed, still needs to be looked after, but is in fact dead is hard to grasp even if it is a routine situation at many large Danish hospitals. I interviewed Karoline, a very experienced NICU nurse. She explained that she found the donor management very difficult, because it interfered with her perceptions of death.

I have seen many people die and I often miss that moment they are dying where you can see there actually is a soul leaving or something. A different look on their face, you can see that there is peace afterwards. I miss that. You do not get that with that treatment. (Karoline – NICU nurse)

Suddenly disregarding the human and focusing on the body is contradictory to normal nursing procedures. And it is confusing that officially the patient is dead, but there is no dead peace with an organ donor. Nurses must navigate between treating the dead as living and the “living” as death. The function or purpose (Kapferer and Hobart 2005: 9) of the aesthetic procedures are suddenly ambiguous. Also in relation to the family often needing explanations why their dead family member is given blood or medicine to keep up the blood pressure. Many nurses regard it a professional and emotional challenge to move between the medical focus of taking care of the organs and the compassionate interaction with the grieving family. In cases where a donor family is (too) quick to claim that they want to donate the organs, or make “the shift” from person to parts

too quick, this can almost be intimidating or rather offensive to the hospital staff and against professional treatment ethics and practices.

Regarding the nursing of the dead, there is a problem of a more practical character. Due to the lack of space in Danish NICUs, the leading doctors have to make some difficult decisions. During my participant observation at the hospitals, one of the most important tasks besides treating the patients was the puzzle of coordinating patients in and out of a very limited number of beds. The doctors could never know when an acutely injured patient would be in need of neuro-intensive care, and the department had to be extremely flexible and also push other departments to take over patients who were not in need of a respirator, even if the patient was perhaps not completely ready for a transfer. In the process of organ donation, a lot of space and resources are used on taking care of a dead patient. Of course it is in order to save other patients in other hospitals, but for the NICU the dilemmas of nursing the dead go above and beyond interacting with a dead patient. It becomes an ethical discussion (Høyer and Jensen 2011).

In the NICU, every patient needs one nurse 24 hours a day and careful neurosurgical and anesthetic monitoring. If there is one available bed, who should have it? The brain-dead patient with no hope of survival who is going to be an organ donor? Or the 25-year-old woman who was hit by a car and who would have a good chance of surviving if she gets surgery and neuro-intensive care? The arguments among organ donation professionals to make the dilemma explicit are often articulated like this: If the 25-year-old woman was your child or your sister, it might be hard to accept that she would have to wait because the organs of a brain-dead patient need medical monitoring. On the other hand, if your seven-year-old son was on the waiting list for a new heart and would die in three days if he did not get this particular heart, you would prefer that the NICU

prioritized the donor management to save the life of your son and possibly several other organ recipients. Who do we choose – who gets to survive?

An example such as this illustrates and represents the many discussions I witnessed every time there was a potential donor and limited space capacity, which was very often. In an interview with a leading doctor, he stated the following:

As a leader in this department, I know all about capacity problems. And if a younger patient arrives and needs that space you will try to fit in both, and that can be necessary. That IS a problem. I know we will do what we can, but I also know that we are ready to interrupt the donor management for the sake of a living patient. Still, we have stretched beyond what is reasonable to make space for it all. WAY beyond the limits of reason. MANY times! (Hans – doctor at NICU)

The doctors stated that their primary task was to take care of the living patients and that their efforts should be directed to the patients belonging to their department (meaning not the organ recipients). But at the same time they were aware of fulfilling the wishes of the family, and to deny a family the option to donate due to lack of space and resources was considered extremely taboo. However, returning to the example above, the doctors would always choose to operate on the 25-year-old woman and save her life. So it was clear to me that sometimes a potential organ donor never became an organ donor due to lack of resources. Nursing the dead only makes sense to doctors if other patients with a hope of surviving are not neglected on that account, otherwise it goes against their morality and professionalism. In some incidences I witnessed discussions about how to shorten the process of organ donation in order to have space available. A neurosurgeon suggested that a young boy who committed suicide might incarcerate quicker if he was given a “turban” meaning a tight band

around his head that would prevent the pressure in his brain from leaking out and speed up the process of brain death. This suggestion at the morning conference resulted in loud outbursts from other doctors stating that this would not be ethical. Later that day, the boy did have a band on his head but when I asked the nurse about this, she told me it was in order to prevent the family from seeing the gunshot wound and the disturbing red mass slowly leaking from his forehead. This is not to say that doctors are killing patients. This boy was not going to survive. But they might find themselves feeling forced to speed up the process of brain death due to the paradox that dead (or dying) patients should not take time from the living.

The Open Donor Body

When they drove away with him to go and have the organs removed, I asked the doctor, please take good care of him. And he said, 'don't worry we will anaesthetize him'. I feel good about that, but I have had some nightmares where Max is lying there screaming and yelling: 'Dad, Dad they are cutting out my heart!!!' (Per – father of Max)

Concerns about the body in the operating theatre played a rather significant role in the family decision-making in their retelling of the donation process. Having to leave a loved one to strange doctors performing surgery where the body is opened all the way from the neck to the pelvis entailed certain hopes, fears and expectations as to how the body looked afterwards and how it was treated until the procedure. Perceptions of and wishes about decent care for the dead body and its parts follow an organ donor all the way from the intensive care unit to the operating table and back. Since organ donation entails rather drastic

interventions in the body, handling the body in a respectful way is very important in the minds of donor families.

Alice and Jim lost their teenage son Morten in an accident. They came to my apartment one winter night and sat across from me with tears in their eyes, holding their coffee cups tight. Alice started explaining the course of events when their 15-year-old son died. When telling me about the question of organ donation, she emphasized her considerations about the body of her son:

My first reaction was no. They shall not touch him. It is my child. They shall not start cutting him open. They shall let him be as intact as he is. They cannot cut into my child. I must look after him. I must protect him. It was really, really difficult for me in the time after we said yes to donation. I felt guilty towards my son. We left him. You feel you leave your child behind who is alive. Because his cheeks were red and he was warm and looked like himself. And then you leave him and say goodbye. I really felt I let him down because I left him while his heart was beating. And then again. Rationally I knew that the heart would stop beating as soon as they removed him from the respirator. But at that time, it did not matter. I let him down. (Alice – mother of Morten)

As his mother, it was an almost impossible task for Alice to leave Morten and thereby stop protecting the body of her child. Ruth Richardson has discussed transplantation in a historical context focusing on how the dead were treated in the UK in the early eighteenth and nineteenth centuries. Richardson describes how, when people said goodbye to a corpse, they touched and kissed it to verify death and to prevent denial of death. It was also considered a duty not to leave the body alone. This was based on the assumption that the dead body still had needs, the soul might still be about and the “hopeful fear that the dead might return to life and require

assistance” (Richardson: 2007: 6). Leaving the dead is simply very difficult and unnatural as Alice describes. And my research showed that this difficulty reaches another level when it is parents saying goodbye to a child. Many of the parents I interviewed explained that it was so explicit in the role of a parent to protect the body of your child. One of my male informants described it like this: “You can leave your wife, but you can never leave your child”. Therefore the family relation to the donor affects perceptions about the body.

When a family is in the process of deciding to donate, ideas about proper ways of taking care of dead bodies are actualized. Most of the families I witnessed who said no to donation stated that they would not like their family member to be “cut open”. Nightmare visions about bodies being cut open in dark basements by teams of greedy surgeons are what keep many people from agreeing to this surgical invasion. There seemed to be a general idea and tradition that dead bodies should “rest in peace” and the surgical procedure of removing organs clearly interferes with this. During the interview it became clear that Alice was still very disturbed about what was going on during the removal of the organs. Especially the doubts whether or not they took Morten’s corneas had caused her many nightmares. She had since come to the realization that organ donation was good because that was what Morten wanted, but it still seemed as if she would never accept what happened to his body in the operating room. By exploring themes as traditional care for the dead, body snatching and dissection in the UK, Ruth Richardson provides a historical and contextual background for understanding the problematic of transplanting body parts (Richardson 1996; 2007). In the 17th and 18th century, dissection was considered a fate worse than death, to be avoided at all costs. People believed that cutting in the body could damage the soul, cause haunting and prevent the possibility of resurrection (1996: 71). While these views

apparently seem out of tune with our modern knowledge society, such issues are still important for donor families in Denmark today. As already mentioned in earlier chapters, many families say no because they do not like the idea that the body should be cut open, and a few families who did say yes contemplate whether the deceased will be allowed into Heaven with missing body parts. Cutting in and removing parts from the body can have spiritual consequences in the minds of families.

When talking about my research topic, I was frequently faced with different people's imaginations and ideas about the organ procurement surgery and their images and metaphors such as "dark basements" and "slaughterhouses". These rather visual statements were often accompanied by the fear that "if I have signed my donor card, the doctors will probably not try to save my life but only take my organs". My informal conversations with various informants are of course not a representative study of Danish attitudes to organ procurement but I argue that it points to a clear tendency that cannot be overlooked. It indicates that the secrecy and confidentiality surrounding this type of surgery has resulted in a public lack of trust and an increasing occurrence of violent images of body mutilation. This is contrary to what my interviews among the medical professionals performing this have shown, namely a sincere dedication to execute this intervention with respect and care for the body of the patient, with the highest level of medical skill and with room to express and discuss the many ethical ambiguities in performing a successful operation that leaves the patient cold and pale. The origin of this barrier is yet to be investigated thoroughly, but one of my interviews indicated that people create visions in their heads about organ procurements based on the increasingly high number of TV shows dealing with crime scenes, pathology and forensic investigation. Steffen, a 21 year old man lost his mother and explained how happy he was that the doctors and nurses

informed him about the procedures and guaranteed a dignified treatment of his mother.

Steffen: I am glad we saw her afterwards. How nice she looked. Perhaps you would have had nightmare visions in your head if you had not seen how calm she looked. You would have imagined a corpse that is completely taken to pieces. Like Crime Scene Investigation - the TV show CSI. The doctors and nurses were good at telling us that she would be nicely stitched together afterwards. They also told us that her chest and torso might appear a bit sunken after the organs were gone. But we could not see anything – she lay really nice. The doctors told us it would be done nicely. They would stitch her as if she was alive, so it was like any other surgical scar. It was not a botched job.

Anja: Did you know in advance how this procedure was done?

Steffen: No we had no idea. We only had the pictures in our head, from the television. Where you see those pathologists taking the bodies out of a freezer and cutting them open to see if there is anything there. And two police men in civil clothes are watching. It was a nightmare vision in my head. If the doctors should give information, I would like to know that she is taken to an operating theatre which is nice and clean and sterile. And perhaps even that they say it is done in a decent and dignified way. To remove those unconscious visions you carry around in your head. But luckily we got all that information.

Skimming through the information materials available to Danes, it is no wonder that people draw on images from TV shows. Public campaigns and information about organ donation produced by the Danish Health Agency tend to focus more on public attitudes regarding “yes” or “no” than thoughts about the procedure itself. This might indicate that policy makers themselves regard the information so precarious that it is dangerous to inform too much about. This can be interpreted as the strategic presence

of silence on a policy level. However, in the clinical context, doctors and nurses are aware that families appreciate honest information about the surgical procedure. The problem is, that sometimes they chose not to give it unless the family asks, because on top of the information about brain death, the question of organ donation and the overall tragedy of losing a family member, it can be too much for families. My study showed that body aesthetics are extremely important to families. And that this information must be given in order to avoid that families start feeling upset afterwards. When interviewing donor families about the surgical process of donation, some of them expressed their concerns and lack of knowledge about letting a family member undergo this surgery. Due to my earlier mentioned dual role as “anthropologist doing research” and “organ donation expert” I was sometimes used as a provider of information who calmed down their anxieties. Their anxieties often evolved around the practices and procedures in the operating theatre. Others expressed vast knowledge about the procedure but still expressed their difficulties in handing over their loved one to surgeons. While the idea, concept and purpose of organ donation can be fascinating and meaningful to some, the surgical procedure of removing the organs is in itself disturbing to many and deeply embedded in wondrous ambiguous layers of secrecy, fear, and unnatural ways of handling dead bodies. Informing about surgical procedures and assuring a dignified treatment of the body is therefore an essential part of the orchestration of death. Organ donation can only be meaningful to families if they trust and know that there has been taken good care of the body of their family member. Processes of aesthetization must be performed but also informed to families.

But processes of aesthetization are also important in order for the staff that perform those surgeries to orchestrate the death of an unknown patient in a meaningful way. It is now time to investigate why the organ

procurements are so extraordinary and what actual happens with the body of the patient in this particular crucial time in the organ donation

Unlike the rest of this dissertation, some of the data in the following section is not based on my participative observation, but rather on statements from interviews with staff who had participated in organ procurement surgery, and on discussions of the operation at conferences and teaching sessions in the Danish organ donation scene. I had to deal with this methodological condition because I was not allowed to observe a full organ procurement procedure. The rejection came from the largest hospital that almost always is present at organ procurements in Denmark so the rejection included many hospitals. This was the only rejection of participation I experienced over the course of my fieldwork. I have described the methodological implications of this in my earlier section about gaining access in the world of organ donation. But in this chapter, the rejection has analytical value. While it is always problematic to be denied the opportunity to gain these groundbreaking and interesting insights, it also serves as an example of the thoroughness, professionalism and gatekeeping that surrounds procedures like this. The official reason was stated as “outsiders not allowed” and “fear of infection”, but I was told that the rejection was also based on earlier experiences with journalists being allowed to observe the operation resulting in rather shocking and, according to the medical professionals, untrue and overly dramatic articles.

Even if the implicit comparison between my research project and tabloid journalism was rather frustrating and classified as “ridiculous” by other medical professionals participating in my study, it taught me a lot about the need to protect the patient and the staff participating in this operation. It also signified the level of trust and confidentiality surrounding the area. Evidently, something is going on that is not suitable for everyone

to see, and that requires an immense level of trust and mutual professional understanding to be allowed to observe.

The medical procedure of organ removal is deeply embedded in a large apparatus of timing, planning and co-ordination. The transplant coordinators are the ones who plan and control the events and decide who is to receive the organs, which teams are to come from what hospitals to perform the surgery and when it is going to take place. It has been decided by law that dead patients should not be moved to other hospitals in order to have their organs removed, so therefore the different teams come to the donor hospital. There is a team connected to each organ, so there are often many surgeons present at the same time, and while this has to be extremely well organized to take place, it is often described as “hectic” or “intense” by the professionals. As in all other sections of the medical system, there is a hierarchy in the organ procurement procedures; surgeons over nurses, and large hospitals over small hospitals. It was, however, my impression that the hierarchy also concerned the organs and was dependant on the “ischemia time” meaning how long a human organ can function without blood. For a heart it is four hours, for a kidney it is over twelve hours. This meant that the heart surgeons were often under the most time pressure compared to, for example, the nephrologists (kidney surgeons), who were in charge of opening and closing the body of the donor. Sometimes the operating team in charge of the heart had to run out the door, rush to a plane and fly to the other end of the country because the heart recipient was lying on the operating table ready to receive the organ. This medical premise meant that heart surgeons were often described as “self-important”. In spite of the almost militaristic precision and timing characterizing these procedures, the implicit struggle between different teams of surgeons determined to get their organ out in the best possible condition and in the right time could cause conflicts.

Therefore, besides the medical challenges of organ procurement, my interviews revealed that staff were very aware about speaking politely and respectfully to the other teams, especially to the local theatre nurses and anesthesiologists, to avoid conflicts even if the time pressure was extremely stressful. Martin, a surgeon performing organ procurements, tried to describe the procedure like this:

Of course there is a peculiar atmosphere; it is rooted in a tragedy. Or you can say that it starts with a tragedy. At the same time, it is also the promise of new life for many people. And there is also a special atmosphere because you meet colleagues you know from other places. And it is crucial that people can cooperate on this.
(Martin – kidney surgeon)

Operating nurses also explained that usually they make jokes in surgery in order to survive their jobs, but never during organ procurements. The way hospital staff interact with the organ donor is fundamentally different from normal patient interaction. It interferes in severe ways with the aesthetics surrounding normal surgery procedures. The patient dies at the table which is the worst thing to experience for operating staff. Even if they know the patient is dead when he enters the room, it feels very wrong. Realizing the importance of orchestrating death, for the surgical team, death occurs as soon as the heart is removed and there is no longer need for respiration or blood circulation. Having the anesthesiologist leave is unnatural and against their professional ethics and aesthetics. It is also very difficult for anesthesiologists to leave the patient. Michael, a very experienced anesthesiologist said that he always “circulated” and postpone the time he left, because it also felt wrong for him, suddenly to have no more tasks while the patient was still under surgery. As Margaret Lock points out, anesthesiologists are sometimes in “disturbing circumstances”

(2002a: 254). As the only staff category they cross the boundary between NICU and operating theatre and might find themselves participating in the organ procurement of a patient they have also cared for at the NICU.

Operating staff have difficulties locating the moment of death because the surgical and ritual procedures are different than usual. Grethe, one of the nurses explained that when she put the paper slip on the toe of the deceased patient after the surgery, she always had to think carefully:

What time of death do I write? Emotionally I must admit that I feel it is when the anesthesiologist leaves the room. But it is not. It is the official time of death after the second brain death exam. But everything turns inside me every time. I cannot help it. (Grethe – operating nurse)

At the same time, as the surgeon Martin indicates, this is a meaningful procedure since it saves the lives of other patients. Operating nurses appreciate this too and explain the joy of seeing a “kidney turn pink” in the body of a recipient. This is often described as “beautiful” by operating staff because it is a sign that the operation was successful and life will continue in the recipient. Some nurses regard the transplantation surgeries as rewards for participating in the devastating surgery on the donor. It was my clear impression that for theatre hosting these special surgeries, organ procurement can be a very disturbing experience. Annette, a theatre nurse who is also a transplant coordinator, was personally very much in favor of organ donation but argued that participating in the procedure entailed a “break” from what she and her colleagues regarded as “good nursing”. Annette was active in giving presentations and educating other nurses and as part of her further education she also wrote a paper on the topic with the main argument that the dual nature of the task of operating on a patient on the one hand, and focusing on the organs on the other, is

considered uncomfortable and may cause stress (Boe 2006). She quotes a colleague saying:

Suddenly the donor patient was no longer the focus; I know she was dead but the anesthesiologists left, the surgeons were at the kidneys and she was left there, all alone. It was odd and uncomfortable. We all felt that. (Boe 2006).

Annette argues that the theatre nurses have a feeling that the surgical teams are quickly and effectively “taking what they need” and “the nurses, the last surgeon and the coordinator are left with what they describe as a ‘stripped’ donor”.

My interviews with the operating staff revealed an incredible urge to make these surgeries as nice and respectful as possible. Kia, a operating nurse expressed it like this:

I prepare myself mentally if it is a young or an old patient. And I prioritize that the patient lies nicely. As the operation progresses it becomes the focus is more directed at saving the organs, and sometimes it must go fast. I prioritize to return the patient in a nice way. We all do. I think it is incredibly important that we tidy up the patient and comb the hair and place him nicely in the bed. And we follow the patient back to the NICU and make sure there is a room. And we make sure to give instructions to the staff up there that the deceased look nice. For me it is all about ethics. It means a lot to me that we have treated the donor with respect. On all levels. Also the way we act around the patient in the operating room. It must not be wild and brutal. It must preferably be quiet and respectful. (Kia – operating nurse)

Making sure that the donor looks nice and is treated with respect is the operating staffs way of orchestrating death. They all emphasized the

actions they performed to treat the donor like a living patient. One nurse explained that had pillow they called jelly pads so their patients would not get any pressure marks during surgery. “We also do that on our donor patients. But perhaps that is for our own sake. We feel good about it”. This can be compared to the intensive care nurses wanting to put lotion on patients’ feet and combing hair on the brain dead patients. It is in order to live up to certain standards deeply founded in their profession. When operating nurses perform these processes of aestheticizing the donor, it can be understood in several ways. It can be a way to orchestrate death according to aesthetic guidelines (Boesen 2008) out of concern for the families. But placing the patient on jelly pads can also be a way of signaling through processes of aesthetization that this brain dead patient is not dead yet, and must therefore be treated a “normal” living patient entering the operating theatre. Aesthetic processes are active in creating a reality (Kapferer and Hobart 2005: 9). The operating nurses create a reality that is not only convincing themselves and others that the body of the donor is treated with respect, but also implicitly indicating the ambiguity they experience when removing organs from a breathing patient and having the patient take his last breath during surgery. As we saw with the nurse Robert showing me the pressure in the brain of Luka, and the nurse Liza letting the family call Lukas name for minutes, the aesthetization can be meaningful by making the body look nice, but also “ugly” or “controversial”. Why place a dead body on jelly pads? Is the patient not dead? Aesthetization has a purpose and a function (Ibid 11). To orchestrate death in a certain way that is “beautiful” and meaningful but also to implicitly perform the personal attitudes of the staff with the body of the patient as a locus for action.

The Empty Corpse

I don't know how hard it is and how fast it has to go. But you have to see or to be sure that care has been taken of the body [during organ procurement] in a compassionate way. For the family. She has two small children who are about to come and say goodbye to their mother. My wife should not be returned as ground beef. That makes me fucking angry.
(Sonny – husband of Katie)

In organ donation literature, focus has often been on the transfer of body parts from one person to another with a special emphasis on the recipients' adoption of the foreign body parts and the transformations and implications this might entail. But what happens to the body of the organ donor after the organs have been removed? This section is devoted to an exploration of the social life of the empty corpse and to the creation and performance of a respectful aftermath.

Many Danish families consider the procedures of removing organs rather uncomfortable. Therefore, families need some kind of reassurance, closure or reinterpretation of experiences. In Denmark, this is attempted by normalizing the death at the hospital. What was frustrating to most families was the circumstances surrounding brain death. Due to the organ management process and the technological surroundings of the intensive care units, families in my research stated it was difficult to find peace to say goodbye and to be present at the bedside of the donor even if the hospital staff was very considerate. I often observed families walking in and out of the wards; many were whispering and acting carefully so as not to disturb other patients or nurses. Even if nurses repeatedly allowed them to do what they found best, some families were clearly uncomfortable with the social surroundings of the intensive care units and, as some of my interviews revealed, found it very difficult to have a private moment to say

goodbye. Therefore, the time after the organ procurement was often incorporated as a way to orchestrate the organ donor death as something peaceful.

During my fieldwork, I met Annika, a Danish woman in her late forties. She lost her husband Carl, the father of their four children, in a traffic accident. Annika was pleased and proud about Carl becoming an organ donor because it was in his spirit and it felt good for her that others were helped by the donation. But the process at the intensive care unit had made her aware of the many very difficult aspects of consenting to organ donation. One of them was saying goodbye while Carl's body was still breathing. She vividly described watching Carl being taken away from the intensive care unit to have his organs removed as "the trip down death row". Annika was a doctor herself and believed firmly in the brain death criterion but she still found the circumstances of the death very hard. Choosing to call it "death row" indicates that emotionally for Annika, Carl was not dead yet when leaving the intensive care unit, and that he was about to undergo some kind of suffering before he died. Annika explained that she was very appreciative that she and her children were offered a chance to say goodbye to Carl after the organs were removed. In their case, a hospital chaplain joined them and prepared them for how Carl looked and what they could expect. In Annika's own words this gave the family comfort and closure, and the reassurance that death had occurred. In this setting they felt they were allowed to cry and it initiated their grieving process in a good way. Annika explained:

You cannot say goodbye to somebody who is brain dead as long as he has colours and is warm and does not look any different. Mentally, that is impossible. It is so important to see him when he is what you understand as 'really dead', meaning cold and stiff and with pale colours. It is so

important. If the situation should arise again, and that was not an option, I am not sure I would say yes.

(Annika – wife of Carl)

In Denmark, the practice is to bring the organ donor back to the intensive care unit after the organs have been removed on the operating table. This is done for the purpose of allowing the family to say goodbye without the patient being connected to the respirator and giving them a chance to see them “really dead” or “dead dead”, to quote many Danish families and nurses. During this ceremonial event, the nurse lights a candle, opens a window and the family has the option to have a hospital chaplain present to say a prayer or sing a hymn. These rituals are a way of restoring something familiar and comforting to the death, namely saying goodbye according to Danish tradition when they are cold and pale and stiff. Boesen, dealing with how medical staff members interact with corpses – bodies that are pale and stiff and looking like “a strange copy of themselves” – argues that the corpse is both a subject - a human, and an object - a strange “foreign body”. She writes that “the double status of the corpse is organized and controlled so we can give death a place in life” and through the already mentioned “aesthetic guidelines” make death look peaceful, like a time of rest (Boesen in Hviid Jacobsen 2008: 123). The actions of the nurses are a strategic way of using the well-known aesthetics of a peaceful death to disguise the fact that the body of the organ donor coming from the operation table has not been treated as dead bodies normally are. By letting the family see the donor after the surgery, their death obtains some kind of visual and emotional closure, which for many families is hard to sense as long as the brain-dead body is still being given medicine at the NICU (Jensen 2011).

My fieldwork showed, surprisingly, that these aesthetic practices are also performed to please the nurses, many of whom find it very difficult

not to perform the well-known death rituals when sending a brain-dead patient to the operating table. Kirsten, a Danish intensive care nurse, explained that she was happy that most patients were brought back to their department after the operation, as she said, “after the vultures had taken what they want”. Although Kirsten was in favour of the idea of organ donation and had been part of several organ donation cases, it still interfered with how she preferred to handle a dead body as a professional nurse. She explained that she prioritized being able to perform the kind of death rituals Danish families usually appreciate, as outlined by Boesen as aesthetic (Jensen 2011).

As we saw in the case of Annika, seeing Carl after the organ retrieval process was extremely important, not only for the grieving process of the family, but also for the attitude towards organ donation. This last visual goodbye and the possibility of seeing the presence of the death peace is very important for the way organ donation is experienced and perceived. The Danish hospital staff therefore stage the performance of the peaceful death by arranging for Danish donor families to return to the intensive care unit to take a quiet moment of goodbye without being disturbed by the many medical procedures of organ management. By visually experiencing a well-known death contrary to the unfamiliarity of the brain death criterion, families and staff in close interaction achieve a proper closure to a hectic process (Ibid).

I argue that bringing the body back is a strategic way to apply certain aesthetic procedures normalizing the rather abnormal way of ending life as an organ donor. This way of aestheticizing the empty corpse was in order both to give the family the opportunity to see the body for a last goodbye and in order to give the nurses an opportunity to perform the last goodbye. The performance of the good death is essential for what is conceived as “good nursing”.

However, it is important to state that not all families accept the offer to return to the intensive care unit. Some prefer to say goodbye while the patient is still on the respirator and others are too exhausted to return. Others again told me they refused because they were terrified of how the dead patient would look. To complicate matters further, not all donor families are comforted by this last goodbye. A few of my family informants were surprised at how pale the donor was, and one family was upset that their daughter, according to the very frustrated intensive care nurses, was not stitched together as well as organ donors normally are. The post-surgery appearance of the body of the organ donor is an emotionally sensitive matter to both families and intensive care nurses. Both groups need some closure or a more peaceful alternative to the ambiguous process of brain death.

The medical practice of organ donation entails interventions in the human body before, during and after the surgical procedure of removing the organs. Somehow this seems to interfere with Danish traditions, rituals and habits when handling dead bodies. Over the past decades, Danes have removed the process of death from the private home to public institutions such as nursing homes and hospitals. Nowadays, it is mostly professionals handling the dead body and families rarely participate in the care for the dead body (Hviid Jacobsen 2008). However, looking into a particular way of dying, like organ donation, seems to reveal the existence of certain ideas about how a dead body must and especially must not be handled in Denmark. Danes do not perform the physical care of the dead themselves but they imagine how it should be done and they have ideals regarding how the body must appear visually and how and in which order things must be done.

When discussing organ donation with informants in this study, the topic of body mutilation quickly became central in the discussion. To some

people, organ donation seemed to interfere with a peaceful and dignified death due to the surgical removal of organs, “the disturbance of the death peace” and the visual changes of the body. This could be the reason not to donate for some families, and the “price” of donating for others.

It was emphasized by donor families how important it was that a dead family member looked “peaceful” or that “the scars were invisible” when saying goodbye to them. Families sometimes had nightmares about how the patient would be treated in the operating room and nurses and doctors had to reassure them that removal of the organs would take place with dignity and respect. In most cases this was also true and transplant surgeons and theatre nurses succeeded in disguising the big scars after the transplant procedure. But what if this particular moment of the last goodbye is not peaceful and reassuring? What happens if the body does not look as expected, what consequences and imaginings does this entail and how can disturbing (or reassuring) visions of the donor body reconfigure the experience of the entire organ donation process? The case of Sonny and Katie introduced with the quote in the beginning will illuminate this. It is one of the only cases in my fieldwork where seeing the donor afterwards was uncomfortable, but even if it is a rare instance, it is important to learn from.

Sonny was a man in his mid 30s. He lost his wife Katie, who was in her early 30s, a couple of years ago in a traffic accident. Sonny was now alone with their two small kids and when I visited him in his apartment in a large Danish city, I immediately felt his pain over being left alone. It was like entering the home of grief. Katie was everywhere, on pictures on the walls and the refrigerator, smiling and looking very beautiful, but at the same time, Katie’s absence was devastatingly evident. Sonny was exhausted in many ways. He was working full time, taking care of the two girls and trying to manage all the practical tasks in the house. For the

couple of hours we were talking he was constantly folding piles of clothes that had just been washed and were covering the entire kitchen dining table. Sonny was very frustrated as his mother-in-law had just told him that Katie had not been looking very good underneath the blanket after the removal of the organs. The mother had discovered that when she gave the nurses the clothes Katie should wear in the coffin. She had chosen Katie's favourite piece of clothing, a low-cut shirt in a colour that always used to look good on her, but that did not turn out to be the best choice. The surgeons had not taken the time to make her body look good after the operation and the body was full of big scars and large band aids trying to cover the deep incisions. When Sonny and his small kids were saying goodbye, her body was fortunately hidden by the blanket, probably by way of a thoughtful nurse. But after some months when a family member had told him how she had looked, Sonny found it very disrespectful and wrote an angry letter to the surgeons he had not yet sent when I spoke to him. Even if he was a doctor himself and always a strong believer in organ donation, he stated that because of this maltreatment of her body, he would not recommend organ donation to anybody, but would rather ask them to consider it thoroughly, because "it comes with a price" as he said. The price was that not only was the body not treated nicely after the surgery, but also that he was not allowed to touch Katie and hug her while she was lying on the respirator and he wanted to say what he called "a physical goodbye".

In this example we see how the processes of aesthetization unfortunately go wrong and disturb the idea about a peaceful death. This affects not only his private moments of saying goodbye to Katie, but also his personal attitudes towards the idea of organ donation. While seeing the body of Carl helps orchestrate a meaningful death for Annika, Sonny adds further disturbance and sorrow to the loss of Katie by knowing that she

did not look good. He loses trust in the doctors who performed the surgery and gets another view on organ donation. Processes of aesthetization play an essential part when constructing a peaceful goodbye to a dead family member. And it can also affect personal attitudes towards donation. The focus of the family is not on the small comfort knowing others are benefitting from the transplants, rather on the mutilated body of the deceased which of course is very disturbing. In order for donor families to orchestrate death in a meaningful way they must see and experience, or be assured, that there are taken good care of the body in all phases of the organ donation process.

This chapter has looked at the processes of aesthetization of the body of the organ donor. Having the body look nice is extremely important for families as well as for staff. It is closely connected to their professionalism and ethics. Dealing with the body of an organ donor is difficult, since it entails a shift in the perception of the body from patient to organs. Also it can be troublesome locating the moment where the patient moves from patient to potential donor. Processes of aesthetization are used strategically as ways to orchestrate death and to underline personal attitudes to the procedures of donation. The surgical staff performing the organ procurements and very aware of how the dead body is treated and how it is delivered back to the families. Families appreciate saying goodbye after the surgery but they can also be extra devastated if the body is not looking nice. However, the chapter has show that performing processes of aesthetization to orchestrate death in a nice and meaningful way is done out of concern for both families and hospital staff themselves.

Now, it is time to turn to the sociality of these exchangeable organs and explore the circumstances and the implications of circulating parts of the dead. The next chapter is devoted to these matters.

Chapter 6

The Sociality of Exchangeable Organs



The Sociality of Exchangeable Organs

So far, my analysis has dealt with the concept of ‘orchestrating death’ as the social performance of trust to make brain death and organ donation understandable in the NICU. Orchestration has furthermore been discussed as the transformative practices of hope when attempting to turn the death into something sense-making during and after the decision to donate. I have also looked upon the orchestration of death as an endeavor to ritually aesthetize the practices surrounding the body of the organ donor in all its phases. I have argued that these performances are strategically initiated in order to achieve an acceptable level of graciousness and ethics and make organ donation socially and culturally tolerable. In line with this overall argument, this chapter takes a broader view of the orchestration of death regarding organ donation and explores the social relations caused by the exchangeability of organs. The social relations are initiated, controlled and articulated in certain ways. I argue that the sociality is performed in order to orchestrate death. This is done not only by the donor families and hospital staff, but also by the national policies of the Danish Health Care System.

According to German sociologist George Simmel, sociality is where individuals engage in reciprocal actions with certain purposes in mind (Simmel 1998: 24, 25). I argue that the purpose of the sociality of organ donation is to orchestrate death so that organ donation is culturally acceptable. Anthropologist Emiko Ohnuki-Tierney has claimed that organ donation is a transaction that is completely devoid of sociality since there is no possibility of a counter gift and hence no relationship between giver and recipient (Ohnuki-Tierney 1994: 241). With this chapter I argue the opposite. I argue that sociality is an integral part of the Danish organ exchange. However, we must not only focus on the exchange between giver

and recipient to investigate the complexity of social relations, we must also look beyond.

This chapter shows that there are many kinds of reciprocal actions in relation to organ donation. Contrary to Ohnuki-Tierney, my focus is not only on the giver-recipient relationship, rather on the multitude of social relationships being acted out in the exchange of organs. Opposing Ohnuki-Tierney I argue the organ donation is embedded in complex social relationships and I see the sociality of the exchange being performed and expressed before, during and after the exchange of organs.

The social relationships are carefully orchestrated on many different levels as yet another attempt to convert this 'strange figure' of organ donation into something that makes sense, and is controllable and culturally acceptable. In this view, sociality is not only the result of an exchange but rather a part of the continuous process of exchanging human body parts that is constantly prepared, performed and reflected upon.

I begin by discussing the exchangeability of dead bodies and how certain parts are ascribed particular social meanings. After this, I show how the clinical context can affect the perception of what kind of exchange it is. Thereafter I discuss how organ donation can be a way of expressing and performing a social relation between person and country. Finally, I describe and analyze the strategies behind the practice of anonymizing relations between the persons involved in this exchange, namely the donors and donor families on the one hand, and the organ recipients on the other. This relation represents what I define as the dangerous sociality of organ donation. It is the overall argument of the chapter that the sociality of exchangeable organs is carefully performed to orchestrate death.

The Social Meaning of Exchangeable Parts

Organs are peculiar things. They are originally living flesh in a dead body; they are removed, transformed and exchanged; and they possess the ability to save the lives of others. In a way they are beyond categorization because they represent death and life at the same time. This quality puts them in a specific category of their own. They have powerful meanings and spiritual characteristics and concurrently their abilities go beyond mere representation and symbolism. They are actually used and consumed by the health care system wanting them to repair and heal sick patients. In this way, the dead not only have legacies and aftermaths but also potentials and alternative social futures. Organ donors contain a specific potential to save the lives of other patients through the donation of functioning organs from their brain-dead bodies. The possibility of exchangeable, circulating body parts challenges our fundamental understanding of death as definitive, and redefines existing ideas about the dead as absent individuals resting in peace.

Organs often carry ambiguous meanings. Lesley Sharp argues that a heart can be a desired object for the transplant surgeon, an awaited gift for the organ recipient and the essence of the soul of a loved one for the donor family (Sharp 1995). The Norwegian anthropologist Alnæs has described human organs as a “biomedical death treasure” (Alnæs 2005), focusing on the explicit desires to obtain these parts and the mystery surrounding them. These views are representative of a tendency in the organ donation literature. The meanings of the body parts are complex and mysterious.

But how can the exchangeability and the sociality of these body parts be understood? The ideas of anthropologist Joost Fontein are a good starting point. Fontein works on the politics of the dead in Zimbabwe and

focuses on the bones of dead victims of political violence. In his analysis, the bones act as both extensions of the dead and as unconscious objects or things. The idea that human objects contain agency comes from Alfred Gell's notion of deferred or abducted agency (Fontain 2010: 431; Gell 1998). From this view, bones are a continuation of the personhood of the deceased and they possess the intentionality of the human spirit to whom they belonged.

Fontain also presents another kind of understanding of the agency of objects that is inspired by the French anthropologist Bruno Latour. Latour's idea of agency is separated from the spiritual quality of the person behind the objects and concentrated on the traits of the object itself. It is "below the level of human agency" (Fontain 2010: 432; Latour 1999). They are non-conscious things that are not dependent on a human subject in order to carry agency. This is very much in line with the way human organs are perceived by the transplant surgeons and the organ recipients trying to focus on the functional and life-saving qualities of the organ and deliberately disguise or silence the fact that it has belonged to another person (Sharp 2001, Birk 2011). They see the organ as an object with specific biological and medical qualities and most importantly, they see it as an object containing future possibilities.

In that sense the organs, even though they come from a dead person, relate to the living and engage in future social relationships and medical destinies. Contrary to the bones in Zimbabwe, organs are not only remains and symbols of political identity; they are in fact an ongoing vital element in the politics and sociality of the health care system meaning the difference between life and death for the people who receive them. That they belonged to the dead, whether it is bones in Zimbabwe or organs in Denmark, interferes with the life of the living. Fontain express it like this:

In this way, bones in Zimbabwe have an ambivalent agency; both as extensions of the dead themselves, as restless and demanding spirit subjects/persons, but also as unconscious “objects”/”things” that resort to and provoke responses from the living. (Fontain 2010: 432)

But if the organs are perceived as carrying the personhood of the dead, are they not “inalienable objects”? (Weiner 1992). How can Danish donor families give these body parts away to strangers without feeling they are interfering with the personhood of the deceased? Ole, who lost his son Thomas, helps us answer this question.

I think I have the distinction that as soon as Thomas was declared brain-dead, the person Tobias was gone. The rest is a maintenance box, a spare parts box. And I have never had any problems or scruples about that. To repeat myself, it is with joy and pride I think about Thomas being so conscious of wanting to help others. All we did was live up to his expectations. That’s it. (Ole – father of Thomas).

The perspective of ambivalent agency is a good way of understanding the mysterious ways Danish donor families perceive and express their attitude towards the characteristics of the organs they agree to donate. This distinction Ole makes between his son and his son’s body influences the way Thomas is remembered and causes the father to feel joy and pride about the consciousness of Thomas and the opportunity Ole got to fulfill his wishes. It is not a question of an organ being *either* an extension of the dead *or* an unconscious object: they are both at the same time, and this in an interdependent relationship. In this case, Thomas’ organs are extensions of his personhood and objects in their own material and functional purpose. It is because organs as objects have the ability to represent future and hope and medical healing in strangers that they

become an extension of the dead person and his values and life philosophy. In this sense the materiality of the organs shape the legacy of the dead.

The potential commodification and reification of human body parts worldwide have been widely discussed in the social sciences for decades. This has been described as a process of objectification, devaluation or dehumanization and considered problematic by many anthropological authors dealing with both organ trade in third world countries, the concept of gift exchange in organ donation, and the problematic of brain death (Alnæs 2001; Appadurai 1999; Fox & Swazey 1992; Healy 2006; Joralemon 1995; Kopytoff 2004; Lock 2002; Scheper-Hughes 1996, 2004; Sharp 1995, 2000). One can argue that the premise for the transplantation business is that the individual lives of donors become reduced into body parts. However controversial this might be, the transformation of personal subjects into desired objects (body parts) should not necessarily be looked upon as devaluating human life or as some kind of identity depreciation. In the world of the bereaved, as we see in the case of Ole, and some of the other families in earlier chapters, the transformation of a person into an object for transplantation is simply a necessary premise in order for the deceased to regain the subject status and for families to orchestrate some purpose with death. Therefore the categories of subject and object are not antipoles; rather, paraphrasing Latour (1993), they come together as hybrids, which is a fruitful way of looking at the body parts of organ donors

It is this ambivalence or hybridism of precious body parts that enables them to become exchangeable. And it is this ambivalent agency of the body parts that enables families to orchestrate death in a meaningful way. Danish donor family members in my study such as Ole look at the human body as a collection of spare parts that could help out others in

need. This perspective helped them not only to create a logical explanation for their decision to donate but also to understand the processes of organ donation. The pragmatic and functionalist statements about the body of the organ donor are not always posted by neurosurgeons wanting consent from the family or by the transplant surgeons harvesting the body parts and transplanting them into the bodies of their sick patients (Sharp 1995; Joralemon 1995; Healy 2006). These utilitarian views can also be observed and heard among donor families trying to make sense of the death. As discussed in Chapter 4 on the transformative practices of hope, many families embrace the fact that these body parts can be put to good use in other bodies, and almost seem eager to make sure that they do not go to waste. That does not mean that they are not terribly devastated, but it might mean that utilitarian perspectives on the body are a significant part not only of the decision-making process but also the beginning of a preliminary healing process and something to hold onto in the time where their lives are falling apart.

In this sense it is not relevant to ask if the bodies of organ donors are reduced to parts or commemorated as persons. Actually it is because their body parts have the ability to save others that the personal qualities and characteristics are immortalized and memorialized. The social lives of the dead are continued by way of the exchangeability of their bodies. However, regarding the organs of the dead as obtaining the same value and meaning is wrong. Different organs have different agencies, meaning that some body parts, such as the heart and the eyes, are often more closely connected to the personhood than, for example, the liver or the kidney. Many donor families consider it as something very special to donate the heart compared to, for example, a liver or a kidney because of the strong symbolism that often is connected to the human heart. Donor families explained that the heart is connected to the feelings and the

affection for the deceased. Poul, the father of Morten, explained how he kept the donation of his son's heart a secret from his elderly mother because she would have had a hard time accepting and understanding it. The heart was too closely connected to the essence of her grandson to be given away. The son also donated kidneys but that was not considered problematic. The father explained that "the kidneys could also be donated when you were alive" thereby emphasizing the vital organs as something special. The heart is something special; Vivi who lost her mother Selma put it like this:

The doctors cannot know how many feelings and how much symbolism that is connected to my mother, her body and her organs. Her eyes have seen, her heart has felt something. Her heart has felt pain for me in my first relationship. If I was sad, she was ten times as sad. And then a doctor will explain that this is not in her heart? I know it is not physically in her heart. But symbolically, it is to me. You don't have to be professor in symbolism to know that. All the way through history, a heart has always been connected to love. (Vivi – daughter of Selma)

In wondrous ways, the symbolism of the heart continued after the transplants. Some donor families carried special thoughts about the recipient of the heart and imagined that some of the personality of the donor was transferred. A mother of a young boy imagined that the 55 year old heart recipient would be "lucky with the girls now" because her boy had been so handsome, and a husband of a woman in her 40s wondered if he would fall in love with the female heart recipient if he met her, since she now carried the heart he had fell in love with.

The difference in the meanings of the organs can also be connected to body aesthetics. It becomes evident in the decision-making process where families have to decide which organs they want to donate and which

they will not. Many families explained that they did not consent to donate eyes or skin. These body parts are externally located and to some families and hospital staff, donating these parts would be the same as maltreating the body. Especially the corneas are declined by families because many cannot stand the idea that somebody is cutting in the eyes of their loved one. This is also the case when looking at the decision-making process of American donor families. Lesley Sharp argues that the eyes “initiate the worst imaginations about body mutilation regarding organ donation” (Sharp 2006 173). I discussed the meaning of the eyes with Petra, a nurse in the northern part of Denmark. She attached the social meaning of the eyes to religious perceptions of life after death and put it like this:

I was at a meeting where we were told about corneas. And I always thought that when donating corneas, they only removed the cornea, but they remove both of the eyes. The eyelids fall down and the eyes are placed in a tiny box that you get along with you. And I just felt that I could not stand that. They shall not touch my eyes. They can take everything else. It is a matter of belief. When I hear about these near-death experiences where people see the light of God, I want my eyes in their place. They should not lie in a box at my feet. Then many say: “If you don’t have your heart, your liver and your kidneys you cannot see shit anyway”. But there is something about these lenses. It is a completely irrational feeling. But you have to be aware about this as a nurse. These matters are very emotional. But to me it is about seeing the light before losing my eyes. And that has to do with the moment when you are convinced that you meet God. (Petra – NICU nurse)

As this shows, the eyes had a special status among organs since they were somehow symbolically connected to the visual idea and aesthetic perception of how your body should look in the coffin, but also to the

future life after death. The eyes should not lie in a box, says Petra. But it does not matter that the kidney is in another body and not with her in the coffin. This represents concerns already discussed in the previous chapter. There is a certain aesthetization connected to the dead body. Apparently, the eyes play a significant role.

Petra's attitude does not represent the attitude of all nurses, but it shows that donor families are not the only ones with anxieties about particular organs. It also illuminates that the reluctance towards donating eyes is based on both the physical circumstances, such as the peculiarity of having the eyes placed in a tiny box in your coffin, and the religious or spiritual idea of seeing the light of God. Corneas are therefore connected not only to the dead person but also to the circumstances of the afterlife. By choosing to keep her corneas, Petra orchestrates her future death in a way so she will be able to see God.

While some families and staff decline donation of the eyes, others find the ability to help others regain sight particularly significant. During my fieldwork I followed the decision-making process of an older man, Aage, who lost his 65-year-old wife Mary due to a brain hemorrhage. Aage was devastated. "What about all our plans, we have so many plans for our retirement," he kept saying. Aage and his family consented to donation of all organs, but Mary was never classified as brain-dead. She failed the test because some of the brain stem reflexes were still there. The test was repeated after some hours but the doctors had to conclude that they had to end intensive treatment instead. Mary was not brain-dead but her life was not to be saved either. The donation process was then cancelled and Aage, who had already left the hospital with his family, was informed over the phone that Mary did not qualify. Mary was still able to donate the eyes (since they are procured after cardiac death), but the staff decided that they would not bother him with another phone call confirming the

donation of the eyes, clearly signaling that they considered the donation of eyes an invasion in her body. The next day, it turned out that other staff members had decided to try to move on about the donation of the eyes anyway. And when Aage was approached over the phone he was actually comforted by this. Aage had said, “Does this mean she will help others to see? We would very much like that,” and then he had talked a lot about Mary and her kind spirit and personality. The fact that Mary was able to help other people made this action in accordance with how he perceived the personal characteristics of his wife.

As this example illustrates, the reluctance towards donation of the eyes came from some of the staff, who did not want to bother Aage with another phone call. While this rarely happens in the donation dialogue in Denmark, sometimes personal staff reluctance, especially towards donation of specific organs, particularly the eyes, can interfere with the family’s own decision-making and thereby their personal orchestration of death.

Contextualizing Exchange

Marcel Mauss argues that gift exchange creates a social relationship between the giver and receiver and is a “total social phenomena” (1990: 3, 7, 15, 18). Sociologist Kieran Healy argues that the entire transplant process can be understood as a reciprocal gift relationship since it contains the moral obligation to give, the uniqueness or inalienability of what is given, and a relation between the exchange partners (Healy 2006:15,35). In organ donation, ‘the gift’ is inestimably precious because it is a body part of the donor carrying biological and genetic traits, thereby producing and defining the recipient as well (Alnæs 2001a:298,299; Sque & Payne 1994:47).

But human organs have also been described as “spare parts” in anthropological literature on organ donation and transplantation, (Fox & Swazey 1992) and a lot of scientific attention has been given to discussing the objectification and commoditization of the human body and its parts due to the fact that there are never enough life-saving organs and the increasing number of people dying on the waiting lists. American anthropologist Nancy Scheper Hughes in particular has dealt with the topic of organ trading and the degradation of humans into parts and discussed how body parts become “things” or “valuables” in high demand. She argues that the organ trade symbolizes the global power structures and the divide between rich Western people on the waiting list and poor people in the third world countries selling their kidney for a minor sum and risking their health in doing so (1996; 2004).

The need for functioning body parts entails a potential risk of looking at human bodies as valuable commodities. Such commodification of the body harms public attitudes towards organ donation because it indicates that a person only consists of valuable parts, and “dehumanizes individuals in the name of profit” (Sharp 2000:293). The commodification of humans represents a moral threat to society. Social scientists researching organ donation in the US have claimed that the gift language dominating the public and organizational rhetoric is a way to associate organ donation with humanism, generosity and altruism (Sharp 1995: 370), thereby overcoming public ambivalence (Healy 2006:2 5) and strategically connecting organ donation with popular, socially acceptable values in society (Jensen 2007) . The ‘gift’ is the dominant metaphor for organs in the rhetoric of organ donation (Alnæs 2001a; Siminoff & Chillag 1999:34; Lock 2002b:316). Most authors use the work of Marcel Mauss as a starting point due to their particular interest in the obligation to reciprocate. This is often considered impossible for an organ recipient

having received 'the gift of life'. If the gift is not reciprocated it causes social disorder and the recipient loses his dignity (1990: 50, 54). However, the gift rhetoric has also been identified by anthropologists in contexts such as childbirth (Layne 1999) adoption (Modell 1999), handicapped children (Landsman 1999,2004), surrogacy (Ragoné 1999), ova donation (Konrad 1998), and foster mothering (Wozniak 1999). In these areas, like in organ donation, there is a moral interest in defining the 'human exchange objects' outside the world of commodities (Kopytoff 2004, Taylor 2004).

One way to orchestrate the notion of organ donation in Denmark in a culturally acceptable way is by publicly associating it with the gift and contrasting it to commodification of the body. The gift language is often seen in public Danish campaigns as with the one titled "Life as Gift" from 2002. On one of the postcards, it said:

Give the biggest gift. One day somebody will feel fortunate to receive it. We have a lack of organ donors. That is mainly because many have not actively decided on the matter. What shall happen to my organs when I am dead? Deciding is really a gift to your family. Of course they really don't want to make that decision. Make it yourself. Talk to your family and sign up for the donor registry.

In January 2011 the Danish assistant professor in Bioethics Thomas Søbirk Petersen suggested that the Danes who signed the donor registry should receive a tax reduction (Søbirk Petersen 2011). This transforms the exchange of organs from a domain of altruism and love of your fellow man into a sphere of individual economic benefit. In a television discussion assistant professor and member of the Danish Ethical Council Mickey Gjerris argued that in a society that already is so commercialised, organ donation was better left out of monetary transactions and instead should

be seen as something that is given between people (Gjerris 2011). Here the theoretical distinction between gifts and commodities suddenly transforms into a public debate about how to solve the problems of organ shortage and what moral values and philosophies would be right to associate with organ donation.

In the book *Spare Parts* (1992), sociologists Renee C Fox and Judith Swazey discuss how the human body has undergone a process of degrading reduction by way of transplantation medicine and the demand for body parts. Fox and Swazey introduces what has since become a milestone in the social scientific understanding of organ donation: the concept “the tyranny of the gift” meaning that a human organ is such a valuable object that when it is given it is impossible to reciprocate and organ recipients are therefore locked in an unpayable debt. The “tyranny of the gift” in the field of organ donation has its special implications in a welfare system such as the Danish one, where solidarity among the citizens is considered high due to the tax system and the free health care (Jöhncke 2007). Denmark therefore seems to have the hidden obligation that in order to receive an organ, one must be willing to give one. Introducing the idea of financial reward to organ donors therefore might result in moral degradation but at the same time it is a concrete attempt to a practical solution to the tyranny of the gift.

But how do Danish donor families perceive the kind of exchange they engaged in when deciding to donate? My research showed that donor families relate very differently to attaching the idea of the gift to organ donation. But it is exactly this complexity in the donor family accounts that enables us to make a more nuanced investigation of the social relationships of organ donation and understand the delicate ways in which this exchange is orchestrated. I discovered that the perception of

exchanging organs was closely connected to the social circumstances under which the decision was made.

Eva was a woman in her late thirties who lost her mother Kristine due to a brain aneurism. When I visited her in her home north of Copenhagen, the interview was dominated by her doubts whether she did the right thing accepting her father's decision to donate her mother's organs. Eva was deeply dissatisfied with the way she was handled by the hospital staff. She felt that the doctors regarded her mother as too old to go through surgery to try to save her brain and was startled by the fact that her mother was then not too old to become an organ donor. Eva was nursing her four-month-old boy when she lost her mother, and she felt alone in the corridors of the hospital. Aside from this, she felt she was not able to cry out her grief and to say goodbye properly to her mother because her mother was put in a four-bed ward in the NICU. In my research, Eva stood out as one of the only family members who regretted agreeing to organ donation. She was haunted by the feeling that her mother could have been saved if the doctors had agreed to operate on her, and she did not feel assured that her mother was in fact dead when doctors declared her brain-dead. When asked her opinion regarding organ donation as a gift in the Danish campaigns, Eva turned my attention towards the significance of the actual circumstances of the donation and how that affects the definition of exchange you participate in.

When giving that gift, the whole process has to be acceptable. It is not a matter of giving a gift and moving on. It is not merely a thing. It is a big responsibility for the health care system. They must not only think of project management in relation to getting a helicopter to fly my mother's heart to the central hospital. They must also consider aspects that are not functional and have nothing to do with physical processes. It is not my mother giving it, it is us. No matter what, they should treat my

mother properly and they should treat us properly. They should have cared more for us. That might be a political issue about economy and human resources. I just think that if it really is such a huge political wish, they have to prioritize that area. Because if the truth is revealed, if people find out how it really is, then many will say no because they won't want to expose themselves and their family members to that.

(Eva – daughter of Kirstine)

Eva points to the lack of attention towards families and emphasizes that donated organs are not ordinary gifts. They are something special, deserving special attention that goes above and beyond logistics, medical organization and politics. In order for organ donation to be considered a gift by the people emotionally involved, the circumstances, empathy and attention towards the grieving must be prioritized. By not providing attention to the needs and emotions of the bereaved, the socially acceptable values usually attached to gift exchange are disconnected from the processes of organ donation. Eva did not feel she was recognized as a person with special needs when she lost her mother. And she did not feel that the system tried to save her mother before showing an interest in her organs, meaning that her mother was discriminated against based on her age. Eva did not trust the system and therefore was not comfortable with the donation.

Eva's experience suggests that disappointing handling by the health care system, meaning insufficient acknowledgement of the rights and needs of citizens, can push organ donation from the intentional placement in the sphere of gift exchange into a market exchange of the objectified body parts of people. Thereby, the positive values usually connected to helping sick people on the waiting lists are transformed into an emotional desire to protect yourself and your family member from further medical encounters. In such situations, where trust is not

performed in the context of exchange, it feels right to say no to the procedure. The only reason Eva's mother was an organ donor was because of her father's wish. In this sense, we learn the gift exchange is more than an ideology or rhetoric; there is also an implicit expectation that the Danish health care system will provide worthy conditions for the people involved in the exchange, and will recognize and fulfill their special needs. In other words, in order for the gift ideology to be reliable, certain standards must be met. If the Danish health care system fails to provide decent conditions that represent the positive values otherwise associated with popular notions of the gift, the association between organ donation and gift exchange will have a hollow sound and result in reluctance towards donating, thus undermining the system.

I also interviewed the Poulsen family who lost their wife and mother Birgitte after a brain hemorrhage. Birgitte was an intensive care nurse herself at a smaller hospital, and the family knew she was very much in favor of organ donation and had encouraged her colleagues to sign the donor registry. For the Poulsen family the decision was therefore easy and unanimous. The process of the Poulsen family was characterised by their positive attitudes towards the staff. The father Benny elaborated on this:

We were so impressed by their professionalism and efficiency. If I had had the energy, I would have written an article praising the hospital and underlining my pride in being Danish. There were nurses in the wards all the time and I was so stunned by those girls. They were extremely dedicated. (...) My sister-in-law felt it was too bad that patients did not have a private ward. But I disagreed. I was like "save as many as you can in the NICU. No matter if they are fucking shoulder to shoulder, as long as they get the treatment they need". (Benny – husband of Birgitte)

When I asked how they experienced giving organs, we discussed the fact that some hospitals in Denmark send out thank you cards to donor families. In stating their opinion about this, the teenage sons Morten and Rasmus made a strong point:

Morten: It is not a gift you would like to give. I would rather have not given it. The question is: Do you want a thank you for a gift you did not want to give? I mean, that you would have preferred not to give?

Rasmus: In this regard, I came to think of something: as next-of-kin, it is not our gesture. It is Brigitte's gesture. It is not us who have given something. I almost feel bad when people say "how nice you made that decision". Then I tell them: "No, I did not. I carried out my mother's wish. And that means a lot to me." And therefore I find it hard to know how I would have felt about a thank you card; because there are conflicting feelings in that.

By this, Morten points to the paradoxical nature of the gift. It is not one you would like to give. The character of the gift is not positive because it is based on a tragedy. But carrying out the gesture or the will of the deceased is considered positive. So if the dead is considered the giver and not the family, then the exchange of body parts become more accepted and more meaningful. This is also in line with the way Danish donor families are approached for donation. Many doctors embrace the strategy: "What would NN have had to say about this if s/he was among us now" as a rhetorical starting point in the conversation about organ donation, thus explicitly placing the agency with the dead person. Often families do not know, but by thinking about the characteristics of the deceased, as we saw in Chapter 4, it becomes easy for families to align the generosity of the person while s/he was alive with the idea that this generosity or "urge to help others" can continue in death.

Donating Organs in Denmark

There seem to be a logic saying death has to be useful. Why are you not allowed to die in peace? Why do you have to be used? There are some small ideologies in our society that are somehow controlling our way of thinking. (Sally - daughter of organ donor)

Various social scientists have argued that organ donation brings about exchange relationships between the donor and the recipient (Healy 2006, Fox & Swazey 1992, Alnæs 2001). But based on my research in Denmark, I suggest that organ donation is a way of performing your position in an already existent system of exchange relationships between a person and the welfare state of Denmark. In this system people pay taxes, behave in traffic and perform public duties while the welfare state, for its part, provides free health care, free education, unemployment benefits and generally acts as a safety net under the citizen. Goods, social services, care and benefits are given and returned back and forth and, I argue, so are our body parts. Relating organ donation to the duties and services of the Danish welfare state is a way of orchestrating death that the following section explores.

Anthropologist Orit Brawer Ben-David, who studied organ transplantation in an Israeli context, describes organ transplantation as an exchange on two levels: a concrete level, where the organ from a dead body is transferred to a living body; and an abstract and symbolic level, where an exchange takes place between death and life (Ben-David 2005). Looking at the Danish scene of organ donation, I will suggest a third level. I suggest that organ donation also has a level of national or existential solidarity. The exchange of organs is closely connected not only to life and

death but also to ideas about what is right and wrong, what is morally and ethical appropriate and what constitutes being a good citizen in Denmark.

One spring morning, I interviewed 68-year-old Jens in his penthouse apartment in a large Danish city. His home was characterized by expensive classical taste in furniture design and while sitting on his couch sipping coffee, Jens told me about losing his ex-wife Kate and donating her kidneys. Jens found the hospital staff extremely professional and he and Kate had been clear about organ donation for many years, so the decision itself had not been a hard one to make when they were approached by the neurosurgeon. Jens was rather surprised to learn that they could use something, as Kate was 69 and he had assumed she would be too old and too fragile to be a donor. While Jens differed from other donor families by not being so emotionally affected by sharing his story, he focused on the background for his family's decision and the more general social obligations of donating organs.

I don't see it as a gift, I see it as an attitude. As a natural thing living in the society we do. I mean, we do expect that somebody will come and pick us up if we fall, and take care of us. And if somebody is hurt and needs a kidney, then I find it reasonable if somebody that is checking out can deliver a useable kidney. I find it natural. And based on my own opinion, I have a hard time understanding the debate. (...) I consider it the same as helping an old lady who falls in the street. I would stop my car and help her to her feet. My fundamental attitude is that as a Danish citizen I can use the facilities in this country. And then it is natural for me that I also have an obligation, when I am not part of the party anymore, that they can use whatever parts and bits they like. And I think that should be a part of Danish citizenship or whatever. Perhaps you could have a cat flap and let people say no. But in my eyes, that is part of the Danish mentality. Like "never go to sea – let the others go". "We might

need organs but not mine or my children's". I think it is part of the Danish folk character; the negative part of it. It is like our attitude to nuclear power. We think it is fine to buy electricity from Germany or Sweden from nuclear power, but we don't think it should be located in our country. It goes way back to the Second World War. We were not sure if we should be on the German side or not. It was not until we saw how the wind blew, that we marked a point of view, or a few did, against the Germans. And that was lucky for the rest of us. That is our attitude to taking a stand: Is it worth it? If you draw on the system you have to contribute to the system. If I need a kidney or another spare part, I might be lucky that society provided me with the spare part I needed. And it goes both ways. So I have difficulties understanding opposing arguments. (Jens - husband of Kate)

Jens's narrative opens a window to investigate how organ donation is closely related to the attitudes, values and the history of the surrounding society and their obligations as citizens. Through his recollection of giving away parts of a family member it becomes clear that the personal and the national orchestration of death are mutually connected in ambiguous ways. While acknowledging he might have felt differently if the decision had been about one of his children, he clearly sees organ donation as an unquestionable part of being a part of Danish society. Mentioning his own expectations about being picked up one day himself, Jens's decision to donate is his way of contributing to the health care system he considers himself a part of.

By comparing the act of donation to the everyday necessity of helping an old lady across the street, Jens constructs organ donation as indisputably good. Jens draws an analogy between being an organ donor and what it means to be a good citizen in Danish society. Not donating and not helping the old lady is selfish and not in accordance with positive

aspects of being Danish. With his argument that you have to contribute to the system if you expect to draw upon the system, Jens places the act of organ donation within a larger system of exchange between citizen and country. It is an expression of solidarity which is an essential feature of being a part of the Danish welfare system (Jöhncke 2007). It is a moral obligation to help others, the expectation of a return in some way or another, and the feeling of being part of a larger exchange system with your country that structures his actions and decisions. And according to Jens and other donor families sharing his views, it is an integral part of living in Denmark and closely connected to notions of being a good Danish citizen. In talking about the experiences of organ donation the social relationship between citizen and country emerges and is expressed. By orchestrating organ donation in this specific way, this medical procedure is deliberately placed in this existing and familiar exchange system. Thereby it is easier to make sense of the decision to give away body parts and it becomes socially acceptable, if not a preferable way of ending life.

In anthropologist Anne Hambro Alnæs's study in Norway (2001a) she gives the example of a young married couple choosing to donate organs from the wife's sister as a way of paying back and saying thank you to the country for having helped them with artificial insemination during the conception of their first child. This adds new perspective to Fox and Swazey's "tyranny of the gift" concept discussed earlier. Donor family statements such as those cited above suggest that giving organs is not like giving a gift, it is a reciprocal action confirming a person's position in an already existing exchange relationship with their country and the welfare state.

Organ donation is deeply embedded in a human system of moral responsibility and ethics. As we see in Jens's account, this marvel of medical technology is placed on the mental landscape as something

natural and obvious. By comparing the public reluctance towards donation to examples of embarrassing selfish hesitation and a national disinclination to take a stand in Danish history, Jens draws an analogy between being an organ donor and representing what is good in Danish society.

To many Danish families such as Jens, giving organs should not result in special treatment or recognition. Danish families are modest about their actions and do not want a thank you or too much “fuss”. Therefore, if the Danish health care system ever considers providing recognition for Danish donor families, the structure, form and contents need to be adapted to reflect Danish socio-cultural values, habits and norms.

When making the decision, Danish families are often deeply affected by the implicit societal demand or moral expectation to help sick patients on the organ waiting lists. The moral imperative that organ donation is good is already evident in the attitudes and approaches by the neurosurgeons. Many regard organ donation as a good decision. But even if most doctors are in favour of organ donation, they make an effort not to manipulate. A neurosurgeon put it like this:

I do not want to manipulate to a yes. It is my patient. I have to do all I can for the patient. And I have done that. Therefore I would prefer telling the family that everything is fine and the patient will get better and return home in two weeks. Now I come to them and say our treatment did not succeed and can we have the organs. You don't want to pressure the family, even if I feel like it. Because I could say: Listen, instead of decaying in the ground isn't it better she helps seven other people? But you cannot do that. So you have to do it without pressure. And I prefer appearing as defense lawyer for the patient and for the family. They should not feel pressure but I would like to give them a lot of

information and answer questions so they can rest assured with their decision if they have doubts. (Bodil – neurosurgeon)

Keeping the balance between not manipulating with words and at the same time acknowledging and supporting positively if families said yes was carefully performed by doctors in the dialogue with families. In face to face interviews with me, doctors and nurses were more explicit about their personal attitudes, positive as well as negative. In these conversations, organ donation was sometimes also framed as an act of solidarity towards Denmark, sometimes even as an explicit obligation. The neurosurgeon Rolf put it like this:

We need North Korean conditions. Not all that democracy. People have an obligation, a civic duty to donate their organs if they cannot use them.
That's it! (Rolf - neurosurgeon)

The organ shortage in Denmark can result in strategic attempts to persuade families to donate by indicating the need and suffering of patients on organ waiting lists. Helping others in need touches upon elements of being a Danish citizen in a welfare society. While most Danish doctors are reluctant to mention the sufferings of potential recipients while families themselves are in the middle of a nightmare, my interviews with donor families revealed that sometimes doctors do evoke the moral and social responsibility when asking about organ donation.

I interviewed Henning, who lost his wife Sonja 13 years ago in a traffic accident and was left alone with their four children. Henning was one of the only Danish donor family members talking publicly about his loss and attaching it to religious reflections due to his job as a hospital chaplain.

When asking about the heart, the doctor had a line saying, “we are in desperate need of hearts” And I said, I know I know, but I cannot decide this immediately. She gave me her heart in 1979 when we got married. I cannot just give that away. But what makes you say yes when it is so hard? In a way it is evident in the room because of the doctor’s approach, that we are capable of helping another human being. Several of them even. And that gives you a responsibility in the situation as a family. We have a responsibility towards our fellow human beings who are suffering and need help. The media makes that clear to us with their good stories about the transformation of a serious disease to a life with hope. You find yourself in an ethical field touching upon the obligation as a citizen to do what you can for your fellow citizens and fellow human beings.

(Henning – husband of Sonja)

Henning here refers to the media often promoting good stories about the renewed lives of organ recipients. But he also draws upon what he calls “the responsibility towards our fellow human beings”. By defining organ donation as a gift in Danish public campaigns and in media stories about organ recipients having received the “gift of life” donor families carry the responsibility to give. In Marcel Mauss’ essay *The Gift* (1923), he underlines how gift exchange is an integral part of the pre-modern societies of Melanesia, North America and New Zealand. According to the theoretical framework of Mauss, certain obligations are connected to the gift: the obligations to give, to receive and to reciprocate. To discuss the dilemma of reciprocation when it is a gift that saved your life, we return to Fox and Swazey’s *Spare Parts* mentioned above. Fox and Swazey argue that in transplantation the psychological and moral burden is especially onerous because the gift is so extraordinary that it is inherently un-reciprocal: “It has no physical or symbolic equivalent” (1992:40). Hence, the giver and the receiver are “locked in a creditor-debtor vice that binds

them one to another in a mutually fettering way” (Ibid). This is what they call the “tyranny of the gift”. Their significant work is primarily on living donation between family members, but the idea that reciprocity is more or less impossible or problematic has also had tremendous impact on the field of donation from a deceased donor (Alnæs 2001a: Lock 2002a, Sharp 1995, 2006, 2007; Siminoff & Chillag 1999) and is to this day one of the accepted ‘truths’ of the theoretical field.

However, my studies in Denmark identify this “tyranny” in relation to the obligation to give. The central point is that when encouraging the public to donate organs, and asking families at the hospitals, national campaigns and medical personnel transform the gift ideology into strategic gift rhetoric as an attempt to construct good citizens willing to share their body parts with others in desperate need when they themselves have no use for them. When the doctor tells Henning that they are in desperate need of hearts, Henning feels the pressure to donate the heart even if it is tremendously emotional for him. The responsibility to donate is somehow evident in the room, as he explains. The gift rhetoric and the invisible atmosphere of the gift, therefore implicitly makes people facing the decision responsible for the well-being of unknown patients. In a Norwegian context, Alnæs has also shown how a doctor asking for consent refers to cultural values of gift exchange and implicit notions of reciprocity by asking a woman if her late husband “had expressed any wishes to donate”, and adding the question if “she would receive an organ herself should she need one (Alnæs 2001a: 110,111). Somehow the gift ideology in Denmark and Norway accentuates the obligations in the social relationships towards your country. It appeals to a certain moral way of behaving – underlining the justice in being willing to give if you are willing to receive. Therefore, orchestrating organ donation as a way of helping others and as part of being a good Danish citizen is not only a way for

donor families to make their decision meaningful, as we saw with Jens and the Poulsen family. It is also a strategic attempt by the Danish health care system and the Danish doctors to get more families to say yes to donation, which can be a pressure for some family members like Henning.

But sometimes the system controls itself, if it cannot fulfil the obligations of exchange and the rights of its citizens. In the last part of my writing process, a nurse from my fieldwork told me about what she called a very interesting and controversial case that caused intense debate at her NICU. A young Arabic boy of only six years had suffered from cardiac arrest and was almost brain dead when he was brought into the intensive care unit. His mother and siblings were devastated and did not speak any Danish and the hospital interpreter had a somewhat different dialect so understanding the medical information was complicated. The family was living at a refugee asylum and did not know what their status was as to whether they could stay in the country or not. In theory, this family should have been asked about organ donation, but the doctors argued a lot over this and finally decided not to ask for donation. They reasoned that the mother would not know what she would say yes or no to, and that it would be unfair to ask a person for organs whose family could risk being thrown out of the country any minute. I suggest that the reluctance to ask this mother indicates that the request for organ donation is based on an idea of expressing solidarity with fellow citizens. The woman is not a member of the Danish welfare society. Notions of what it entails to be a citizen in Denmark are the reason why this woman was not asked. The health care system apparently regards organ donation as a part of a larger exchange system where you should not contribute if you cannot potentially receive something back as a citizen of the society. Therefore, making sure that the question of organ donation is never asked is also a way to orchestrate death – and to signal a missing social relation to Denmark.

Disguising Biographies, Disguising Relations

Anthropologist Arjun Appadurai argues that things have social biographies (1986). In relation to organ donation you can argue that the biography or history of the organ is deleted when it is transplanted and focus is on its possibilities as serving a purpose in a sick body and giving the patient more months or years to live. But the perception of organs is ambiguous since it is only some of the biography that is deleted. For the hospital staff, the quality and function of the organs are constantly controlled and monitored before and during the removal from the organ donor, and the medical history of the organ donor is carefully considered. Their spiritual ownership is put in the background and their physical condition and health biography emphasized. This is evident in the mandatory investigation during the donor management of whether the donor smoked, suffered from alcohol abuse or had a high blood pressure.

Joost Fontain argues that the politics of the dead has to do with notions of materiality and the transference of substances. The central question is who has the power to control the substances of the dead, the processes of moving from fleshy bodies to dry bones. Fontain argues that it is the moment when the dead become dry bones that they are turned into ancestors with a story and a certain legacy deeply embedded in the political environment of Zimbabwe. Focusing on substances, it therefore takes a special kind of strategy to control the sociality of human organs, since they continue as flesh in others and never become “dry bones”. In this view, the dead organ donors never become ancestors as long as parts of them are never transformed into dry bones. Rather, their body parts go on and are consumed by others.

Often this continuation or extension of the dead lacks a final destination. Some donor families state that their loved one is “out there somewhere”.

This thought is comforting because they imagine that the body parts are doing good, meaning being the difference between life and death for the organ recipients.

According to sociologist Kieran Healy, donor families can form a meaningful sense of the continuing survival of the donor (Healy 2006: 34). They look at death as a continuation of life – it is just in another form, and it is not with them. But my study also revealed examples of the opposite. For some families the idea of ongoing life by way of organ donation is very disturbing.

Anja: Have you been told what organs.....

Eva: No, God damn it. And I would never want to meet anyone walking around with her. I would want to rip their heart out of them. I would not want to know that out here, a carpenter might walk around with her liver. I cannot relate to that. I would rather pretend I do not know. My mother is dead and I would like her to remain that way. Half of her should not be running around everywhere. I just want her to be dead and I have to understand that. I might sound selfish but that is the only way I can move on. If I sensed you had her lungs it would be very strange for me. Of course if it was somebody I knew and they were nice but no – I don't want to make something big out of that. When you ask about this, you objectify my mother's organs and you objectify her as if she was a store of spare parts. "Look at my silver car, the engine somebody else has got and isn't that nice". My mother is not a thing. My mother is not my mother without a liver and a heart and corneas, everything is a symbolic whole. I cannot relate to her being split in atoms. And I will not. I just want everything to be gone. There will always be people with a child needing a heart and that is the problem. You cannot talk to each other because you are in different positions. I am deeply emotionally attached to my loved one; they are deeply emotionally attached to their loved one. And of course they have a chance to rescue their child. But I have to

rescue – me. I have to move on. And I have to rescue my mother and feel that it is okay what I have done to her. My mother has always done everything for me and I want to pay back. Usually you can do that by bringing crême cakes to your 80-year-old mother at the nursing home and caring for her. But I cannot give anything back now and I feel bad about that. And if what I gave her was dying that way, I am not sure that is the best way for her. (Eva – daughter of Kirstine)

Eva cannot come to terms with parts of her mother being in other bodies. Not only is it disturbing to know that unknown strangers are carrying her organs, but it is also frustrating that her mother's death peace is somehow disturbed. While the continued social existence of the deceased by way of organ donation is sense-making to some families, Eva is frustrated that her mother is not allowed to rest in peace. Transforming her mother into spare parts by focusing on the continued biography of her organs is devastating to Eva. She is uncomfortable at the thought of social relationships that are somehow established with strangers because she feels it is interfering with her own relationship to her mother. Therefore Eva is the one disguising the ongoing biography of her mother's organs. That is the only way she can orchestrate death so it is comforting to her.

The biography of the organs is not the only thing that is disguised, so is the identity of not only organ donors but also donor families. We have seen how the gift ideology was used as a way to convince families to say yes to donation. After the donation of organs, one might say that the gift ideology is used again; but this time as a substantial argument for forgetting and disguising the identity of the organ donors and the families who lost them. There is a tremendous administrative and medical system in order to maintain borders between organ donors and recipients. The only people knowing who got organs from who are the Danish transplant coordinators. But it is not only in the relations between donor and

recipients that donors are anonymous; donors are not acknowledged in the public stories about organ donation. There is no public memorializing or recognition as we see in the US (Jensen 2007, 2009a, 2010; Sharp 2006). Forgetting the dead has been considered a cultural and social taboo for centuries. But strangely, the collective national and cultural forgetting of dead organ donors and their families in Denmark today is carefully organizationally maintained and considered culturally acceptable by way of the same strategy that encourages people to become donors. The gift is tremendous. It is so big that the obligation to reciprocate becomes too big for the recipients. Therefore the givers, both donors and families, must be socially disguised and forgotten and their actions must not be publicly acknowledged.

But this strategy has consequences for some donor families. Henning talked about this lack of reciprocal action towards him and his family making the decision:

You have invested everything and then the door is closed. I cannot relate to that. And then heart recipients say they owe thanks to the medical system! I cannot make sense of that. What would happen if they made an annual ceremony where the society showed appreciation? Is that a shady business that has to be disguised? (Henning – husband of Sonja).

The power of the gift ideology in Danish society today is therefore not only its ability to associate organ donation with the cultural ideals of a society and be a strategic tool to achieve political goals. It is also its paradoxical capacity to change according to time and perspective and provide socially acceptable arguments for national strategies of maintaining borders between donors and recipients and disguising potentially dangerous social relations. I interview Jonas, a man in his 40s who lost his wife Line when she suddenly suffered from a brain hemorrhage. Jonas was the only one of

my informants who tried to contact on of the recipients, but as we shall see, that did not turn out well.

A couple of months after I lost my wife, I saw a young man on TV. He said he got a new heart March 26th. That was the day Line died. He is very open about organ donation and getting a new heart and he like to proclaim that organ donation should be mandatory for all. Then we googled him and we gave him a call. And while we are speaking he turns all strange on me and does not want to talk to me. In the end he says, "Do you really think I want a heart from an old lady?" Well. Line was 43. But I am sure it is him. Afterwards I get a call from the hospital where we donated. They say I cannot contact him. Honestly I feel I get an earful. I am corrected as if I am ruining their system. I am told I am not allowed to know anything because it is anonymous. Then I started to regret I had called him. I did not want to bring a young man out of balance. I had just hoped he would have showed some interest in knowing the background of the life which saved his life. If he had wished, I would have been happy to invite him to my house and tell him about Line (Jonas – husband of Line).

Jonas was not interested in bothering the heart recipient in any way, but he explained that since he stepped forward on TV, he had not imagined that the young man would be bothered about talking with him. But the system steps in here and corrects Jonas. They make sure that he is not establishing a social relation to the heart recipient and they protect the recipient from further contact. This is an example how death is orchestrated in order to underline that donor families and organ recipients will not ever meet. This is considered dangerous and unpleasant and it must be avoided at any stake. Apparently the moral standards of organ donation and transplantation in Denmark are kept by preventing social contact between those groups. That is the policy of most countries practicing organ donation, although in Great Britain and the US there is

an option to communicate anonymously, and thereafter meet in person if both parties allow.

A few Danish families were eager not only to meet their own recipients but I interviewed Maria, who lost her husband Jimmy in his early thirties. Maria wanted to meet his recipients, but instead, she met another recipient:

Maria: By coincidence I meet Vera. Her mother received a new heart and she cried when she told me. It was a scary experience. We were shocked afterwards. She is one of my dear friends now. I have spoken to her mother. And I benefited a lot from knowing how grateful they are and how much they think about the family who said yes to giving Vera's mother an extra chance.

Anja: What did it mean to you to meet somebody who experienced it so closely?

Maria: I got the answers to some of my questions. I have thought a lot: "Do they ever think about me?" Do they ever consider that two small boys have to live without their father and how hard that is?" And they told me: "Yes, we think about the bereaved family almost daily and how grateful we are."

Anja: Have you received other kinds of thank you?

Maria: No unfortunately not. I appeared on the TV show *Good Evening Denmark* a month after, so it could not have been so difficult. I mean a young man of 33; it cannot have been hard to figure out for their families. Somebody must have seen that show.... Deep down I had hoped that after I appeared in that show and in those magazines, that suddenly some day maybe I would have received a huge bunch of flowers or a letter or something from somebody.

Anja: Would you like to know how they are doing?

Maria. Yes, but only if it went well, of course. If it did not go well I would not want to know it. I would like to hear from the little one-and-a-half-

year-old girl. I have kids myself and my God, how grateful they must be. I would like to know if that little girl has a good life today, and the little 11-year-old boy.

Anja: What you think about the 50-something man who received Jimmy's heart?

Maria: I thought: "Oh no – if only it had been a child." Because you think that a man who is 50, maybe he has smoked 80 cigarettes a day – and I know you are not supposed to think like that, because what if it was your own Dad, then you would ... but I do hope he is a good person.

Marias statements shows that she is not only interested in meeting recipients she is also interested in receiving some acknowledgement or recognition based on her difficult decision to donate Jimmy's organs. Simultaneously she is happy that his organs were able to help young children. Often the knowledge that young lives have been prolonged are very sense making to families. It allows them to construct the explanation that now their family member died too soon, it was good that others did not. Helping older or middle aged people were different. Not only is Maria afraid that the heart recipient will not take care of his body, she wishes he would be younger. And, to briefly return to the social meanings of the organs, she hopes he is a good person. Meaning that not only does the heart carry the personality of the donor, it is also important for families that a good heart does not end up in a bad person. Even if Maria is eager to learn about recipients, she also states the reason why social contact is silenced and information is limited. What if the transplantations did not go well? Then she would prefer not to know. Therefore, while knowing about the success of the transplantations and the age of the recipients can be a way to orchestrate death as something meaningful, bad information can cause discomfort and upset donor families. Disguising biographies and relations can therefore be interpreted as the health care system's way of

protecting both donor families and organ recipients. They might benefit from knowing more about each other, but it might also cause further devastation. That is why I argue that it can be classified as dangerous sociality.

But if we for a moment disregard the organ recipients, I argue that the donor families who search for them are perhaps more than anything searching for understanding and acknowledgement of their decision and their special situation. As we shall explore further in the next chapter, donor families in Denmark are somehow outside familiar categories, and that is frustrating to some. In other realms of medical technology new groups of patients and relatives have emerged getting their problems acknowledged and their special needs met. Paul Rabinow has termed such social relationships as 'biosociality'. These emerging groups are based on the sharing of experiences, the urge to lobby and educate about the particular medical field, and the possession of certain medical specialists, narratives and traditions (Rabinow 1997:102).

Nikolas Rose argues that a new kind of citizenship has emerged due to the technological advances of biomedicine; namely "biological citizenship. Contrary to earlier notions of citizenship as fundamentally national, Rose uses biological citizenship to embrace the citizenship projects linking conceptions of citizens to belief about biological existence of human beings (Rose 2007: 132). But apparently, that has not yet happened for Danish donor families. To return to the question of Henning: Are donor families "a shady business that needs to be disguised?"

Biological citizenship not only entails "making up citizens" imposed from above, Rose argues that it also affects the way people understand themselves and their relation to others (Ibid: 132). Drawing from Adriana Petryna's study of post-Chernobyl Ukraine (2002), Rose concludes that biological citizenship embody a demand for particular protections and

access to special resources (Rose 2007: 133) as is the case for populations suffering from biological damages that must be acknowledged and compensated. Rose also describes the sociality of biological citizenship as for example emerging in the new biosocial communities which he defines as the active form of biomedical citizenship. People facing complex decisions regarding their health and their bodies due to medical technological advancements can be seen as moral pioneers (Rapp 1987) or as Rose suggests “ethical pioneers” because they had to create new ways of relating to their bodies, to their choices and to their social networks and to society (Rose 2007: 146).

Taking the insights of biological citizenship to the context of organ donation, one might argue that donor families in Denmark are “isolated pioneers”. They are indeed facing difficult choices interfering with their notions of the body, their identity and their familiar and social relations. In the politics of organ donation it is not only the biographies of the dead donors that is disguised, it is also the existence of the donor families. Making the decision to donate a family member’s organs does apparently not provide access to a community or a network of fellow sufferers. Such a community does not exist. There is however a nation state with citizens demanding protection and access to resources when they become sick. In the case of organ donation, the dead donors are the resources to repair sick bodies. Organ recipients are organized in patient organizations, web sites and social networks and these are the ones benefitting from access to these “special resources”. Therefore how notions of biological citizenship come into play regarding the medical technology of organ donation is very different for organ recipients and donor families. This difference affects the way the sociality of organ donation is orchestrated.

This chapter has shown the sociality of exchangeable organs on many levels. It has investigated the different social meanings of body parts and concluded that organs carry ambivalent agency. And different organs can carry different agency and meanings. Organs are functional parts and they are extensions of the dead (Fontein 2010). It is this ambiguity that allows donor families to orchestrate death in meaningful ways by way of organ donation. The chapter also showed how the context of the exchange affects donor family perceptions of organ donation. It is hard to orchestrate death as a precious “gift of life” if families do not engage in a good and trustworthy social relationship with the hospital and the health care system due to disappointing treatment. The sociality between families and the welfare state of Denmark was also discussed. My research revealed that some families use the option of donating organs as a way to express their solidarity towards their country and perform the duties as good citizens. That was a way for families to orchestrate death in close relation to values about what it entailed being Danish. Finally the chapter discusses the strategies of disguising and anonymizing social relationships between donor families and organ recipients. In this it is not only the biographies of donors that are deleted it is also the acknowledgement of donor families as a group with special needs.

This takes us to the last chapter dealing with the stories of organ donation. Here it is discussed how families, health care staff and policy makers use stories of organ donation to orchestrate death in certain ways. This is done by creating meaningful memories, but also by carefully controlling the public stories and managing the recognition of the ambiguous heroes of organ donation, the Danish donor families.

Chapter 7: The Stories of Organ Donation



The Stories of Organ Donation

In this chapter I investigate a number of stories about organ donations and how they are performed and staged in different ways in a Danish context. I argue that stories are deliberately used or silenced by donor families, hospital staff and policy makers in order to achieve certain goals and frame organ donation in a certain way. As the chapter shows, the construction and performance of organ donation stories constitutes an essential part of the orchestration of death. Talking about organ donation in a certain way is necessary to transform the strange figure of organ donation into something familiar and understandable.

In the influential book, *The Politics of Storytelling*, anthropologist Michael Jackson discusses how storytelling can be a comforting way of coping with tragedy and making sense of it. He writes that “in telling a story with others, one reclaims some sense of agency, recovers some sense of purpose and comes to feel that the events that overwhelmed one from without may be brought within one’s grasp” (Jackson 2002: 36).

But stories also contain a potential danger, such as the many myths and taboos surrounding organ donation coming from media, television, people’s imagination, or unfortunate events at the hospital. Focusing on stories enables insights into the way organ donation is promoted and controlled and the way organ donors and their families are spoken of, remembered and acknowledged in Denmark. It is done in special ways, to construct and reconstruct the system of organ donation in Denmark. Therefore this chapter also looks into what Edward Bruner calls “dominant narratives”, meaning “major interpretive devices to organize and communicate experience” (Bruner 1986:18). In her work on Alcoholics Anonymous (AA), anthropologist Vibeke Steffen has worked with this theory and identified a process of “shaping experience” and making it fit

into a “superior narrative context” which she sees as a “process of socialization” (Steffen 1997:106). In Denmark there are no efforts to structure and control the stories of donor families, as is the case in the US. But dominant narratives clearly exist among health care staff and organ donation professionals and play an important role in their orchestration of death and cultural acceptance of organ donation.

This constitutes an important point in the overall framework of the orchestration of death. Stories are not only individual attempts to talk about organ donation experiences; they can also be the country’s way of socially ascribing values and attitudes to this special way of ending life. The way organ donation is articulated and staged forms an essential element of the social performance of the medical practice.

This chapter also goes beyond the context of Denmark. Based on my earlier research in the US it takes a comparative approach in discussing the role and function of organ donation stories in the orchestration of death. I do not set out to evaluate best practices, but comparing Denmark with a country like the US helps to highlight which elements are particular Danish traits in the organ donation stories.

As this chapter shows, the orchestration of organ donation by way of stories happens on several levels, beginning with the donor family story that attempts to construct meaningful memories. Thereafter the chapter moves on to explore how the stories are controlled in order to construct specific truths about donation. Finally the chapter discusses the acknowledgement or recognition of donor families and how it differs between the US and Denmark. Framing this as “ambiguous heroism” suggests that these stories are also either staged or silenced in an organizational or national attempt to orchestrate death and organ donation in advantageous ways.

Constructing Meaningful Memories

One hot day in August, I spend several hours sitting at the kitchen table of Betty, a woman in her 40s who lost her brother John a couple of years ago to a brain haemorrhage. Betty explained in detail about his rough life. He was divorced from his wife ten years before his death, which pushed his already serious drinking habit into severe abuse, isolating him physically and socially from his family and friends. After several attempts to treat his alcohol abuse, he ended up in a home where his drinking habits continued. Betty gave several examples of her efforts to straighten out her brother over the years and it was clear she directed blame at herself. She emphasized one night when he had run away from the hospital and Betty and her husband went searching for him in the dark. They eventually found him running around in a parking lot, waiting for his “boss to pick him up”. Persuading John to get into the car and come back to the hospital with them was devastating to Betty. “Why was I not able to help my brother?” she said. “I felt like a failure.” Some months later, John was rushed to hospital with severe intracranial bleeding. While at first there seemed to be hope that he would wake up, the situation worsened. Betty watched her brother lying in the bed on the ventilator. He looked like he was sleeping, but things were very serious. After a couple of days, she was sitting in the hallway when two doctors came towards her with serious faces wanting a conversation with her and her dad. They were told that John was brain-dead and asked if they would consider donating his organs. “We said yes right away,” Betty told me. “John was that kind of person, and it made perfect sense if somebody could benefit from this.” Betty revealed to me that despite the tragic situation, she thought the time following the decision to donate was exciting. Doctors were running in and out for tests and blood samples. What organs could be used, who was

going to get them, and how would everything turn out? Blushing from embarrassment, she even told me she secretly planned to sneak in to hallways of the hospital in Copenhagen to see the recipients of her brother's kidneys. "I can only imagine the newspaper headlines," Betty laughingly said. "Mysterious woman caught sneaking around in the kidney department at the Copenhagen University Hospital." Somehow surprised I laughed along with her, wondering why she was not referring to the days and nights at the hospital as some kind of traumatic surrealistic nightmare like most of my other informants. But by the end of the interview, it became clear to me that Betty had finally achieved what she wanted by way of her brother's death. She was not able to help John, but by donating his organs, she was able to help others and to find meaningful closure to his life. Other lives would be saved, and associating this with John's personality was so much better than remembering the severe alcohol abuse, the loneliness and the many failures that characterized his last decade. "It is a good aftermath," she said. When discussing the fact that families in other parts of Denmark receive a thank you letter, Betty said: "I would have liked such a letter. Such a letter I could have put in the folder I have with all his papers with pride. I would have placed it in the front as a way to wrap up the life of my younger brother."

As this example shows, some Danish donor families such as Betty use the story of donation of body parts to construct a meaningful closure and reframe the life of the deceased. By way of two donated kidneys Betty enables herself to give some kind of purpose to death by focusing on the positive transplant outcome. But the organ donation story also helps her transform the life of her brother. Looking at the many failed attempts in Betty's life to help her alcoholic brother, it is no wonder that organ donation in the midst of the sorrow of losing John was welcomed as an opportunity to make a difference. Betty had an urge to see some change

after all her struggles and that might be why she was overwhelmed by curiosity about the transplant outcome. She wanted to see that her efforts to help had a positive outcome, if not for her own brother, then at least for the two people receiving his kidneys.

Telling a story about a loss can have a therapeutic effect, and help donor families like Betty gain a sense of structure or control, even if the death will never become understandable or acceptable. Returning to the argument of Jackson, “the events that overwhelmed” Betty are not only her brother’s death, but also his severe alcohol abuse causing decades of devastation. While the story of organ donation cannot change his abuse, it can somehow change his life history. And it can change her until-now failed attempts to help and do well. In the case of Betty, the organ donation story gives her agency not only in the death of her brother, but somehow also over his life. Suddenly because of organ donation, she is able to stage the life of her brother differently and ascribe cultural values such as generosity and altruism to his existence. In this example the story of organ donation is not only about orchestrating death. The life is also retrospectively orchestrated. When suggesting that a thank you letter for organ donation could be placed in front of the folder as an introduction to the life of her brother, Betty expresses the wish to frame his life with the usefulness of his death. This adds an enhanced time frame to the orchestration of death. Storytelling bears the potential not only to reinterpret death, but to somehow stage the life that went beyond death and make it in accordance with socially prestigious values often ascribed to organ donation. By using stories about organ donation to orchestrate death in a certain way and with a certain purpose, it is also possible to transform a life.

But not all donor family stories are like Betty’s. In the case of organ donation, it is not only the death that is hard to capture with stories, it is

rather the circumstances surrounding death that are lacking familiar classification and framework. As described earlier, donor families say goodbye to deceased family members that look alive; they picture the removal of the organs in the operating theatre; they experience a fundamental change in the well-known procedures and traditions surrounding death, and they might wonder about whether they made the right decision or not. Remembering my initial argument that organ donation can be understood as an unfamiliar and rather precarious figure, this figure is also hard to speak about, since few people possess an appropriate vocabulary to transform its unfamiliarity into something comforting and understandable.

Some families pointed to the difficulties in speaking about organ donation, especially to those needing extra-considerate explanations such as young children. In the last chapter we met Henning, the hospital chaplain who lost his wife Sonja in an accident. Henning's story was dominated by many existential questions. Henning found the process of organ donation extremely hard to articulate. He was a very eloquent man and used his abilities to formulate complex messages and communicate to various audiences in his professional life, but attempts to speak about organ donation caused many frustrations. Henning somehow needed a frame of interpretation for what had actually happened at the hospital.

I have no language for what has happened. I don't know how to explain to my kids what has happened. What can I answer when they ask me where Mom is? And Jeppe, my six-year-old, asked me, "If we can find out where the heart is, will Mom be there?" That was his question. And I answered "No, that is not how it is. Mom is dead. And her heart is working in another person." And I started making up something, because we could not know, and that is our premise as donor families. We have to make it up, because we cannot meet the people who have received, so to speak,

our organs. But there is no language. How can my kids and I cope with this death? Where is Mom? And after the funeral my wife's sister asked, "Who did we bury, we buried an empty case." And I said, "Oh, my God." But it is true. And I could not find the words for it. And I felt so God damn alone. That's why I was so happy about my contact nurse, she was my lifeline. Perhaps I should have driven to the hospital and asked "Isn't there some kind of club I can join? Can't you do something? You owe me an explanation. Somebody has to do something.

(Henning – husband of Sonja

Henning's narrative expresses the frustration over the lack of language to explain to his children about what happened. But it also points to the lack of closure often connected to organ donation, making these stories hard to finish in a proper way. The final destiny of the body parts remains unknown due to the organizationally structured attempt to protect the anonymity between donors and recipients. Henning calls this the "premise as donor families", and it clarifies another characteristic of the figure of organ donation: It is hard to construct a story with a beginning, a body and an end, since the premise of not knowing the outcome is unavoidable due to the greater attention to the needs of the organ recipients. If knowing the final destination of the body is necessary to finish the story, the organ donor death never reaches closure, and the organ donor story will remain open-ended. Returning to the point of Michael Jackson, Henning does not regain agency or purpose by telling the story. His story manifests existing frustrations over the practical consequences of organ donation; donor families cannot know where the organs went. Henning told me that he had been rather active in telling his story to journalism students and in church societies around the country when organ donation was a topic of debate. But even if he had told it many times, it was dominated by this lack of words, lack of closure and lack of knowledge about how to frame and

perceive what he and his family went through in the medical process of organ donation.

Comparing his story to Betty's, Betty also lacks the language and the knowledge of the final destination of the organs but this is not frustrating to her. Rather it is an opportunity for her to frame the life of her brother differently, because of those two unknown people who might be having a better life because of the transplant. Betty had an explicit need to transform the sad life of her brother and her own sense of failure to save him. As our interview revealed, organ donation was a good opportunity to do so. In the case of Henning, where Sonja, a wife and mother of four children dies and becomes an organ donor, there is not the same need to transform her identity. Like Betty, Henning found some purpose in helping others and that is why he consented to donation, but the need to know where she went, and especially for the children, where the mother's heart went, overshadows the comfort of saving other lives. Depending on the social circumstances and the family perception of organ donation, the donor family story is orchestrated very differently. Betty constructs a meaningful memory, whereas Henning's attempt to orchestrate death through telling his story underlines and reconstructs existing frustrations.

The Social Staging of Experiences

At the end of Henning's story above, he expresses his need for an explanation, and also for a social forum of fellow sufferers. Henning asks if there is some kind of club he can join. This indicates a need to share stories with others and thereby find a way to get closer to an understanding of organ donation. Henning was therefore one of the families wanting some kind of follow-up care or organizational initiatives to

inform and support families in a social group with fellow sufferers, “some kind of club”.

As Jackson argues, “storytelling is a coping strategy that involves making words stand for the world and then, by manipulating them, changing one’s *experience* of the world” (Jackson 2002: 18). Jackson continues with saying that by “constructing, relating and sharing stories, people contrive to restore viability to their relationship with others”. (Ibid) Jackson makes a strong point to “emphasize storytelling over stories”. What is important is not so much “the product of narrative activity”, but rather storytelling as a social process (Ibid). The work of anthropologist Edward Bruner suggests that experiences are affected by how they are articulated. According to him, experience structures expressions but expressions also structure experience. For Bruner, it is in the performance of an expression that culture is re-experienced, re-told and re-constructed and that meaning is created (Bruner 1986: 6,11). Therefore, by telling stories, by performing the expression, experience can be reinterpreted and given new meaning.

Let us turn the American context for organ donation. In the New York Organ Donor Network (NYODN), all donor families were automatically enrolled in the Aftercare Department. Aftercare for donor families was a two-year program consisting of bereavement cards, letters of thanks from the President of the NYODN, phone calls to the families, information about the organs, invitation to social events and acknowledgement ceremonies. The Aftercare program also offered donor families the option to communicate anonymously with the organ recipients and to meet other donor families. Aftercare staff was available by phone if families wanted to call with any questions or concerns. My research showed that these conversations could concern doubts about whether “brain death” really meant dead, the wish to know what went on in the operating theatre when

removing the organs, or finding out how the organ recipients were doing. Sometimes the conversations expressed a mere need to talk to somebody who was on the phone to listen and show understanding (Jensen 2007, 2010).

According to the manager of the organization, one of the major ways to support the family was to “provide them with terminology” through which to speak about their experiences. (Jensen 2010). This terminology included statements such as “organs are gifts”, that organs were “recovered” not “harvested”, and that their loved one is “spiritually living on”, and will “never be forgotten”. The specific use of words acted to provide families with value-laden superlatives to classify their actions. As a fundamental part of the program, the staff continually emphasized the impact of the donation and honorably acknowledged the families’ decision, knowing that this was comforting and reassuring. The intention was twofold. The process of creating good stories would counsel and comfort traumatized grieving families. But the good stories about organ donation could also persuade new recruits to sign the donor registry and limit experiences that would act as negative PR.

Among the NYODN staff members, I often heard two foundational sentences expressing the organizational philosophy about donor family aftercare. The first was: “Donor families are our best advocates” and the second was: “If donor families have a good experience with organ donation, they will tell 50 people; if they have a bad one they will tell 500”. Hence, the organization had a great strategic interest in making sure that the positive family stories were promoted and the negative ones were transformed into something else or silenced. To meet this goal, the organization provided donor families with a certain specialized terminology in order to help them speak about the donation and articulate the painful

emotions of losing a loved one and making the decision to give the organs to others.

The organizational influence on the creation of donor family stories became evident to me during my participation in a volunteer training program at the NYODN where donor families and recipients were taught by two members of an organization called 'Transplant Speakers' on how to construct and tell their personal story to the general public. The stories should contain an introduction stating who you were and where you came from, for example: "I am a donor mom from NYODN". After that, families should have "the body of the story" with the personal experience of loss and donation and perhaps some tactful humor. Thereafter, families should deal with "myths and misconceptions", for example by invalidating the myth that "doctors let people die to take their organs" or "donation disfigures the body and delays the funeral". Families were also told to use up-to-date statistics on the waiting list numbers. Finally the story should have a "close" where the storyteller should personalize it to the audience, call people to action by encouraging them to sign the registry, and finally say thank you and invite people to ask questions. This event showed how families were taught to transform their individual experiences into shared organizational narratives with different content but following a shared structure. Almost exactly the same idea unfolds in anthropologist Vibeke Steffen's significant study of Alcoholics Anonymous (1997). The stories have several functions: Creating a community among fellow sufferers, making stories recognizable to an audience and reshaping and confirming the legitimacy and social existence of the organization. This is clearly a way of making sure the dominant narratives of the organization are expressed by families and thereby a special community is created in this process of socialization (Bruner 1986; Steffen 2007).

In Denmark, the option of Aftercare and vocabularies which might be seen as either 'comforting' or 'manipulative' is not present. Rather, it is left to the hospital staff to accompany families in their attempts to make the rather peculiar death of an organ donor make sense by visually emphasizing the occurrence of a more familiar death after the organ removal. In the US, the follow-up efforts of Aftercare rhetorically translate the frustrations of death and organ donation into something heroic, honorable and sense-making. Although there are regional, cultural and organizational differences between the US and Denmark, the purpose is the same: to create an alternative version of death that is more reassuring, comforting and peaceful than the emotionally disturbing elements that can dominate the donor family experience of brain death and organ donation.

Henning's story of organ donation is about lacking words to describe what happened; he cannot manipulate them into a story that can change or reframe his experiences with organ donation and his frustration over not knowing where his wife actually is. Following Jackson's and Bruner's argument, the social process of sharing and relating stories is an important aspect of storytelling, and meaning can be created in performing the expression. But Henning is not able to achieve this either, since there literally is no socially negotiated vocabulary and no club he can join. The information arrangements for donor families he desires do not take place either. There is no stage and no audience where his story can be shared or performed, and thereby re-interpreted into something socially acceptable. That is why, for Henning, the story of organ donation will never become meaningful. The social context for orchestrating death in a certain way by way of storytelling is missing.

Therefore, the donor family story is dependent on context. The stories of donor families are played out differently depending on the network and support the donor family receives in the time afterwards. As

we saw in the last chapter donor families can find comfort in the continuing survival of the donor (Healy 2006: 34). Many American families regarded the exchange of organs as a means to ensure the ongoing survival of their dead loved one and as a way to maintain a social relationship to them. Knowing that organs were still out there in other people helped them in their grief and gave a sense that the donors were not entirely dead. These perceptions were very evident in the stories of American families. Jack, an American donor father stated the following:

I know he is not dead. He is alive in other people that are out there today. He is just not with me, but he is out there in other people... And that for some reason has given me great solace, knowing that other people are benefiting from my son's death instead of just putting his body in the grave and saying goodbye. And that is the end of it. That is not the case.
(Jack - American donor father)

This focus on organs still living on appeared helpful to some American families. The idea of a pounding heart functioning well in another body was perceived as solid proof to the families that death had occurred, but that the death was not to be understood as final. To grieving donor families, the organ recipients are the concrete evidence that the life of the donor goes on because of the use of their body parts. This corporeality seemed to be the most meaningful way for the bereaved to keep the idea of the donor still being alive (2007; 2009a, 2011).

Such ideas are generated by organizational understandings of organ donation that makes these new patterns of interpretation possible (Jensen 2007: 43). Using the theory of Steffen, you can say that the American organizations play an active role in shaping the experiences of families (Steffen 2007). But the ideas are also generated by the opportunities given to organ donor families to do public speaking, which

fits very well with the PR strategies of the organization. The American organizations do not only shape the structures and values for speaking about the organ donors; they also provide a stage where the memories and the continued lives of the deceased are celebrated and acted out without questions. In this social performance, donors are still present because of the articulation of organ donation and the value-laden biographies. These stories and the strategic purpose they fulfil might not make sense outside the organizational context. But the organizational context acts as a certain kind of social forum in which the dead live on through the performance of stories about the revitalization of their spirit through the donation of organs (Jensen 2010). An American donor mother told me that she remembered somebody saying, “a person is only dead when you stop talking about them”. Therefore she was very active in talking about her dead daughter. She actively used the many forums of the organization to tell and retell her story in order to reinterpret her daughter’s death (Jensen 2011).

Anthropologist Edward Schieffelin discusses something similar in his classic work *Performance and the Cultural Construction of Reality* (1985) where he examines the performance of non-discursive spirit séances among the Kaluli people of Papua New Guinea. According to him, performance does not construct a symbolic reality, rather it socially constructs a situation where participants experience symbolic meanings as part of the process of what they are already doing (Shieffelin 1985). Therefore, the performance of organ donation is deeply dependent on the options for constructing a setting in which the performance make sense.

In Denmark, there is no public acknowledgement of organ donors and their families. It is kept within the family and is rarely a topic for public discussion. Danish families connected organ donation to the rather undefined idea of helping others. Sharing experiences is not an option for

donor families. Therefore the death and the organ donation cannot be socially translated into familiar cultural narratives (Jensen 2011). That does not mean, however, that Danes do not place organ donation in a cultural or national frame in order to construct a meaningful aftermath. Denmark is a welfare state with free health care. Many Danes have a very strong social relationship with their country and see the national infrastructure as something that will help and support them if needed. This luxury entails certain obligations, and for many Danes, organ donation is one of them. The story of Jens from the previous chapter illuminates this. Expressing the donation of organs as an expected act of solidarity towards fellow citizens constitutes a meaningful aftermath for Jens. Contrary to the American donor families needing a stage to perform their meaningful recollections of organ donation, the actual and largely private action of donating organs at the hospital constitutes the stage upon which Jens is able to perform his social relationship and articulate his solidarity towards his country.

Therefore for some Danish families, an organizationally structured reframing and reinterpretation of experiences is not necessary, as the social meaning is self-evident. Simply by framing your own actions when donating as an act which is a fundamental part of 'being Danish', the donation of organs in itself can shape a meaningful aftermath and give families peace of mind. The NICUs in Danish hospitals can be understood as the stage where donor families express their loyalty and belonging to Denmark by consenting to organ donation. Following Schieffelin, a reality is created where organ donation is the 'right thing to do'. For some families, the hospital is where meaningful stories of organ donation are staged (Jensen 2011).

Controlling Donation Truths

Stories of organ donation are not only personal attempts to grasp the overwhelming experiences of giving or receiving organs. They are also a very influential tool in the ongoing promotion of organ donation. In this regard, it is important to tell certain stories, while others should preferably be kept silent.

Donor family stories were rarely told publicly by donor families themselves, but they were surrounded by enormous curiosity. Hospital staff was extremely interested in the donor family experiences and their recollections of the organ donation process at the hospital. Their sincere interest and dedication to my project was often expressed and grounded in a fascination that I was collecting the stories of families in the time after the donation. Simultaneously I identified a kind of reluctance to use the donor families themselves as speakers, publicly as well as within the health care system. Often the reluctance from hospital staff was based in a sincere wish not to cause the families any further sorrow by asking them to present their experiences but, as this chapter will show, the reluctance could also be based in insecurity about the content of these stories.

Public stories about donor families have been very rare in Denmark, whether in the media or in the organ donation context. The stories being told at conferences and seminars are often those of organ recipients explaining about their sickness, their transplant surgery and their new life, underlining the transformation in their life conditions. This means that for education purposes, organ recipients are often brought in as an emotional proof that organ transplantation works. Their stories and their presence are a reminder and a visual argument for the hospital staff working with the donation side that the struggles to ask the difficult question and the medical struggle to keep the organs functioning in a body

that is deteriorating really has an impact. But in the history of organ transplantation, the experiences of donor families have very rarely been used for education purposes. However, on rare occasions, Danish donor families were speakers at education seminars for hospital staff. Doris was one of them.

Doris was a woman who lost her 52-year-old husband Benny during a vacation at a friend's house. Benny fell onto the bathroom floor with a brain haemorrhage and the doctors were not able to save him. Before Benny was declared brain-dead he was moved across the country to an NICU closer to their home. Coincidentally Doris had a cleaning job at that exact department at that hospital, so she knew everybody up there and was happy that she had so many people to talk to about it afterwards. Doris had no regrets about the decision to donate Benny's organs. Comparing this decision to an earlier decision to have an abortion in her younger days, Doris described herself as a person who did not regret hard decisions. When saying yes to organ donation, it was a yes. Doris was extremely satisfied with the way she and her family were treated by doctors and nurses. She was happy that Benny could help others, and she never felt bad about the doctors cutting into Benny or the fact that he was buried without his organs. But she often wondered how the recipients were doing with their new organs. Doris got close to Beatrice, one of the older, more experienced intensive care nurses. She asked Doris to come with her to teach young intensive care nurse students at a small hospital by talking about her experiences. Doris therefore found herself in a rare position compared to other Danish donor families. She was one of the only ones being used as a speaker and educator within the hospital system. Doris explained that the nurses had told her they were often reluctant to contact donor families but they found that Doris was strong enough to deal with it, and it was important that they knew her already. Doris accepted right

away, but as she said: “I did not know what I agreed to. I thought I was supposed to answer some questions, but they expected me to tell my entire story, so my throat was a bit dry.” I heard Doris a year later when she was invited again to an organ donation theme day. When asking her how she felt about speaking, she answered that she had always been very open about her experiences and that it felt good speaking to the young nurses.

They were very quiet and very interested and afterwards they asked many questions and seemed happy about it. I also got a lot out of it. I drove with Beatrice and was participating in the entire arrangement. I learned a lot about what happens on the other side – behind the curtain, where we families do not see or hear what is going on. That actually gave me a lot – knowing about the apparatus when there is a potential organ donor. It was good for me to know what is going on and all the people involved. You think that they just open him and that’s it, but they have to find recipients, it has to be timed. You never think about that. I might have given something, but I have gotten something back. It was so interesting to hear about what is going on. I felt good about all that information. It is something I would have never known otherwise. Somehow I found it exciting to hear what was going on behind the scenes. It is a tremendous task. Also about being declared brain-dead – that is a lot of work. Perhaps I have heard something about it on TV, but this was more detailed information. You get some insights into a world you do not know.
(Doris – husband of Benny)

Doris ended by telling me she would be happy to go out and speak about it again. The story of Doris is significant for young nurses trying to learn about donor family experiences. But what is interesting about this story is not what is said, but rather the social context in which it is told: a course for young nurses on the topic of organ donation. At such arrangements the entire course of an organ donation process is outlined in detail and

participants have the option to ask questions and discuss the various steps of the procedures. Usually such arrangements are for hospital staff only, but for Doris, her story is her ticket to a world that is otherwise closed to donor families. In this particular setting she is able to gain knowledge on what actually goes on from the hospital staff perspective. Witnessing their discussions and hearing about their achievements and desire to do better gave Doris something extraordinary – she sees organ donation from a different perspective, from “behind the curtain”, to use her own words, and this perspective helps her to re-interpret the donation experience. For Doris it is not only organs that are exchanged. Her story about donating is currency, too, and she is giving interesting information in return.

As this chapter has already shown, telling stories about organ donation is an essential part of the orchestration of death. Danish donor families need a new vocabulary to be able to grasp the events of organ donation and try to transform them into something meaningful. But donor families also need a specific social forum in which they can not only share or perform their story, but also meet an audience that can provide some of the missing information and answer many of the questions arising in the process of donation. By participating in this event and exchanging the story of loss for additional perspectives, Doris enables herself to construct a revised story about the loss of Benny and takes comfort from the extra information. Therefore I argue that regarding the role of storytelling in the orchestration of death, what is essential is not only the stories donor families tell but also the ones they are told, as this can help them to understand and contextualize their own experiences. If we understand storytelling as a social process like Jackson (2002: 18), we are now able to reach a closer definition of what kind of social process it is. The social process is an exchange of stories, not only among fellow sufferers as is the

case in other therapeutic settings, but an exchange between different actors participating in different parts of the process, supplementing each other with various kinds of information from different perspectives.

Together, these stories enhance the orchestration of death from a one-sided version of the experiences to a socially negotiated performance of coming closer to understanding the complex processes of organ donation.

In Denmark there is a rather mysterious paradox regarding the stories of organ donation. When orchestrating death in a certain way through stories of organ donation, some stories are told repeatedly, some are re-articulated and some are silenced. The performance of storytelling is mostly about controlling the stories in some way or another. That is also why Doris is carefully chosen. She is not just any random donor family member. The reason Doris was invited was probably, as she herself pointed out, that they knew her well already. Beatrice knew that Doris was appreciative of the care she received and that she was happy that Benny became an organ donor. Donor family stories possess dangerous potential, because of the consequences for the organ donation system if donor families express frustrations in public. But donor family stories are not the only ones with dangerous potential. There seemed to be some other “dangerous” stories doing the rounds as well. One circulating in the field, for example, had the donor, due to spinal reflexes, suddenly sitting up on the operating table, causing the terrified operating staff to run out and boycott the organ procurement. I also came across the story of a doctor approaching a family for organ donation way too early, only to shake hands with the “donor” visiting the NICU a couple of months after having recovered from the brain injury. I am not able to, or intending to, judge whether such stories are true or not. But the fact that they circulate under the surface and are considered dangerous teaches us that organ donation

professionals are aware they might hurt the cause whether they are true or not.

Another level of dangerous stories was defined as “myths”. During my fieldwork, it became evident that myths in the transplant world could come from the ordinary Dane having no basic knowledge on organ donation, such as that brain death patients could wake up, that doctors would not save the life of patients if they had a donor card and that organ procurements were like a butcher house. But myths could also originate from hospital staff with little education or experience on the subject. In this matter, a distinction was often made between the large NICUs where organ donation happened rather frequently, and smaller hospitals in the countryside, where taking care of a donor was a rare and challenging task. The transplant coordinators in particular, who often served as the connecting link between the donor hospitals and transplant units, had to deal with many myths and spent a lot of time visiting hospitals making sure that hospital staff obtained the right information. They worked hard to defeat such myths in the efforts to establish good cooperation, especially with the smaller hospitals. During recent years, the Danish Centre for Organ Donation has organized organ donation theme days in order to educate staff from both large and small hospitals. In one of my interviews with the most experienced transplant coordinator in Denmark, she expressed this need to control the stories of organ donation.

There are many myths about organ donation. When we give presentations it is good to talk about this, and get rid of the myths. For example, the idea that “she was brain dead for seven years and suddenly woke up”. People remember such stories. I have experienced several times that I get a call from the smaller hospitals from a doctor who does not understand what brain death is. They call about a brain death patient who is breathing on his own. And that can cause a lot of frustrations at the

hospital, if they do not know what it means to be brain-dead. That is not a myth – that is more lack of knowledge. But such things can create myths. If you are not absolutely sure what brain death is, it can create myths in the public. And discomfort. It is extremely important to talk about the sharp distinction in Denmark between the donor units and the transplantation units. Some think that the transplantation surgeons are watching over donors like hawks. But the surgeons do not know anything about an organ donor before he becomes an organ donor. And that is not until he is declared brain-dead and the family has given consent. Transplant surgeons are not allowed to participate in the care of a potential organ donor. But in many American TV shows such as ER, the donor and recipient are lying side by side and the doctors go back and forth. But that is clearly separated in Denmark. The doctors doing the brain death tests know nothing about the patients on the waiting list. That is really something I emphasize. There are no conflicts of interest. It is important to get rid of that myth. We usually say that when a neurosurgeon does a brain death test it is because he has lost a patient. (Ida – Danish transplant coordinator)

Ida mentions some very important issues in the understanding of organ donation. Her many years of experience in the field has taught her about possible obstacles to the idea of organ donation. By strategically classifying some ideas or perceptions about organ donation as “myths”, Ida is able to construct certain truths about organ donation, certain dominant narratives (Bruner 1986) that is unquestionable. In these truths where there are no conflicts of interest, brain death really is dead and donors and recipients are located in different units. This special vocabulary helps classify truths about organ donation, and the linguistic classification of what is true or not in turn helps transplant professionals orchestrate organ donation in an advantageous way. Through such narratives the staff experiences of organ donation are not only shaped but also adapted and

converted in meaningful truths socially construction a certain organ donation community (Steffen 2007).

The question remains: What are the myths or stories staff are not happy to talk about? My interviews revealed that in the early days of transplantation, there were heart surgeons with “big egos”, to use the phrases of my informants, running around among potential donor families in the intensive care units convincing them of the importance of organ donation and telling them about dying heart patients. And in some rare instances at a general intensive care unit, a deceased organ donor and a potential liver recipient in a respirator could be located pretty close to each other. Only specialized neurologists or neurosurgeons perform the brain death tests, but the patients and their families could be close to each other unless the staff take precautions.

Even if these stories belong to the past or happen extremely seldom, there is a reason that they are not a part of the official bank of stories about organ donation. They are potentially dangerous. If people, meaning the public as well as sceptical hospital staff, suspect that instances such as these happen frequently, it would be hard to believe in the qualities and the ethical values of organ donation. These dangerous stories are important, however, because they were told to me during my fieldwork as something exemplifying earlier days of lesser excellence and illustrating a development towards better practices. Classifying doubts about brain death and other insecurities as “myths” is a strong tool in the articulation and promotion of organ donation, but sometimes this word is a strategic term, not only for things that can never happen, but also for inconvenient truths that should not have happened.

Ambiguous Heroism

Writing about organ donation in an Israeli context, anthropologist Orit Brawer Ben-David claims that a “heroic death” involves giving one’s life for one’s country. When soldiers die in battle the personal body becomes symbolically a part of the social body of the nation (Ben-David 2005: 108,127). Other types of deaths such as suicides or traffic accidents do not have the same social significance or symbolism and are therefore not categorized as heroic deaths. However, consenting to organ donation can transform such ordinary ways of dying into “heroic deaths” which are thus deserving of national attention and recognition (Ben-David 2005). As earlier mentioned, Linda Hogle argues that in order for a nation or a health care system to accept apparently inhuman procedures for handling dead bodies, a “cultural mechanism” to translate the concepts of brain death and organ donation must be initiated (Hogle 1999). That is what I have framed as ‘the orchestration of death’ in this study. I suggest that reframing and restorying organ donation as something ‘heroic’ is also an element of the orchestration of death.

In the New York Organ Donor Network, the idea of an organ donor being a hero was constructed partly with a therapeutic purpose for the donor family, but also to associate organ donation with culturally admired values. Many American donor family informants adopted this idea about the donor as “a hero saving other people’s lives” because it reassured them that there was a purpose or a meaning to the death, thus providing families with a socially accepted model for re-interpreting a tragic loss (Jensen 2010).

During my fieldwork in 2005, I went to an information day about organ donation at Mount Sinai Hospital in the US. I listened to the story of Joseph, the father of two small children who lost his wife due to a bleeding

in the brain. Joseph was still very upset about the loss of his wife, and talked about the difficulties of daily life with two small children. But during the interview, it turned out that some elements of his story were carefully orchestrated and thought through. Sitting across from me, Joseph quickly returned to one of the important elements of the story, the hero narrative:

Then I went home to explain to my kids what had happened. And my daughter was only five and did not understand life and death, so when I told her, she cried, she begged and pleaded for me to take her to heaven just for one minute to say goodbye to Mom. But my son was 13 and he understood what was happening. And when I told him that his Mom had died, he cried and cried and we hugged for a long time. In search for something to tell him, I started explaining organ donation to him and that she was going to be able to save somebody's life. Through his tears he looked up at me and said "That makes Mom a hero, doesn't it". And I said, "I guess it does". And from that day on, we think of her as a hero, as someone who maybe ran through a burning building and pulled some people out before being overcome by the smoke and flames herself. And it is that, that has really gotten us through this whole grieving process. (Joseph, American donor husband)

As I have argued elsewhere (Jensen 2007; 2010) for donor families in New York the heroism of saving others often had a reference to the terror attacks on the World Trade Centre on September 11, 2001 (9-11). Families often incorporated their version of 9-11 into their stories about losing a family member and consenting to organ donation. However, the heroism in the stories of the families was not exclusively confined to the urban context of the terrorist attacks; it also acquired a national character in the personal and public remembrance of organ donors. Anthropologist Lesley Sharp points to the similarity between donor memorials and war

memorials, arguing that the hero theme is very evident in how organ donors are officially memorialized in America (2006). Personal stories were placed in a nationalistic frame of understanding:

And I can think of nothing else other than standing in front of a bullet and getting shot for the President of the US or something that a secret service agent will do that is more heroic than being an organ donor and having made that decision to let the medical team do whatever they need to do with their body to help other people to live.

(Jack, American donor father)

While hospitals in Denmark prioritize the clinical care for organ donors and their families, a public or official recognition of dead organ donors are as good as absent in a Danish context. In Denmark there is no culturally familiar rhetoric to classify and acknowledge the actions of organ donors and their families and no public or political intention to do so. However, on rare occasions, acknowledgement of the actions of donor families appears on a public stage.

In June 2008, the Danish Centre for Organ Donation hosted their opening symposium in Skejby with over 200 guests and presented a comprehensive program of speakers, including the Danish Secretary of Health, the manager of the centre, a neurosurgeon, a transplant coordinator and a kidney surgeon to explain about the procedures of organ donation and the Danish strategies for future work in this area. But this event also embraced personal stories so among the speakers was a young man who had received a heart and Susan, the mother of a young boy who was in a car accident and became an organ donor three years ago at that time. To my knowledge, this presentation from a donor family member was the first of its kind in Denmark. The mother, standing alone on the huge stage in the auditorium, started out by showing a picture of her 18-year-

old son Christian, asking the audience if he did not look beautiful. Then she explained that she would read aloud from a letter she had written to Christian after his death. As she read the letter, the auditorium was in complete silence, unlike earlier presentations where there was whispering. The letter starts with Susan describing the shock of receiving the phone call that he was in a traffic accident. Susan then explained about the hours at the intensive care unit, describing the common holding hands and saying a prayer and the awful message from the doctors, underlining how difficult it was to realize that nothing could be done. Susan described how 46 people came and said goodbye and how strange it was to see that the treatment of Christian was to save the organs alone and not his life. While Susan was talking I observed the audience, many of whom were crying. The letter carefully described every thought and reaction of the family and ended with the following words:

A week after the funeral we received a letter from the organization Open Doors. You had signed up to hand out Bibles in the Middle East in the summer. Your friends knew it, but you had not mentioned anything to your mother, because she should not worry. When you dared taking such a chance for others in life, was it not according to your personality to save others in death? We really did our best. Forgive us if we have acted against your will. Love Mom. PS I miss you madly and look forward to seeing you again. (Excerpt from letter – from the website of the Danish Centre for Organ Donation)

While the experiences of this story do not differ significantly from other donor family narratives in this study, the important point here is that this personal account is performed publicly in front of an audience. After Susan ended her story, the entire audience got up from their chairs and gave her standing applause. I emphasize this moment since this is a clear

acknowledgement of the sufferings of Susan and her family. After Susan's story, there was a break in the program and several of the participants expressed how affected they were by this story. During the break I observed the Secretary of Health heading towards Susan, then shaking her hand and talking to her.

Many Danish organ donation professionals are hesitant about the form and content of public acknowledgement of organ donors in Denmark. They often compare this to the showy honoring represented by the US and argue that medals are "too much". They also claim they have discussed the issue with Danish donor families, who say they don't want to participate in events like the ones in the US. But this incident with Susan points to the fact that recognition can take place in Denmark. She was not given a medal, but she was given time to speak and she received a standing ovation, which is a clear sign that the audience of the opening symposium showed their sincere empathy and respect. The case shows that the idea of public recognition of donor families is not absent in Denmark, but forums in which the recognition can be performed in ways that are acceptable in Danish culture are rarely organized.

However, in May 2011, the head of the Danish Ethical Council, Jacob Birkler, suggested the establishment of a memorial grove for organ donors. While this is normal in other countries such as Great Britain and the US (Sharp 2006), the idea is new in Denmark. Public or national recognition of organ donors and donor families has been absent in the history of transplantation in Denmark. On the other hand, Danish organ recipients have a strong tradition of celebrating themselves and their hardships (Birk 2011). When talking to people in the Danish Centre for Organ Donation and in the Danish Board of Health about this suggestion to publicly honour donor families, it became clear to me that Danish organ donor families are beyond category, so to speak. They are nobody's

responsibility. Who will pay for this memorial grove? The Board of Health makes sure the medical and juridical procedures are followed; the Organ Donation Centre deals with educating staff to take care of families while they are in the hospital and the organizations for organ recipients look after their own members and their sufferings. Therefore a memorial grove and other initiatives to publicly honor donor families are rarely suggested and never carried out.

It becomes relevant to ask why the donor families in Denmark, apart from a few exceptions, are embedded in public silence. This question is not motivated by data from my Danish fieldwork showing a strong donor family need to receive public attention for the decision to donate. Rather, it springs from a comparison with countries like Great Britain and Norway and especially the US, where the recognition of donor families is, or has begun to be, a natural part of the organizational work with organ donation. By publicly recognizing and memorializing organ donors as people who have gone through special circumstances to save others, society indicates that such a decision is something extraordinary. Acknowledging this way of ending life suggests to the public that a personal sacrifice has been made to benefit the country or other people, and that dying as an organ donor entails suffering in some way or another. But by doing this, society would also suggest that organ donation should not be taken for granted and that would undermine the idea that Danes should be organ donors unless stated otherwise, as the idea of presumed consent represents. The point is that if the Danish state suddenly decides to orchestrate the death of organ donors as something extraordinary that deserves attention and honouring, current policies would need a revision.

This chapter has showed how stories of organ donation play an important role in the orchestration of death. They help donor families construct

meaningful memories but experiences of organ donation can also be hard to articulate if families do not feel they have the language to comprehend the donation. In the US, the aftercare departments help donor families construct their stories and they provide them a social context where the stories can be staged. This work is done because they want to support families after the donation and because they know the public impact of good stories. In Denmark the stories of organ donation are also controlled but not by indulging the good stories of donor families, rather by shaping and controlling the various truths and myths existing in this field. That is a strategic way of orchestrating death and organ donation so bad stories or misinformation does not circulate. Finally by comparing with the heroism surrounding donors and their families in the US, the chapter looked at the public recognition of donor families in Denmark and argued that the absence of heroism or acknowledgement is an intentional strategy of orchestrating the death of Danish organ donors as nothing deserving special attention. If dead organ donors are celebrated for their actions, it could imply that organ donation was a painful sacrifice and not obvious and natural decision.

With that, it is time to move to the conclusion of this thesis.

Chapter 8: Conclusion



Conclusion

“So, what have you found out?” Writing these final pages about Danish donor families and organ donation in Denmark, this fundamental question, so often asked by my informants, repeatedly echoes in my head.

In this particular study, my analytical objective has been to investigate the experiences of Danish donor families during and after the loss of a loved one and the decision to donate organs. Rather than focusing on the outcome of the decision and the transplantation of organs into sick patients, this work examines the families facing sudden death at the Danish neuro-intensive care units. What do they go through, how are they supported and informed and what is important for them in these moments and afterwards? Investigating this group and their emotions, attitudes and actions showed that organ donation is more than the question of deciding yes or no. It is a fundamental change in familiar traditions, processes and rituals surrounding death.

The thesis proposes that we understand organ donation as a ‘strange figure’. Even if organ donation from brain dead patients has taken place in Denmark since 1990, there is no familiar framework, values or language to fully grasp this rather new way of ending life and this way of making dead bodies usable and available to others. Organ donation challenges boundaries between life and death and it changes familiar ways of handling the bodies of the dead. Inspired by Linda Hogle’s point that a cultural mechanism is needed in order to transform the use of human bodies and make it consistent with cultural values (1999: 42), I set out to explore what happens in order to make organ donation comprehensible and culturally acceptable in Denmark? How do families make decisions about donating the body parts of their loved one? How do they come to terms with the occurrence of an unfamiliar death as brain death? How do

families talk about their experiences afterwards? And what role do the doctors and nurses play when practicing the medical tasks of organ donation and supporting families? Such questions were central in my research endeavors.

I discovered that assuming all families would have troubles understanding brain death and regard organ donation as some kind of gruesome mutilation of the dead was very wrong. It is one of the most important contributions of this thesis that many families have no difficulties in understanding brain death and know that it is a necessary premise in order for organ donation to become a relevant question. Families are sometimes initiating the topic of organ donation themselves and many think helping other sick patients to survive has provided them with some purpose or solace in the midst of tragedy. Thus organ donation is a strange figure, because I discovered that an essential part of the strangeness is its complexity of being disturbing and sense making at the same time.

My observations as well as my interviews revealed that donor families do not categorize in good or bad, their experiences regarding organ donation are often meaningful and devastating at the same time. Rather, my task was to investigate the many different ways families attempted to go through the process of losing and how they framed organ donation in ways as reassuring and comforting as their situation allowed them. Organ donation is not merely a question of making a decision, but it is a special way of ending life including several interacting processes with staff, technology and the social circumstances of the hospital and the surrounding society. The experiences of families are therefore deeply affected by the people they encounter and interact with in the clinical context.

This study argues that the experiences of donor families are created and negotiated in close social interaction with first and foremost, the hospital staff, but also on more abstract levels, with the health care system, meaning the Welfare State of Denmark. As a result I chose the overall analytical concept of 'orchestration' as my way into theoretically discussing and unfolding the complexities of organ donation in Denmark. Orchestration means arranging, manipulating, or organizing through clever planning and maneuvering and has root in the world of music. In anthropology it has mostly been used in relation to describing the staging of rituals or ritualization, but this study applies the concept in a broader sense.

While the concept of orchestration entails the ritualization of death in the clinical context, it also has the potentiality to embrace the actions and practices strategically initiated to introduce, convince, comprehend and interpret organ donation. Orchestration has temporal elements. It can be understood as a careful plan to structure processes of organ donation, such as for example the staff training preparing doctors and nurses how to perform the conversations with families, or the Danish campaigns trying to talk people into signing the donor registry. It can be understood as an immediate response to react on sudden occurrences such as for example the nurse trying to explain to the family who has doubts about brain death why the dead patient moved his arm. And it can be a reflection or interpretation of current or past experiences, such as for example a family claiming that organ donation is a good decision because the father always helped others. All three often happen simultaneously in the processes of organ donation. And they all constitute a part of the orchestration of death.

Importantly, orchestration also holds elements of improvising and negotiation. My research has showed that the processes of organ donation

can only be planned and structured to a certain degree. The actions taking place and the support given to families are sought adapted to the individual needs and concerns of each family. In addition, families themselves strategically try to arrange, manipulate, organize and improvise so they can try to comprehend and interpret what is happening.

Orchestration helps us to discover and discuss the complex practices of attempting to make sense of organ donation carried out by all actors of organ donation, before, during and after the decision to donate and the processes of death.

Resume of Chapters

In this study, orchestration was bracketed down into five aspects essential for understanding the experiences of donor families. Each aspect is represented in the analytical chapters of the thesis. In chapter 3, I discussed how the death of the organ donor is ritualized and orchestrated as a performance of trust in the clinical context. Leaning on van Gennep and Turner, this chapter showed that in the process of losing a loved one and deciding for organ donation, donor families as well as the hospital staff need rituals. Not only to accompany the patient from life to death but to grasp and understand that this journey happens in unfamiliar, and sometimes unpredictable ways due to the brain death criterion and the medical procedures of organ donation. This chapter also argued that the process of losing and deciding about donation can be understood in line with Turners social drama (1974). In a social drama actors perform for an audience in order to show each other what they are doing and in order to go through the crisis. As a result, families and staff constantly attempt to invent, initiate and perform certain practices or rituals that make sense in this very special clinical context. I therefore used Catherine Bell's notion of

ritualization (1992). Ritualization is the performance and practices of creating and shaping rituals. By applying this theory, the variety of practices performed by staff and families in order to translate the strange figure of organ donation was unfolded and I discovered the importance of trust in these ritual performances constituting an essential element of the orchestration of death in a clinical context. If families do not trust the information and the actions of the doctors and nurses, accepting brain death and agreeing to organ donation becomes an impossible task. This chapter also showed that the technological surroundings of the hospital matter to the experiences of families and the performance of trust. Drawing on Michael Jackson's theory of intersubjectivity I showed how technology plays an important role when staff and families attempt to ritualize the body of the patient in order to understand death has occurred and to make decisions about organ donation. Focusing on how families make decisions about organ donation, indicated that timing, careful planning and choice of words is important in the process of ritualizing death and performing trust. Finally, the chapter showed how staff and families try to perform what I defined as 'the good death', meaning a death that is as close as possible to well known values regarding death, such as constructing a peaceful goodbye and watching over the dead body.

Chapter 4 investigated the transformative practices of hope. Based on the work of Cheryl Mattingly (2010) and Vincent Crapenzano (2004), I argued that hope is a complex practice and that hope is subject to change. The empirical examples showed that for the donor families, hope is not only hoping for survival. If families find that the severity of the brain damage is so big that their loved one will not be able to live a dignified life, then they start hoping that death will occur. I also argued that in this process of transforming hope, families turned their hope for survival of their family member into hoping that other patients would survive by way

of the donation of organs. In this process I showed that some families apply utilitarian language and perspectives otherwise confined to transplant surgeons. Objectifying the parts of the body is therefore not only a strategy for organ recipients and transplant surgeons to handle that these parts come from a dead individual and might carry personal traits (Fox Swazey 1992; Sharp 1995; Lock 2002a). Objectifying organs is indeed also an element in the donor family transformation of hope attempting to make death more meaningful. This transformation of the practices of hope regarding the body of the organ donor is essential in the donor family orchestration of death. Chapter 4 ended with discussing the donor family urge to make strong points about how they were treated at the hospitals which came out very evidently in my interviews. I argued that these statements were a practice of hoping that other families should not go through the same difficulties. This way of retrospectively orchestrating the death they experienced and the death others might experience is an indication of the existence of some kind of implicit or imagined feeling of community or solidarity between donor families in Denmark. My interviews became a way of expressing this because the organizational system in Denmark never offers donor families the option to meet and share experiences or to give feed back about their experiences.

Chapter 5 discussed how the orchestration of death can be seen as processes of aesthetizing the ambiguous body of the organ donor in all its phases. The chapter was divided according to the process of the body of the patient. From being a potential donor body, to a consented donor body, to an open donor body at the operating table and finally an empty donor body returning from the organ procurement so the family can say goodbye. I discussed how the body is perceived and handled in order to make it look as nice and familiar as possible even if the medical circumstances are very different due to the practices of organ donation. This chapter leaned on the

theory of Hobart and Kapferer (2005) arguing that aesthetics is an essential element of performance. Here I showed that aesthetization is closely connected to the professionalism and ethics of the health care staff and to the experiences of donor families. Nurses and doctors constantly try to make the body look nice and be treated with respect. They too are challenged by the ambiguity of the body of the organ donor balancing on the boundaries between life and death. The chapter discussed the challenges in defining the moment when the patient becomes a potential organ donor and the shift in the care when attention goes from saving the life to taking care of organs. This chapter also explored the efforts made by operating staff to take care of the body during the organ procurement and afterwards when the empty body of the patient is returned to the intensive care unit so families can have a peaceful and undisturbed goodbye. Chapter 5 showed that interacting with the donor body and aesthetizing the processes of organ donation is a way to orchestrate death for families as well as for hospital staff to translate the strange figure of organ donation into something familiar that is close to being visually recognizable.

Thereafter, chapter 6 discussed how death is orchestrated through managing or controlling the sociality of exchangeable bodies. Leaning on the theory of George Simmel that sociality is reciprocal relations with a purpose (1998), I showed how social relations in this field are carefully performed and handled with a purpose; namely to orchestrate organ donation and make it culturally acceptable. By comparing organs to the bones of Zimbabwe, as analyzed by anthropologist Joost Fontein (2010), I argued that organs possess ambivalent agency. They are on one hand objects with their own function and on another level they are extensions of the dead. This ambivalence is how many families regard the body parts, they have a function and they are connected to the dead. Families often

connected the fact that the organs have saved others to the characteristics and personality of the deceased. I argued that it is this functionality and ability to save the lives of others that connect organs to the personality of the deceased. Thereby donating organs become sense making through the social meanings of the organs. Chapter 6 also showed that the social context of the exchange is of great importance, meaning the physical surroundings and emotional resources of the hospital. As earlier established, trust is a crucial element of the donor family experience and if the social contexts of the intensive care units are not of a certain standard, families lose trust and the exchange of organs moves from the intended sphere of gift exchange to a cold and impersonal exchange of spare parts. Chapter 6 also investigated the role of the nation state in the donor family orchestration of death. Many families' expressed notions of obligation, solidarity and ideas about being a good citizen when clarifying their reasons for donation. Therefore, chapter 6 introduced the idea that donating organs is a way not only of establishing new exchange relationships among donors and recipients, but also to confirm existing relationships between citizens and country in the Danish society. Chapter 6 ended with exploring the dangerous sociality of organ donation, namely the relationship between donor and recipients that are sought carefully anonymized in Denmark out of concern for the organ recipients. This led me to argue that orchestrating death in the context of organ donation is also about hiding and underplaying the social relationships that are defined as threatening to the cause of organ donation.

Finally, chapter 7 investigated how death is orchestrated through the staging of the stories of organ donation. I used the theories of Michael Jackson to show how telling a story can help regain a sense of control after tragic circumstances (2002, 2005). I argued that telling a story about organ donation can reframe and re-contextualize the life of the deceased.

But at the same time the story of organ donation can be impossible to tell for those families feeling they lack the language to do so. Especially those needing to know the outcome of the organs will find it hard to tell. Chapter 7 also included some of my earlier findings from the donor family context in the US in order to have a comparative approach to the donor family situation in Denmark. Leaning on the theories of Vibeke Steffen (1997) and Edward Bruner (1986), I discussed the difference in the staging of donor family experiences, and why the notion of organ donors as heroes are so evident in the US and not present in Denmark. I concluded that the values surrounding organ donation and the deeds of organ donors and their families are carefully constructed, adapted and negotiated according to the existent values in the current country. That is why the Danish donor family stories are expressed so differently than in the US. There is no public stage to do so and no national recognition celebrating and encouraging the stories of donor families.

Contributions and New Directions

Denmark has transplanted organs from brain dead patients since 1990, but the area has never undergone any larger anthropological or social scientific studies. This thesis therefore constitutes the first comprehensive study of organ donation and donor families in Denmark.

Internationally, many studies have dealt with the nature of the exchange of body parts discussing the relevance of applying the gift language contra the increasing commodification of body parts (Sharp 1995 2001, Lock 2002a, Joralemon 1995, Fox & Swazey 1992). While recognizing the relevance of such academic discussions, my aim was not the nature or the definition of the exchange, rather to unfold how families experience being part of the exchange of organs. By focusing on how the processes of organ donation are socially negotiated and performed, this thesis has

provided insights to the attitudes and strategies of donor families. They too play an important role in the orchestration of death.

Due to the significance and the controversy of the brain death criterion, it could have been appropriate to devote the entire thesis to exploring this. Authors have produced highly relevant discussions of the intentions and the motives behind the brain death criterion with the underlying agenda to question whether brain dead was really dead (Lock 2002a; Sharp 2006). Without dismissing this central question, I have not been interested in proving the criterion right or wrong. Focusing on the experiences of donor families, I have investigated the practices surrounding this criterion since it is these actions and this language that affects the donor family experience. I have shown that brain death is a matter of trust, especially for those families that are not familiar with the concept. And I hope to have updated the existing discussions about brain death in and outside academia by showing that not all families are reluctant and strangers to brain death. Most publications about brain death and organ donation in Denmark (Bøgh 2005; Etisk Råd 2008, 2010) seem to overlook this large group of families and disregard that organ donation can cause other problems than understanding brain death.

This thesis also taught us that the national context in which organ donation is played out matters to the experiences of donor families. It is not only the policies and legislation of the country, but also the underlying cultural values that affect how organ donation is perceived and performed by families. Looking at the experiences of donor families in Denmark might open up for ways of understanding organ donation and donor families in other parts of the world too.

The concept of orchestration was helpful in investigating the complex world of donor families and organ donation in Denmark. But the concept also has potential to be applied in other empirical fields.

Orchestration could be a good analytical tool to unfold areas of the medical context, such as reproduction technology, cancer treatment or genetic counseling, where patients and families face fundamental challenges and deal with matters out of familiar categories. Orchestration turns our attention to the attempts to make something meaningful and culturally acceptable. It teaches us that it is not always successful but it turns our focus towards the many actions, performances and re-interpretations humans tend to engage in when needing models for explanation. The concept of orchestration also showed that the experiences of donor families and hospital staff are mutually created and that they are not necessarily representing opposite views, rather similar concerns. Therefore, the notion of orchestration might be applicable to illuminate areas of conflict studies too, and turn the focus to the interplay of performing opposing interests rather than the differences.

Methodologically, this study provided a contribution to the study of human tragedy. It gave insights in the careful strategies anthropologists have to use in order to gain access and be present in highly emotional situations such as asking a family about organ donation. Navigating in such ethical contexts is difficult since anthropological standards have to be adapted to the values and ethics of the current hospital. Conducting anthropological studies without being able to reveal the true agenda of your research endeavors is problematic. When going into family conversations I could not say I was there to study organ donation, since often the families had not understood the severity of the situation yet. My thesis shows that in some special cases, such as this, the concern for informants is more important than living up to current anthropological standards. In addition, the careful negotiations with staff and families on how to be present in such situations contributed with important analytical insight. This thesis has shown the analytical value of engaging in a

methodological dialogue with some informants. The study also presented a new version of fieldwork, namely “being on call” and having to rush to the field due to the unpredictability of the occurrence of organ donation situations. It shows that methodological premises can provide knowledge about the unpredictability, the importance of time and the working conditions of a particular field. It was also shown how the anthropologist gets personally affected by the tragedies of the field, and how it is possible to gain new analytical knowledge by sharing those insights with the informants. I believe such knowledge is relevant to all anthropologists working in sensitive and emotional fields.

Recommendations for Future Improvements

“So, what have you found out?” While repeating the question from the beginning, I realize it is still hard to answer. But it does represent the positive interest I have been privileged by from day one. I have had the option to conduct research in a medical field that was very interested in my findings and did not hide that they could not wait to read my work. The question also accentuates the need doctors, nurses and policy makers have for some kind of a solution or concrete suggestions to the field of organ donor families. Solution can mean how to care for families in a better way, but also how to get more families to say yes to organ donation. From some perspectives, the interest in donor families is based on a sincere determination to support them the best way possible no matter what they decide. From others, the interest in donor families is closely connected to the fact that their decisions are crucial for organ donation statistics. The need to get more available organs has been an underlying factor surrounding this study that I had to move along and around. It was never my intention to provide solutions to get more organs. I am however aware, that some readers will search for answers to this in this study. I

will be happy if this research can provide some solutions to taking better care of Danish donor families during and after the decision to donate. This final section is therefore devoted to outlining some of my personal recommendations for improving circumstances for families based on my research in the field. I am aware that many of my suggestions entail channeling more financial resources to the area of organ donation, but that is a necessary condition in order to improve organ donation and family care in Denmark.

- I recommend using more resources on the campaigns for organ donation and to make sure the campaigns inform about all processes of organ donation, also the surgeries. Often families found the campaigns too hollow and not providing relevant knowledge. Staff members mentioned how easy their work would be if families arrived at the hospitals with more information. Therefore public information would help not only staff but also future donor families.
- I recommend creating more bed space at the NICUs. Doctors and nurses struggle with lack of available beds for patients and this might mean that potential donors cannot receive treatment and some families are not given the option to donate. In addition, many families express frustrations over saying goodbye to a family member with other patients and lots of medical activity in the same ward.
- I recommend having two nurses on each organ donation case. Families who had a bad experience about donation often stated lack of personnel as a reason. If staff are busy and stressed families are affected by this. And they have a good experience if the staff have time to care for them. As the hospital staff claim themselves, it is

therefore better to be able to have one nurse focusing on the family, while the other participates in organ management.

- I recommend providing better information about the procurement surgery. Many families are troubled by nightmares due to scary imaginations about slaughterhouses. And many families refuse to donate because they are afraid what will happen to the body. While accepting a family no, it is important that families base their decision and their experiences on correct information.
- I recommend producing visual aids, brochures or using x-rays to help inform families about brain death and organ donation. Some families have a hard time understanding the oral information, but seeing an x-ray or a curve can help. Brochures with pictures about the procedures of organ donation and the removal of organs would also help families envision what they say yes or no to.
- I recommend creating better facilities for donor families at hospitals. Families were very troubled and frustrated if the family rooms were too small, if the rooms were dirty and messy and if they were not offered anything to eat and drink during the long hours of waiting. If families find the physical surroundings bad, they have a hard time trusting the doctors and nurses. And that makes consenting to organ donation very difficult. Therefore, families must be practically and physically supported during the process of organ donation.
- I recommend offering families the option to see the family member at the NICU after the surgery. As shown, it is important for families to experience a peaceful goodbye and to see the donor with well known

signs of death. Getting to perform the traditional care of the dead is also very important for the staff. In relation to this, I recommend that the NICU cooperate closely with hospital chapels. If something goes wrong at the chapel, the whole family experience at the hospital is deeply affected by that.

- I recommend focusing on children as family members. Many donor families had troubles supporting their children because they themselves were extremely devastated. Hospital staff also claimed they needed the knowledge and the resources to provide better care. The option to call a crisis psychologist or a person with knowledge on children and grief was often mentioned.
- I recommend initiating better follow up services for donor families. Many families experienced questions regarding organ donation or brain death popping up in their minds afterwards and did not know where to turn for answers. It can be hard to call the hospital again, so families appreciated if they received calls from staff. Some were also happy to be offered a conversation afterwards with the doctor in charge explaining the process. It could also be considered to establish a national follow up initiative for donor families, either online or a phone number to call since returning to the hospital can be emotionally hard.
- I recommend continuing existing education activities for hospital staff in Denmark. Staff explained that they could use what they learned at courses and they also had a need to meet and discuss the ethical challenges of organ donation and learn from the experiences of staff at other hospitals. During these activities the efforts of

supporting families are exchanged and developed meaning that families also benefit from this dialogue.

- I recommend using Danish donor families actively in the development of new practices and policies regarding organ donation. Donor families constitute an incredible source of valuable information based on their experiences, and many of them are willing to contribute. Therefore they should be allowed the option to participate in the efforts to improve the area. That can be on a political or administrative level, but also at hospitals or conferences.
- I recommend an annual social gathering or conference where donor families can receive information and meet intensive care staff, operating staff, other families and organ recipients. Some families expressed the need for meeting others who have gone through the same. And some were curious to know more about the benefits of organ transplantation by meeting recipients, not necessarily the recipients of their own family member's organs. I believe many families would also benefit from hearing about staff experiences with organ donation.
- I recommend maintaining existent legislation of informed consent and not change to presumed consent. This recommendation is based on my personal attitudes since my informants, both staff and families, were divided in this. Based on my research, I find that if organ donation is taken for granted as something everybody must do unless they say no, it would create resistance and reluctance among the Danes. In addition, it could mean that the efforts of thoroughly informing families at the hospitals would lessen. Changing

legislation would however be a good at provoking Danes to talk about the topic of organ donation, but I am not sure it would result in better care for families.

With these recommendations, I end my thesis and my investigation of donor families and organ donation in Denmark. This work has constituted my attempt to 'orchestrate' the empirical findings and initiate relevant anthropological discussions. I hope this will only be the first step in a long journey of understanding and exploring the experiences of Danish donor families.

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Appendixes

Appendix 1 – Letter to the NICUs

Regarding anthropological research on families of organ donors

My name is Anja Marie Bornø Jensen, and I am an anthropologist. As per the 1st of January 2008 I have started to work on my PhD project on the topic of organ donation and Danish families of organ donors. The name of the project is "Death giving life – an anthropological study of organ donation and families of organ donors". Based on conversations and recommendations from senior doctor XX and senior doctor XX, I address you as the management in the hope that you and your department will be supporting my research and let me conduct my field study at your department

My project is focusing on the relatives' experiences and reflections in relation to organ donation, both at the hospital in the actual situation as well as in the time after. The study is financed by the Danish Research Council for Culture and Communication and I cooperate with the Danish Centre for Organ Donation who contributes with information and feed back.

The research is at this point the only greater research study of Danish relatives to organ donors. Hence I hope to be able to contribute with new knowledge to this underexplored area of the Danish healthcare system, which will be of benefit for future endeavors in the area. I aim to clarify the thoughts and feelings felt by Danish relatives regarding brain death and organ donation - both in the acute situation and in time after the hospital staff has said goodbye.

As a mandatory part of the PhD project I am conducting anthropological fieldwork for a period of 12 months. I am traveling around Denmark where I make in-depth interviews with Danish relatives who have made donations within the past years; I am following EDHEP personnel training in organ donation and I am participating in various conferences and events on the topic organ donation.

A very important part of my fieldwork will consist of observing acute donation procedures in Danish neuro-intensive care units. This has not been done earlier in Denmark, a similar study has however been done in Norway by the end of the 1990'ties by the anthropologist Anne Hambro Alnæs. These observations are in my opinion crucial in the effort to gain an understanding of the relatives' experiences during the acute procedure, the interaction and the dialog between the relatives and the hospital staff; and

the difficult situation both parts are placed in - in connection to the question regarding organ donation.

In February 2009, I will conduct fieldwork at XX Hospital. During this period senior doctor XX will be my contact person. I will make a presentation of my project and myself at a staff meeting in the beginning of my fieldwork at XX Hospital. Hereafter I will be connected to the department 4 to 5 days a week for a period of 3 weeks, both during the day, evening and night. This will enable me to get a clear view of the everyday life in the intensive department and in the acute work situations. After the three weeks period I will be on call by phone for incidents where a patient might be in a situation, where the relatives will be asked for an organ donation.

I would be grateful if a similar approach can be a reality in your departments. This methodology can of course be adjusted to your specific needs and demands.

The fieldwork in your department could look as follows:

- * Learn from/observe the everyday life in your department – with the focus on organ donation - 3 to 5 days a week for a period of three weeks in different shifts. This type of observation can be compared with the practical observation experience of medical students.
- * Interview with key staff members at a length of 30-60 minutes, to get their views, experiences and knowledge in the area. Interviews with the staff involved in an organ donation procedure a few days after an incident. The participation in the above mentioned is of course based on the individual staff member's consent.
- * The possibility to be on call and come to your department at the hospital in urgent organ donation cases (if you find it appropriate in the given situation), during the rest of 2009. During these cases I would be the observer during your dialog with the family and following the routines in connection to donor management and additional aspects related to organ donation.
- * The possibility to contact the families who have been involved in organ donations, either as donors or who has rejected the possibility, at your department during the past five years to ask for an interview. My suggestion is (based on a recommendation from the Danish Centre for Organ Donation) that I write a letter, which you approve and send to the relatives – possibly accompanied by a letter from your side. Then the relatives can contact me directly by email or phone, if they should wish to participate. In this way mutual anonymity will be secured. I will of course cover all postage expenses.

If there are other aspects in your procedure connected to organ donation, which you find relevant regarding my research, I will of course be open minded for possibilities to include these in my fieldwork.

It has to be said that everyone participating in my research of course will stay anonymous in my thesis, as well as in any future publications. Furthermore I am subject to confidentiality related to all collected information and data. It is also important for me to emphasize that neither the interviews with the staff nor the observations made while working in your department, are serving the purpose as an assessment or evaluation of the staff or the way they perform their job. It is my expectation that the dialog with the staff and the insight in their everyday life can give me an understanding of how the staff meets the relatives, and a greater insight in how the procedures in an organ donation are carried out in practice. It will therefore function as a qualified starting point in the process to understand the donor relatives' experiences – and in the long run give a broader view in my thesis.

I will also like to emphasize that I am aware of the ethical and emotional issues and dilemmas that your job area is covering. I am conscious that it is the staff and not me who has the experience and expertise in these situations and therefore I will of course always follow advises and guidelines given to me by the management and staff. Therefore I also believe that the specific circumstances of my presence must be negotiated with and adapted to the individual department.

I hope that you and your department would like to participate in this study and share your experiences and knowledge related to organ donation and families. This knowledge and this kind of fieldwork are crucial for my research, and in the long run it should also produce a research result, which can be beneficial for the entire organ donation setup in Denmark.

If needed, I will be happy to attend a department management meeting and present my project and answer questions prior to an agreement of a stay. For your information then I will give a presentation of my fieldwork at the kick-off meeting for organ donation key persons on the 29th of January 2009. If you have any questions or would like some further information, you and your colleagues are more than welcome to contact me on my mobile 30 55 93 21 or by email: anja.jensen@anthro.ku.dk.

I will be calling you within a few weeks to follow up on this inquiry.

Best regards

Anja Marie Bornø Jensen, PhD Student

Appendix 2 – Notice about project at the NICUs

Anthropological field study on families of organ donors

Hi. My name is Anja Marie Bornø Jensen. To those of you who I have not yet met, I would like to share some information about my project. I am an anthropologist and employed as a PhD student at Copenhagen University. I am doing fieldwork for my research project on the topic of organ donation and families of organ donors.

The project is at present the only greater scientific research in Denmark with the focus on donor families and hospital staff in relation to organ donation. As a mandatory part of the PhD project, I am conducting an anthropological fieldwork. I am interviewing Danish relatives who have experienced organ donation within the past years, I am interviewing doctors and nurses who requests for donations and support the relatives, I am following EDHEP staff training, and I am participating in conferences and events concerning organ donation. All efforts are made to gain a better understanding of the reality surrounding organ donation in Denmark.

A very important part of my fieldwork consists of learning from the everyday life in the Danish neuro-intensive care units and to observe acute donation procedures, where families are asked about donation. I have been observing the daily life here at XX Hospital in the month of February, at XX Hospital in March and at XX Hospital in April/May. These stays have been incredible rewarding and educational. I have been participating in some acute donation situations until now, I will however be grateful to be able to conduct some more.

Due to ethical reasons I will not make interviews with families who are experiencing an acute crisis. However by being present and observing what happens, I will try to gain an understanding of the families' experiences during the acute procedure, the interaction and the dialog between the

relatives and the hospital staff and the difficult situation both parts are placed in - in connection to the question regarding organ donation.

For the remaining year of 2009 I can be called in on my mobile 30 55 93 21, if a family is likely to be asked about organ donation.

You can call me in at all times 24-7.

Thank you in advance.

Requests for organ donation in 2009:

Please contact Anja on mobile 30 55 93 21

Appendix 3 – Letter to donor families from the NICUs

Dear “name”

We are contacting you in connection to the death of “patient” at the Neuro-intensive care unit at XX Hospital ”month – year”.

Since the beginning of 2009 the neuro-intensive care unit has been involved in anthropologist Anja Marie Bornø Jensen’s comprehensive research study on the topic organ donation in Denmark. She has been onside in our department and have made investigations on how we are handling organ donations, and what work related tasks we as staff have in that connection.

Anja’s study focuses on the situation and the experiences of the families of organ donors. Anja would therefore like to talk to families, who have been asked about organ donations here at our hospital in the years of 2008 and 2009. We wish to support Anja’s study and therefore we forward her query in the attached letter.

We hope you would like to participate in the study.

Best regards

XX
Nurse

XX
Clinical Nursing Supervisor

XX
Head of the Clinic, Senior Doctor

XX
Senior Doctor

Appendix 4 – Letter to donor families from Anja

Dear Families,

My name is Anja Marie Bornø Jensen. I am an anthropologist and employed as a PhD student at Copenhagen University. I am working on a greater three years study on the topics organ donation and organ donor's relatives. This is the only major study on these topics in Denmark.

I am contacting you through the neuro-intensive care unit at XX Hospital, as I would very much like to talk to you about your family's experiences and reflections in connection to your loss of a family member and to the decision you made on organ donation. I would like to learn from your experiences as relatives in such a tragic situation, which thoughts you generated on organ donation, both while it was happening in the hospital and now in the period after.

Through my studies I gain knowledge about organ donation by talking to people who have been involved in organ donations, both families affected and the hospital staff. Furthermore I have been doing observations on how organ donations are handled in various Danish hospitals. Therefore I am travelling around Denmark to conduct interviews with families, doctors and nurses and I am participating in conferences and seminars on the subject organ donation too.

During 2009 I visited different Danish neuro-intensive care units where I followed the staff and observed how they acted and handled the organ donation procedure and how they talked to the relatives in the situation.

Now it is very important for me to learn, how you as relatives have experienced the time at the neuro-intensive care units XX Hospital and your decision on organ donation. The experiences from families are the key starting point in my study. All information and data collected will be used in my PhD thesis and hopefully also in the ongoing development of organ donation in Denmark, the present circumstances around the relatives and the understanding of their situation.

I therefore hope that you (and maybe your family members) will be able to find the time to have a talk with me. The interview will be a conversation, where I will be listening to you telling your story about what happened and how you experienced everything regarding the organ donation. Afterwards I will be asking some questions. The entire session will be lasting for a couple of hours.

The interview can take place at a time, which suits you. It can take place at your home, your workplace, at my workplace in Copenhagen or where you would prefer to meet.

All relatives participating in my studies will stay anonymous in both my thesis and in future publications. Furthermore I am subject to confidentiality related to all collected information and data.

If you will like to participate, then you are more than welcome to contact me on my mobile 30 55 93 21, by mail anja.jensen@anthro.ku.dk or you can use the enclosed envelope.

I hope to be hearing from you. Thank you in advance.

Best regards

Anja Marie Bornø Jensen

Abstract in Danish

Denne afhandling analyserer danske donorpårørendes erfaringer og organdonation i Danmark. Den er baseret på feltarbejde på fire danske neuro-intensive afdelinger, på interviews med donorpårørende og personale, samt på deltagelse i forskellige konferencer om organdonation i hele Danmark. Ud fra dette omfattende feltarbejde er det afhandlingens argument, at set fra de pårørendes perspektiv handler organdonation om meget andet end et spørgsmål om ja eller nej. Det er en fundamental ændring i velkendte traditioner, processer og ritualer omkring døden. Organdonation kan forstås som et "besynderligt fænomen". Det udfordrer kutymen og holdninger til grænser mellem liv og død og til de praksisser der omkranser døde kroppe. Men det kan også være en trøst og gøre nogle familier i stand til at finde en smule mening i et pludseligt og tragisk dødsfald.

Gennem hele afhandlingen bruges begrebet 'orkestrering' som den overordnede teoretiske ramme til at forstå hvordan pårørende, personale, og på et højere niveau, det danske samfund, forsøger at praktisere, genfortolke og oversætte den exceptionelle død og organdonation til noget der er kulturelt acceptabelt og meningsgivende. Studiet viser at donorpårørendes erfaringer er stærkt påvirket af det personale, der hjælper og støtter dem i processerne med at forstå hjernedød og samtykke til organdonation.

Skabelsen af tillid er et vigtigt element i orkestreringen af denne exceptionelle død. Hjernedøden er et sanseligt paradoks, fordi den døde ikke ser død ud. Derfor indgår familier og personale i komplekse processer med at ritualisere døden og interagere med teknologien for at være i stand til at træffe beslutninger om organdonation. Det vises også hvordan danske donorpårørende transformerer håb. Ud fra opfattelser af hvad der udgør et værdigt liv, bevæger nogle familier sig fra at håbe på overlevelse til at håbe på at døden indtræffer. Disse praksisser omkring

håb omfatter også at håbe på et godt udfald af transplantationerne og at håbe på forbedringer i omsorgen for fremtidige donorpårørende.

Ved at analysere æstetiseringen af organdonorens krop, diskuteres det hvorledes personale og donorpårørende prioriterer at donorens krop ser ”pæn” ud og bliver behandlet med respekt. Æstetiseringen er tæt knyttet til lægers og sygeplejerskers faglighed og etik, og det fremhæves at æstetiseringen er en strategisk måde at orkestrere døden af hensyn til såvel donorpårørende som personale.

Afhandlingen diskuterer også de sociale betydninger af organer og argumenterer for at de indeholder ambivalente meninger. Socialiteten omkring organernes udveksling er tæt knyttet til de sociale omgivelser på sygehusene og til de forskellige måder donorpårørende opfatter deres relationer og forpligtelser overfor Danmark som en velfærdsstat. Formålet med og konsekvenserne af de nationale strategier for at skjule og anonymisere de farlige sociale forhold mellem donorpårørende og organmodtagere diskuteres også. De anskues som et strategisk værktøj til at orkestrere døden og de offentlige opfattelser af organdonation.

Afslutningsvis fokuserer afhandlingen på historier om organdonation og diskuterer hvordan det at fortælle en historie kan være meningsfuldt for pårørende, men også frustrerende hvis familien ikke har noget sprog for deres oplevelser. Ved at sammenligne med indsigter fra det amerikanske organdonationsfelt, diskuterer afhandlingen også de særlige måder danske pårørende bliver håndteret og anerkendt efter de har sagt ja til organdonation.

I konklusionen understreges de vigtigste pointer og baseret på denne forskning foreslås der konkrete fremtidige initiativer på området.

Abstract in English

This thesis analyses the experiences of Danish donor families and the context of organ donation in Denmark. It is based on fieldwork at four Danish neuro-intensive care units and on interviews with donor families and hospital staff and participation in various events on organ donation all around Denmark. Based on this comprehensive field study, the thesis argues that from the family perspective, organ donation is more than a question of deciding yes or no. It is a fundamental change in familiar traditions, processes and rituals surrounding death. Organ donation is a 'strange figure'. It is challenging customs and attitudes regarding the boundaries between life and death and the practices surrounding dead human bodies. But it can also be comforting and enable some families to make sense of a sudden tragic death.

Throughout the thesis, the concept of 'orchestration' serves as the overall theoretical framework to understand how families, hospital staff and, on a larger scale, Danish society attempt to perform, reinterpret and translate this exceptional death and organ donation into something culturally acceptable and sense making. The study shows that the experiences of donor families are deeply affected by the hospital staff helping and supporting them in the processes of understanding brain death and consenting to organ donation.

The performance of trust is an important element in the orchestration of this exceptional death. Brain death is a sensory paradox because the dead does not look dead. As a result, families and staff engage in complex processes of ritualizing death and interacting with technology in order to be able to make the decision about organ donation. It is also shown how Danish donor families transform hope. Based on perceptions of what constitutes a dignified life, some families move from hoping for survival to hoping for death. The practices of hope

also entail hoping for a good outcome of the transplantations and hoping for improvements in the care for future donor families.

By analysing the aesthetization of the body of organ donor, it is discussed how staff and donor families prioritize that the body of the donor “look nice” and is treated with respect. Aesthetization is closely connected to the professionalism and ethics of doctors and nurses and it is argued that aesthetization of the donor body is a strategic way of orchestrating death not only to support donor families, but also the hospital staff.

The thesis also discusses the social meanings of the organs and argues that they carry ambivalent agency. The sociality of exchanging organs is deeply connected to the social surroundings of the hospital and to the various ways donor families perceive their relationship obligations to Denmark as a welfare state. The purpose and implications of the national strategies to disguise and anonymize the precarious social relationships between donor families and organ recipients are also discussed as a strategic way of orchestrating death and the public perceptions of organ donation.

Finally the thesis focuses on the stories of organ donation and discusses how telling stories can be meaningful to families but also frustrating if families do not have any language for their experiences. Comparing with findings from the American context for organ donation, the thesis also discusses the particular ways Danish families are handled and acknowledged after donating organs.

In conclusion the main points of the thesis are underlined and future improvements based on this research are suggested.

This Ph.D. thesis explores the experiences of Danish donor families and the context of organ donation in Denmark. Based on comprehensive ethnographic studies at Danish hospitals and interviews with health care professionals and donor families, readers are invited on a journey into the complex processes of facing brain death and deciding about organ donation.

This study suggests that organ donation should be understood as a 'strange figure' challenging traditions and attitudes regarding the boundaries between life and death and the practices surrounding dead human bodies. Simultaneously, organ donation can be comforting and furthermore enable some families to make sense of a sudden tragic death. Throughout the thesis, the concept of 'orchestration' serves as the overall theoretical framework to understand how families, hospital staff and, on a larger scale, Danish society attempt to perform, reinterpret and translate death and organ donation into something culturally acceptable and sense making.

With chapters focusing analytically on the performance of trust, the transformative practices of hope, the aesthetization of ambiguous bodies, the sociality of exchangeable organs and the organ donation stories, the complexity of the donor family experiences and organ donation in Denmark is unfolded.