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Shining a Light on Organ Donation after Death

- on various aspects influencing organ donation

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Shining a Light on Organ Donation after Death
-on various aspects influencing organ donation
THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Introduction: The willingness to donate organs after death is widespread in our country, Sweden. Nevertheless, the donation rate is rather low and patients still die while waiting for an organ. One of the obstacles to organ donation is that people tend not to tell anyone about their decision. Consequently, the relatives of a potential donor are often unaware of the intention of the deceased and the decision is seldom found in the National Donor Registry. Adding to the complexity is the fact that an organ donation is such a rare event within the intensive care units (ICU) and this leads to staff lacking experience and knowledge of how to handle the donation process appropriately. Thus we believe that the reasons behind the low donation rates are multifactorial – this thesis will explore some of these factors.

Aim: The general aim of this thesis is to improve knowledge and understanding of various aspects influencing organ donation after death.

Methods: To explore the impact of information campaigns targeting the general public, three opinion polls were conducted: before and after a short term information campaign, and after a long term information campaign (Paper I). Furthermore, the impact of donation specialised nurses (DOSSes) on donation rates was assessed through reviews of medical records from three different periods (before the first DOSS, during an initial local project and during a permanent service covering the whole county). In addition, the ICU staff's views on the impact of the DOSS function was evaluated through questionnaires to ICU staff (during project and permanent service) (Paper II). Finally, the donor relatives' experiences of the medical treatment enabling organ donation was explored through in-depth interviews as was the donor relatives' own decision-making process, and whether their personal experiences of the donation process had influenced their own inclination to donate organs (Paper III).

Results: The short term information campaign had no impact on the general public. After the long term campaign, however, some changes were observed – these were most clearly pronounced in the group of middle-aged women. Through the introduction of the DOSS function the donation rate increased significantly and it was maintained at a high level after the transition into the permanent DOSS service. Furthermore, the ICU staff stated that the DOSS function clearly improved the working conditions during the donation process as well as the information given to the donor relatives. Finally, though brain death and organ donation proved to be hard to understand for many donor relatives, and though the comprehension of the medical treatment enabling organ donation was rather low, the donor relatives' personal experience of the donation process seems to inspire a willingness to donate.

Conclusion: Firstly, in order to inspire the general public to talk about and also to formally inform about their decision on organ donation, there is a need for continuous information targeted at different subgroups of the general public. Secondly, the rare occurrence of organ donation within the ICUs renders the involvement of specialised staff – such as the DOSSes – of great value for donation rates as well as for the quality of the handling of the acute donation process and the situation for donor relatives. Thirdly, in order to help donor relatives better comprehend the circumstances surrounding an organ donation, there is a need for a greater transparency and clarity regarding all the steps taken during the donation process. However, having experienced the donation process closely did not discourage the donor relatives from donating their own organs – but rather inspired a willingness to donate. This indicates an acceptance of the medical procedures necessary in order to enable organ donation after death. Hence, our studies indicate that there are various ways of influencing and also optimising organ donation after death.

LIST OF SCIENTIFIC PAPERS

I. Linda Gyllström Krekula, Silvia Malenicka, Margareta Linder, Annika Tibell.
From words to action - influence of two organ donation campaigns on knowledge and formal decision making
Clin Transplant, 2009;23(3):343-50

II. Linda Gyllström Krekula, Silvia Malenicka, Anders Nydahl, Annika Tibell.
From Hesitation to Appreciation: the transformation of a single, local donation-nurse project into an established organ-donation service
Clin Transplant, 2015;29(3):185-96

III. Linda Gyllström Krekula, Ulla Forinder, Annika Tibell.
What do people agree to when stating willingness to donate? On the medical treatment enabling organ donation after death
Submitted Manuscript

CONTENTS

LIST OF ABBREVIATIONS

DAL	Donation Responsible Physician
DAS	Donation Responsible Nurse
DBD	Donation after Brain Death
DCD	Donation after Circulatory Death
DOSS	Donation Specialised Nurse
EDHEP	European Donor Hospital Education Programme
EMA	Early-Middle-Aged
ICU	Intensive Care Unit
LMA	Late-Middle-Aged
OPO	Organ Procurement Organisation
PMI	Per Million Inhabitants
SD	Standard Deviation
VAS	Visual Analogue Scale

PREFACE

MY PERSONAL JOURNEY

This year I celebrate 20 years as a social worker, an occupational identity I hold with pride. I also celebrate 10 years of working with organ donation. As I now sit in my room, in this anniversary year, and I start writing on my thesis, I must admit that it feels rather solemn.

To work with organ donation, and in recent years also with transplanted patients, has been a journey for me in terms of knowledge and also emotionally; from being rather ignorant while working with the organ donation issue in an organisation that very clearly promoted organ donation, and without fully being at ease with what I wanted after my own death, (did I really want to donate my heart?...) to also meeting patients who indeed had received organs, and who were granted the opportunity to start a new era in their lives. It has not always been easy to relate to the field of organ donation and transplantation, and probably quite rightly so, as this field is filled with advanced medical innovation, ethics, feelings, existential perplexities... but over the years the picture has become increasingly clear.

I owe a lot to my husband and I also owe a lot to my two amazing sons – Folke and Rune – whom I have had the great fortune to give birth to during my doctoral studies. Becoming a mother was a humbling experience for me. Through my sons' entry into my life the organ donation issue was simplified – all of a sudden it became so clear that life is here and now, and that I would 'do anything' to keep on living with my boys and that I also would 'do anything' to help them to continue their lives, if they were struck by severe illness. This insight also reinforced my empathy with other people in need of organs and my position on organ donation suddenly felt much easier. If my family can help someone in need, in the same way as we would want to be helped, there is no doubt. To be able to give someone – a son, a mother, a husband, a grandmother – their health or 'life back', after one's own death, suddenly felt like a wondrous grace.

***The fusion of research and clinical work** ... While working on this thesis I have had my starting point in my professional identity as a social worker, and I have looked at the organ donation issue from many different levels and perspectives. In my professional role I have enjoyed the favour of both doing research within a field that never ceases to engage me, and at the same time meeting patients who hopefully, ultimately, will benefit from my research. Having had knowledge about organ donation as a medical social worker with kidney transplanted patients, has been a privilege. Being familiar with the entire chain of events, from the sudden death in the intensive care unit; to the donation; to the transplantation of the patient, has proved to be meaningful, especially when I met newly transplanted patients. Having received an organ and carrying it in one's body, often raises existential questions about life, death and organ donation. This process is filled with joy, gratitude, and a newfound zest for life – as well as reflection, existential pondering, guilt, anxiety and uncertainty. To then be able to share my knowledge and help patients by making this process more understandable, feels meaningful and I believe that it has often helped patients to be more at ease with their new organ.*

***Breaking taboos ...** Furthermore, I want to break the old taboo concerning the mention of organ donation and transplantation in the same context – thus to build an imaginary bridge between the* *donor and the transplanted patient. When I began my work with organ donation just over 10 years ago, it was almost taboo to talk about the recipients of the organs – this, as the good of a donation was considered enough in itself. But then, none of us would donate organs if there were no recipients. Ultimately, it ought to be the well-being of the recipients that is the strongest driving force for anyone who, in one way or another, is involved in promoting organ donation. The meaningfulness that many donor families also feel when their deceased family member donates organs, is seldom primarily about the donation itself, but about the fact that someone else – through an often seemingly meaningless death –is actually helped to a better life, or is saved from an imminent death. I believe that the intensive care staff should inform the donor relatives about the circumstances surrounding patients in need of a transplant, in the same way as I inform the transplanted patients about the circumstances of a typical donor. My experience tells me that donor relatives actually do want to know if a donation really is useful: are there really patients waiting for an organ and, if so, do they indeed get a better life after a transplantation? I don't regard this information as an improper influence – I rather see it as guidance in a delicate situation – as one piece in a puzzle that needs to be put together in order for a well-founded decision about organ donation to be reached.*

To nuance the picture... *During lectures, seminars and courses that I have had the privilege to lead over the last ten years, I have met hundreds of ICU staff. Thanks to their openness, I have gained valuable knowledge and understanding of the work at the Swedish ICUs and I have been allowed to follow the discussions of the developments within the Swedish ICUs during the last decade. I especially want to highlight the valuable insight that I have gained through my function as moderator for EDHEP, European Donor Hospital Education Programme, which is an interactive seminar where, during two full days, the participants personally reflect in depth on the donation issue. When involved in these contexts, one task that I have valued highly is to modify the undifferentiated picture of organ donation and transplantation that sometimes is painted. When I mention that I work with transplanted patients, the first reaction I get, is often: Oh, isn't it amazing that it's possible to help people to a new life through a donation! However, when I mention that I do research about organ donation, the reactions are often different: Oh, isn't that a difficult subject, isn't it hard to work with death all the time? We humans seem to have a need to simplify things, but I believe that it sometimes is appropriate to question our perceptions. Why do we, within the health care system, so often label the conversation about organ donation with donor families as the "difficult conversation", and why do we talk about organ donation as something solely dreary and difficult? More so, why do we talk about a transplantation as a solely positive and desirable final destination, when it really is the starting point of a new life-changing journey? Organ donation is not solely dark and difficult – and it is not only bright and easy to be transplanted.*

Two sides of the same coin ... *In this thesis I have endeavoured to direct the spotlight to that side of the coin which is often, undeservedly, held in darkness; organ donation after death. Finally, I hope that we are ready to build a bridge of knowledge between organ donation and transplantation, two areas that deserve equal attention as they, inevitably, are two sides of the same coin.*

Cambridge Dictionary: "If two things are two sides of the same coin, they are very closely related although they seem different."

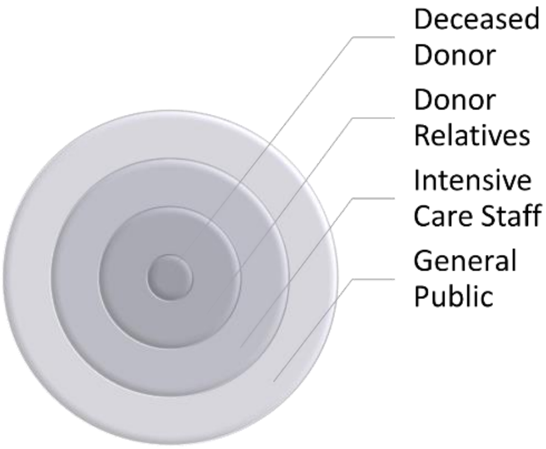
1 INTRODUCTION

Regardless of how hard the medical professionals strive to save the lives of patients with life-threatening bleedings in the brain, there are occasions when this just cannot be done. If a patient subsequently dies at an intensive care unit (ICU) while treated on a ventilator, organ donation may become a possibility. In this defining moment, the attitudes and knowledge among the ICU staff, the awareness and experiences of the patient's relatives, the intention of the deceased as well as the regulatory framework surrounding death and organ donation are crucial elements for the way the donation process proceeds. There are many links in this delicate chain that can potentially break. However, in order to respect one of the last wishes of the deceased, the chain of actions surrounding an organ donation needs to be handled appropriately. Hence, this thesis focuses on four key actors involved in the donation process: the deceased donors, the general public, the intensive care staff and the relatives of the deceased donors.

1.1 THE ORGAN DONATION CONTEXT

The field of organ donation is wide and complex, and in order to describe some of the dynamics of this field, a broad introduction will be provided. The aim of this overview is to put the papers included in this thesis in a relevant context, and to give the reader a better understanding of the various aspects of the papers included.

Hence, the introduction will cover: definitions of importance for the understanding of this thesis; organ donation history – who were the early donors in Sweden?; the Swedish regulations – what impact do the various regulations have on the donation process?; organ donation rates – on the Swedish donation rates followed by efforts to reach national self-sufficiency and the prevention of a black market. Finally, the four key actors that this thesis addresses are introduced: the deceased organ donors; the donor relatives; the ICU staff and the general public.



1.2 DEFINITIONS

Organ donor: The most common Swedish donor is a person who, unexpectedly, was struck by a spontaneous, life-threatening bleeding in the brain, admitted to an ICU, treated with a ventilator and subsequently died due to a total brain infarction, all this within a short period of time.

Donor relatives: In this thesis the use of the term 'donor relatives' was chosen to indicate that the formation of families differs greatly in a modern society. For some, the closest relatives are still the family members, but for some, friends or colleagues are the closest relatives. Many also live in single households – hence, the term 'donor relatives' includes close family members, other relatives or life companions and friends.

Intensive care staff: In this thesis the categories included in the definition 'intensive care staff' (ICU staff) are nurses, assistant nurses and physicians (anaesthesiologists and intensivists), all working at an ICU. When any one specific category is referred to in this thesis, this will be indicated in the text.

Donation Responsible Physicians (DAL) and Donation Responsible Nurses (DAS): The DAL and DAS are responsible for the overall donation activity at their own hospitals and in their regions, and for ensuring that the work with organ donation is organised and carried out satisfactorily. Furthermore, they are responsible for the availability of organs intended for transplantation and for the quality assurance of the donation process.

Donation Specialised Nurse (DOSS): Nurses trained in, and specialised in, organ donation. The DOSSes provide support to an ICU team during the acute donation process. In the acute situation, the DOSSes primarily focus on: the medical treatment of the donors; being a support for the ICU staff, and the care for and information to the donor relatives. This category of staff (DOSS) is unique for Stockholm County.

Medical treatment enabling organ donation: When the life sustaining treatment no longer is benefitting the patient, some treatment may still need to be prolonged and additional treatment may need to be introduced during the dying process, in order to maintain the possibility of organ donation. This treatment aims at maintaining organ viability in order to make the organs transplantable. In this thesis this treatment will be referred to as 'medical treatment enabling organ donation'.

1.3 THE HISTORY OF ORGAN DONATION

Far from what is a typical Swedish donor today (described in chapter 1.6), are the donors that we find in stories, thousands of years old, describing transplantation: we find them in ancient myths, in the Bible and other historical documents and archaeological records [1-3]. One of the most famous stories is “the miracle of the black leg” [1]. This story is about the Arabian twins and physicians, Cosmas and Damian, who lived in the third century AD. The brothers practiced medicine in a way that, at the time, was seen as miraculous, and without accepting any payment for their services. This led to them being made saints in the 11th century. Allegedly, they replaced a man’s malignant and gangrenous leg with a leg from a recently deceased Ethiopian man. In order to procure the transplant, one of the brothers went to a gladiator churchyard, and disentombed the body of the recently dead man [1-3].

The Healing of Justinian by Saint Cosmas and Saint Damian, Fra Angelico, 1438-40. Museo di San Marco, Florence, Italy. The transplantation of a leg from a dead man to an injured soldier.
(Painting reproduces with permission of Museo di San Marco)

During the 18th and 19th centuries, within the donation and transplantation field the focus of the early pioneers was on experiments with animals. During the 19th and the early 20th centuries tissues mainly from animals, but also from humans, were transplanted into humans with relative success [1-3]. During World War I, the need for finding ways to successfully transplant skin was escalated by the many wounded men in need of skin [3]. At the beginning of the 20th century the first attempts were made to transplant organs from animals into humans, and a goat and a pig kidney were transplanted, but with tragic outcome [3, 4].

The first human-to-human organ donation and transplantation in modern times were performed in 1936 in Ukraine. On this occasion a woman received a kidney from a deceased donor, but the kidney never functioned and the woman died [2-4]. The growing knowledge of the body’s natural defence mechanisms and the immune system’s impact on the rejection of the graft, was one of the essential findings that led up to the first successful kidney transplantation in 1954 in Boston, Massachusetts, between identical twins [2, 5]. The recipient lived for 8 more years and the donor lived another 56 years. From then on, several identical twin donations and transplants were performed worldwide [1-4, 6]. From then on the story of the transplanted patients is well documented, as are the challenges and accomplishments within the transplantation field. Today, transplantation is a successful and well-established part of the medical health care in many countries.

In this thesis, though, the focus is on deceased organ donation – and on the donors and their relatives. Although organ donation is the prerequisite for any transplantation, there is much less obtainable information about the historical perspective of the deceased donors than about the transplanted patients. In 1962, though, the first successful transplantation of a kidney from a deceased donor was performed, also in Boston, Massachusetts [1, 2].

In the absence of documentation of the early deceased donors in Sweden, the framework that regulates death provides complementary information. This, as the historical development of the concept of death, from the cardiorespiratory definition of death (cardiac death) to death caused by a total brain infarction (brain death) tells a story of who was considered a potential donor in general. Furthermore, one of the transplant surgeons who participated in the procedures surrounding the early deceased organ donors in Sweden has contributed information about the history of deceased organ donation in our country [7].

In 1964, the first deceased donors donated organs in Sweden. These first donations were performed at a hospital with a transplantation unit already practicing living donation – the Seraphimer Hospital [7]. However, at that time there was no legal definition of death, but a person was traditionally declared dead after the loss of heartbeat, breathing and circulation. Hence, the organs from the early donors were recovered after the patient had been declared dead according to practice at that time [7]. Yet, a different surgical team at a different hospital recovered a kidney from a patient who instead had suffered a massive and fatal bleeding in the brain and who was treated with a ventilator [2, 5]. Today, according to current praxis and legislation, this patient would most likely be pronounced dead due to total brain infarction. However, at that time the concept of "brain death" had not yet been accepted and consequently the patient could not be declared dead [2, 5]. Still, one single kidney was procured without the explicit consent of the patient, but with the consent of the patient's relatives [2, 5]. The donor was declared dead due to cardiac arrest two days later [2, 5]. This case provoked an intense debate in Sweden among the medical profession and the governmental authorities, as the patient, according to practice at that time, was regarded as alive when the kidney was recovered [2, 5, 8, 9]. Hence, the so-called "dead donor rule" was considered to have been violated [2, 10] and the concept of brain death was not introduced in Sweden until 1988 [11].

During the early era of donation and transplantation in Sweden, the kidney donors were mainly patients who arrived at the emergency room with acute cardiac arrest and whose function of the heart could not be restored [7]. The patients were subsequently declared dead according to the cardiorespiratory definition of death, and the kidneys were then recovered [7]. This is what we today would call 'donation after circulatory death' (DCD). At that time, a patient was considered to be willing to donate if there was no explicit contradictory decision from the deceased. However, the donor relatives had the right to, on the patient's or even on their own behalf, oppose the donation [12]. In practice, though, there was usually no time to consult the patient's relatives, as the kidneys needed to be procured immediately in order for them not to be destroyed by the lack of oxygen, which is an immediate consequence of death. Hence, the organs were often recovered without communication with the donor relatives, as the relatives were seldom present at the hospital at this early stage [7]. Between the years 1956-1988, Sweden was the country that had transplanted the highest number of patients with kidneys from deceased donors, of the Scandinavian countries (N=3960) [13, 14]. In 1974 the first pancreas was recovered from a deceased donor and subsequently transplanted, and in 1984 the first liver was recovered and transplanted [6, 15]. The first heart transplantation was also performed in 1984. This heart, however, was recovered from a donor in Germany [6, 14] as the heart needed to be donated from a brain dead donor in order to function in the recipient. Three more Swedish patients were transplanted with hearts from abroad before the legislation was changed and the concept of brain death was introduced in Sweden in 1988. This change finally opened the possibility for Swedish donors to also donate hearts [6].

The first kidney from a deceased donor transported within Scandinavia in June 1969 [13].
(Picture reproduced with permission from John Wiley and Sons.)

However, the introduction of the concept of brain death was vividly debated among the medical profession and the politicians in Sweden, and the transition from ‘cardiac death’ to ‘brain death’ took much longer than in many other western countries [2, 5, 8, 9, 16]. Nevertheless, the development and use of medical devices supporting the functions of the heart, made it apparent that a patient could still be alive even though the heart could not beat on its own. On the other hand, a patient could actually be dead even though a ventilator maintained the breathing and though the heart was still beating. Furthermore, with the development of better surgical techniques and the first immunosuppressive drugs, transplantation had become a realistic and effective therapeutic treatment for many patients in need of a transplant, which emphasised the demand for new regulations [2, 3, 5]. However, at the time, transplantation was considered by some to be unethical and a luxury that prevented seriously ill citizens from receiving the medical health care they needed [6, 16, 17]. The first transplantations were surrounded by intense media attention questioning the procedures: News headlines claimed that the transplantation activities were carried out in secrecy, and that they were illegal and unnatural, and performed to make the surgeons shine [6, 15, 16]. Nevertheless, in 1988 the brain death criteria was formally introduced by law in Sweden [11]. Since then, a person is dead when the function of the whole brain is totally and irreversibly lost [11].

The introduction of the new legislation also led to changed routines surrounding organ donation after brain death, which further emphasised the need for a newly formed medical profession: the transplant coordinators. In 1985 the first transplant coordinator was appointed in Sweden and ever since, medical records have been kept of each deceased donor. Since then, between 97-166 deceased donors in Sweden have donated one or more organs every year [14].

1.4 THE REGULATORY FRAMEWORK SURROUNDING DEATH AND ORGAN DONATION

There are several Swedish laws, provisions and general guidelines that regulate organ donation. In the following chapter the regulations will be introduced in the order in which they become relevant during the dying and donation process.

The following Swedish legislations and regulations concern death and organ donation:

- Health and Medical Services Act (SFS 1982:763)
- Act concerning Criteria for Determination of Human Death (SFS 1987:269)
- Transplant Act (SFS 1995:831)
- The National Board of Health and Welfare’s provisions and general advice concerning Criteria for Determination of Human Death (SOSFS 2005:10)
- The National Board of Health and Welfare’s provisions concerning donation and procurement of organs, tissues and cells (SOSFS 2009:30)
- The National Board of Health and Welfare’s provisions concerning the management of human organs intended for transplantation (SOSFS 2012:14)
- The National Board of Health and Welfare’s provisions and general advice concerning life-sustaining treatment (SOSFS 2011:7)
- The National Board of Health and Welfare: To give or not to give life-sustaining treatment - Handbook for caregivers, managers and staff
- Patient Act (SFS 2014:821)
- Personal Data Act (SFS 1998:204)
- Public Access to Information and Secrecy Act (SFS 2009:400)

1.4.1 Regulations before death

Measures to medically prevent, investigate and treat diseases and injuries are regulated in the Swedish health and medical services act [18]. The goal of the medical health care is good health and care on equal terms for the entire population. The opening paragraphs regulate the medical health care in general, and the Swedish health and medical services act as a whole, regulates the medical care provided before death.

1.4.2 Regulations during the dying process

When a critically ill patient is deteriorating, in spite of being provided optimal therapeutic treatment, the patient-responsible physician shall assess if further life-sustaining medical treatment is benefitting the patient, or if further medical treatment is futile [19, 20]. This means that the life-sustaining treatment, including the ventilator treatment that all possible organ donors are treated with, ought to be withdrawn if the assessment leads to the conclusion that the patient not will survive. However, in order for a donor to be able to donate organs, the medical treatment instead needs to be prolonged until the patient has developed a total brain infarction (brain death). The medical treatment provided in order to maintain the possibility of organ donation during this phase – from the time point when the medical treatment is declared futile, until death has been declared – is not addressed in the current regulations. A strict adherence to the current regulations would rule out organ donation, as the medical treatment necessary to enable organ donation would have to be withdrawn. Nevertheless, a prolonged medical treatment is instead needed while it is being determined whether the patient is a potential donor or not, and also in order to maintain a good quality of the organs. To clarify the regulations of this phase of the dying process, The National Board of Health and Welfare has stated that the care and treatment (such as the ventilator care) of the vital functions of a patient expected to develop brain death, may be maintained and prolonged until the diagnostics of brain death are possible to conduct [20]. The regulations during this phase, however, are currently being reviewed by an investigation initiated by the Swedish Government, aiming at clarifying the current regulations [21] (see paragraph 1.4.7).

1.4.3 Regulations after death

If a patient cannot be saved and subsequently dies, the framework that regulates the declaration of death is the Act concerning Criteria for Determination of Human Death complemented by provisions made by The National Board of Health and Welfare [11, 22]. The said law states that *a human being is dead when all the functions of the brain are totally and irreversibly lost*. This law also regulates the preservation of organs or other biological material, pending transplantation surgery. When death has been confirmed the medical treatment can be maintained for a maximum of 24 hours, unless there are compelling reasons. Furthermore, The National Board of Health and Welfare has clarified the regulations surrounding organ donation and the handling of human organs intended for transplantation [23, 24]. The board also specifies that the caregivers are required to promote donation from deceased donors and to make sure that all potential organ donors are identified. Hence, the regulations that define the medical activities needed in order to make organ donation possible are mainly found in the framework that regulates the activities after death. However, there is a need for medical interventions before death, in order for a donor to be able to donate organs.

1.4.4 Regulations concerning the consent process

1.4.4.1 Explicit consent

The basis for all medical care is the informed consent of the patients [25]. However, the fact that it is not possible to communicate with the patients who can potentially donate organs, complicates the consent process. The Transplant Act regulates the specific consent process in connection with organ donation after death [26]. The organs from a deceased patient can be recovered for transplantation, if the patient has explicitly consented to donation during his/her lifetime. At least one donor relative should then be informed about the intended donation.

1.4.4.2 Interpreted consent

Furthermore, the organs can be recovered even if there is no explicit consent – if it is considered by the donor relatives to be in agreement with the intention of the deceased.

1.4.4.3 Presumed consent

The law also opens up for a recovery of the organs according to the so called presumed consent (an individual is automatically seen as willing to donate) provided that;

- the deceased did not during his/her lifetime explicitly oppose a donation verbally or in writing
- it cannot, in any other way, be assumed that the deceased was unwilling to donate.

To establish the two latter conditions, at least one of patient's relatives must always be consulted.

1.4.4.4 Relatives' right to veto

When there is no explicit consent from the deceased, and the parties involved in the investigation of the intention of the deceased (in most cases the closest relatives of the patient) oppose organ donation, proceeding with an organ donation is not allowed. Hence, when the intention of the deceased is not known – but only then – the relatives have the right to veto. Furthermore, if the parties cannot come to an agreement on the intention of the deceased, proceeding with an organ donation is not allowed.

The regulations concerning the consent process do not specify the time point for the investigation of the intention of the deceased.

1.4.5 Ways of stating the decision

In Sweden, there are three equally valid ways of stating one's intention regarding organ donation:

- The National Donor Registry
- Donor Card
- Verbal Statement

If a person has stated her/his decision at more than one time point, the most recently dated decision is valid.

When the current Transplant Act was introduced in 1996, a National Donor Registry administrated by The National Board of Health and Welfare was formed, in which one can register a positive or negative decision regarding organ donation [27]. The personal data in the registry and the integrity of the registrants is to be protected. This is regulated in the Personal Data Act [28] and the handling of the personal data is also controlled by the regulations in the Public Access to Information and Secrecy Act [29]. When the registry was formed, The Swedish Data Inspection Board developed routines concerning the access to the registry and decided that the registry was not to be accessed until a patient had been declared dead. This decision was valid until the 1st of October in 2001. However, The National Board of Health and Welfare is still administrating the registry accordingly.

Another way to declare one's positive or negative decision regarding organ donation is to sign a Donor Card. Finally, one can simply tell one's positive or negative intention to relatives and friends, or communicate it via social media such as Facebook and mobile apps.

When stating one's decision regarding organ donation, one can choose to donate with the intent of transplantation only, or with the intent of transplantation and other medical purposes. One can also make exceptions for specific organs, but one cannot condition to whom one wants to donate.

1.4.6 The position of the patients

The position of the patients, and the patients' rights, have gradually been strengthened from the time of the first organ donation in Sweden in 1964. During these early days of organ donation, the organs were often recovered solely based on a presumed consent, without knowledge of the explicit intention of the deceased or of the donor relatives [7, 12]. Since then, the position of the patients has gradually been strengthened [30]. In the early 1980s the health care legislation was renewed, stressing the rights of the patients, and in year 2014 the current legislation was again rewritten with the intention of further strengthening the rights of the patients, and their possibilities to influence the care provided [25].

According to The Health and Medical Services Act, all care must be conducted with respect for the patient's autonomy and integrity [18]. However, in connection with deceased organ donation the patients cannot directly express their wishes regarding the care provided. In order to better clarify the unique circumstances surrounding organ donation, the praxis and regulatory framework is currently under investigation [21].

1.4.7 Government Investigation

During recent years, parts of the Swedish ICUs have drawn attention to the framework regarding the medical treatment enabling organ donation, and to other prerequisites for enabling organ donation within the medical health care [21, 31]. Criticism has been conveyed concerning the framework, which is perceived to not optimise the possibilities for organ donation, and to not sufficiently protect the intention of the patients during the donation process. In addition, many also state that the issue of organ donation currently is depending too much on the knowledge and attitudes of individual staff, and they therefore call for congruent national guidelines for organ donation.

In February 2013, during a cabinet meeting, a decision was made to initiate a government investigation, addressing some of the issues mentioned above [21]. The areas covered in the investigation are: information to the general public and the general public's possibilities to decide about donation; the organisation and working methods within the health care system and their impact on donation and transplantation activities; the prerequisites for promoting donation within the health care system; data exchange with Scandiatransplant and the process of living organ donation.

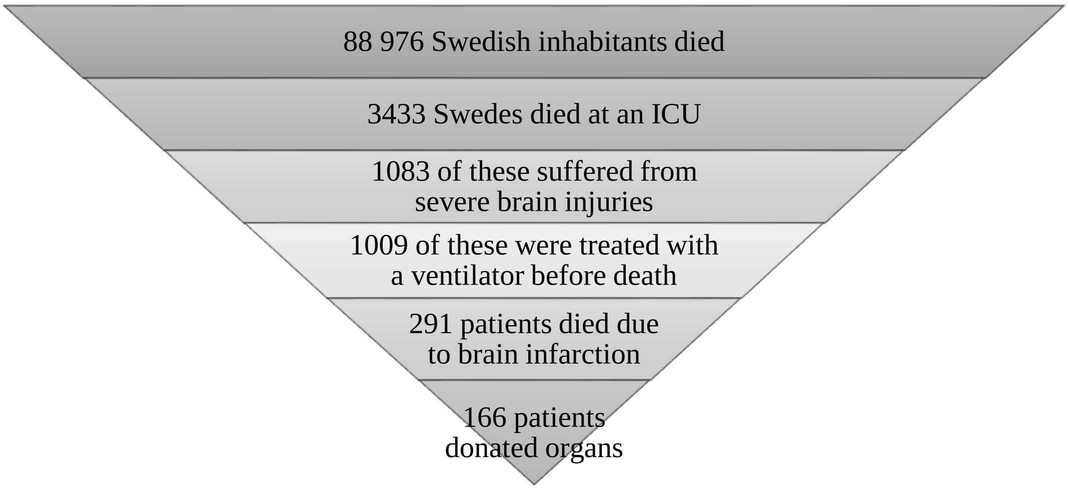
1.4.7.1 Regulatory framework – Relevance for the papers included

A clear and legally binding decision is of great importance for both staff and donor relatives during the acute donation process. However, there is little knowledge of what makes people inform about their decision on organ donation. In this thesis, Paper I highlights the impact of information campaigns on the public's inclination to donate and to formally inform about their decision. In Paper II, the donor relatives' inclination to use their veto when the intention of the deceased in unknown, is discussed. Finally, in Paper III, we aim at broadening our knowledge regarding an area little explored; the donor relatives' acceptance of the medical treatment that today is not completely regulated, but yet is provided in order to enable organ donation.

1.5 ORGAN DONATION RATES

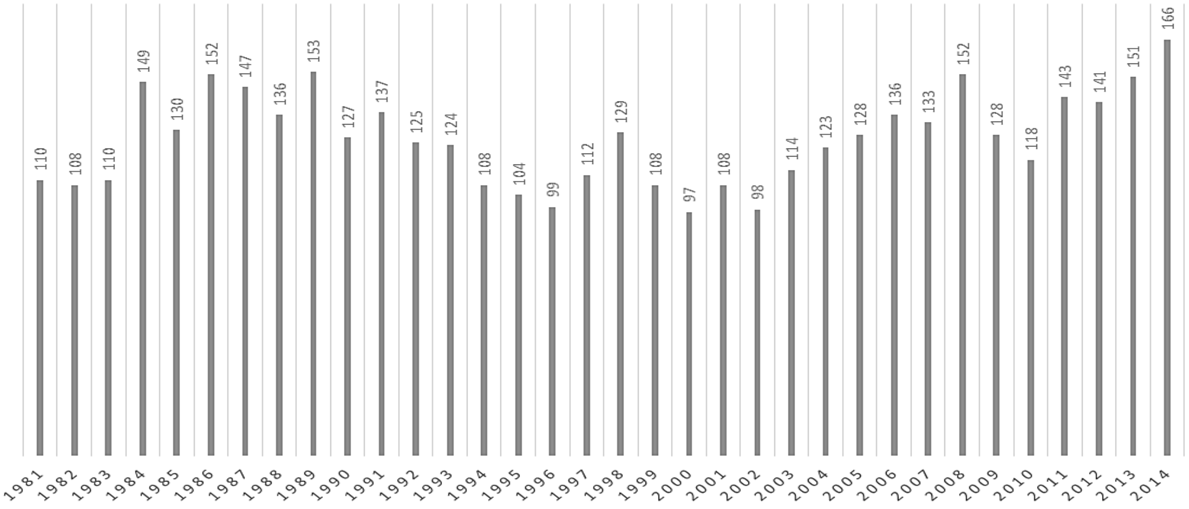
Each year, approximately 90 000 Swedes die – of these approximately 3300 die at an ICU [32, 33]. During year 2014, of all ICU patients with severe brain injuries (N=1083), 1009 were treated with a ventilator before death; of these 291 died due to a total brain infarction and 166 of these became donors [33]. Hence, only 4.8 percent of all the patients who died at an ICU became donors during year 2014 (Figure 1). Figures have shown the same tendency for decades [33]. Consequently, very few Swedes are ever in question for organ donation.

Figure 1. Illustration of deaths and donors in Sweden in year 2014



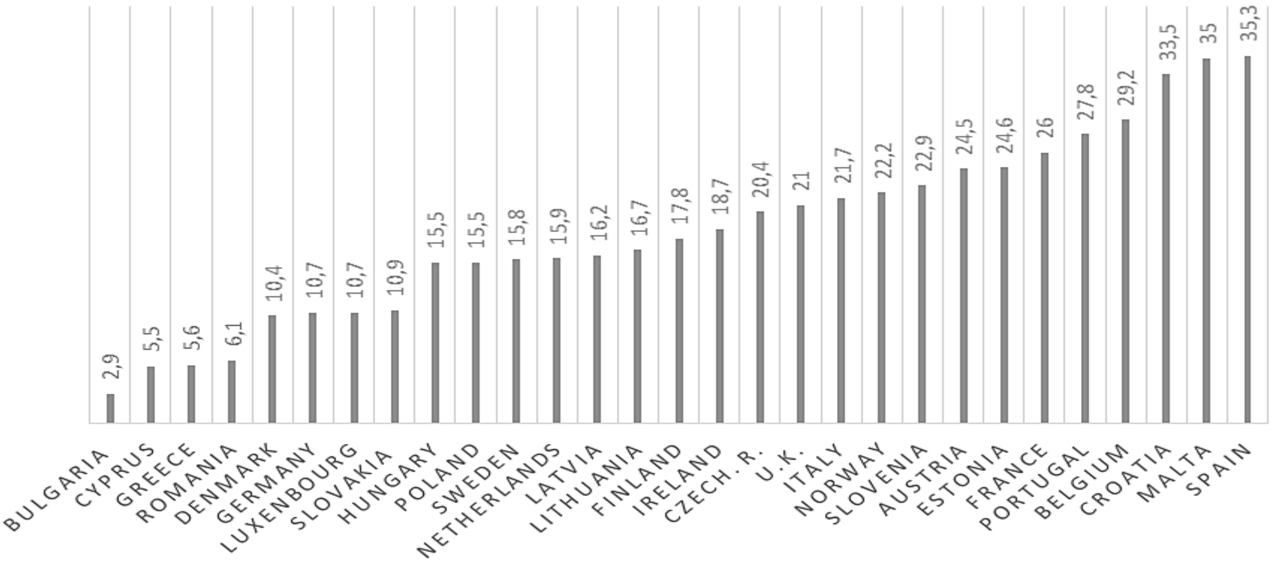
However, the donation rates in 2014 – with 166 donors – were higher than ever, resulting in 17.1 donors per million inhabitants (PMI) (Diagram 1) [14].

Diagram 1. Number of deceased donors in Sweden between the years 1981-2014



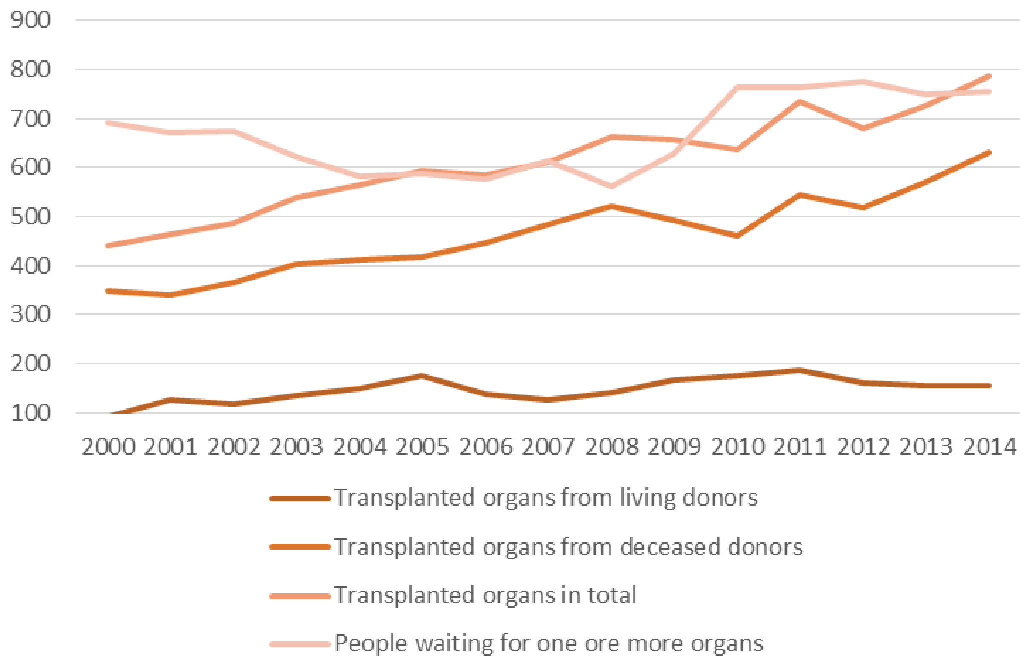
In comparison with many other countries, though, the number of deceased donors in Sweden is low in proportion to the number of inhabitants (Diagram 2) [14, 35]. One consequence of the relatively low donation rate from deceased donors is the frequent use of live kidney donors (Diagram 3) [33, 34]. Spain is the leading European country in terms of deceased donors per million inhabitants (PMI), with approximately 35 donors PMI. In Scandinavia, Norway distinguishes itself from the other Scandinavian countries with 23 deceased donors PMI in year 2014 [33, 14]. However, the donation rate in Sweden, as well as in many other countries, would most likely be different, taking factors like mortality and mean age of populations into account. In addition, Spain also includes DCD donors in the donation rate, which precludes a fair comparison. In order to standardise the international definitions of donors, which would enable a more accurate comparison of donation rates, definitions have been formulated in “The critical pathway for deceased donation: reportable uniformity in the approach to deceased donation” [36]. However, the necessary data in order to make such comparisons are not yet available internationally [36].

Diagram 2. Donation rates PMI within EU and Norway during year 2013, donation after circulatory death and donation after brain death included



Nevertheless, transplantation is a well-established part of the Swedish health care, and the results are good. However, due to the low donation rates patients are often forced to wait for an organ for a very long time, and some even become too ill to be candidates for a transplantation, or may even die, while waiting for a suitable organ [34]. The uncertainty of whether an organ will be available before a patient becomes too ill to be transplanted, may cause individual patients to seek organs elsewhere, from unregulated services abroad.

Diagram 3. Transplanted organs from deceased and living donors and people waiting for organs during the years 2000-2014 in Sweden



1.5.1 A continuous effort for national self-sufficiency and prevention of a black market

According to the Madrid Resolution, every country should strive to be self-sufficient when it comes to providing its population with donated organs. No country ought to depend on other countries when it comes to providing the inhabitants with organs. Each country is responsible for developing a national system for organ donation and transplantation if its inhabitants are to be offered transplantation as a therapeutic treatment [37, 38].

Internationally, however, there is still a lot to be done in order to fulfil these conditions. In order to promote national self-sufficiency, and uphold a high medical and ethical standard within the donation and transplantation field, The World Health Organization (WHO) has defined 11 guiding principles that provide a basis for the development of a regulatory framework concerning organ donation [39]. The Transplantation Society (TTS) also actively supports the development around the world of organisations and regulations enabling organ donation, according to the said guiding principles. This work is seen as one of the most important strategies to prevent and stop the abuse and exploitation of the often poor and marginalised inhabitants in various developing countries, who too often are victims of organ trade and trafficking [40-42].

Countries lacking an organisation for donation after death, or countries with very low deceased donation rates, are depending on living donors, but there are not enough living donors to fill the need. Furthermore, a living donor can only donate one kidney and in some cases also a piece of the liver. Hence, in these countries there is no, or limited access, to organs like heart and lungs and there is a shortage of donated kidneys and livers. All these limiting circumstances constitute a risk for the development of a black market with trafficking, organ trade and organ tourism, which is not to be neglected [40-42]. There are also examples of countries that systematically allow payment for organs [43]. In year 2007, 10 percent of the transplantation activities around the world were the result of unacceptable donations, according to the WHO [41]. The Council of Europe, the WHO, The United Nations, and the TTS clearly renounce the buying and selling of organs, and international guidelines – both ethical and medical – are continuously promoted to make organ donation and transplantation a well-organised, medically safe and more equally accessible treatment for people suffering from organ failure around the world [39, 44-46].

Even though no country has a true surplus of organs to be routinely offered to members of other countries, there are occasions when it is not possible to find a recipient within one’s own country which matches a specific organ immunologically. In order to share these organs Sweden is a part of Scandiatransplant, which is an established organisation for international organ sharing, guided by common principles, policies and a regulatory framework based on consensus voting of a board of directors [47]. The European Union has also defined an action plan for a strengthened cooperation between member states [48].

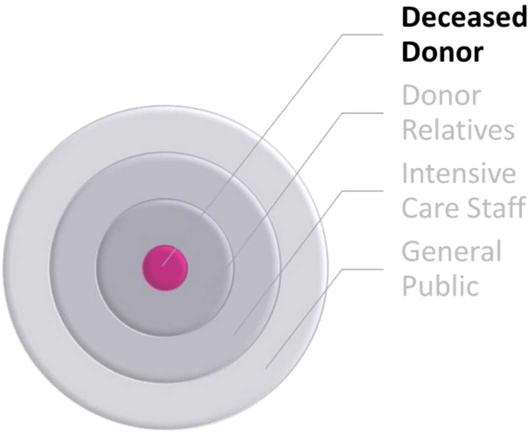
1.5.1.1 Donation rates – Relevance for the papers included

There are many factors that have an impact on donation rates, and it is of great importance that every country takes responsibility for the provision of organs within its own borders. In Paper I we therefore address the importance of informing the general public and of encouraging people to formally inform about their decisions so that their willingness to donate may become reality. In Paper II we describe how specialised staff can contribute to significantly improved donation rates. Finally, in Paper III, we explore how the donor relatives’ trust in and acceptance of the medical care provided during the donation process impact their own inclination to donate.

FOUR IMPORTANT KEY ACTORS

For organ donation to come about, there are several conditions that have to be met, both medical, ethical, regulatory, emotional, etc. In this process, there are four categories of individuals that play an important role and which this thesis evolves around; the deceased donors, the donor relatives, the intensive care staff, and the general public. In the following paragraphs these groups will be introduced, to serve as a context for the three papers included in this thesis.

1.6 A SWEDISH ORGAN DONOR – A COMMON SCENARIO



1.6.1 Spontaneous bleeding in the brain

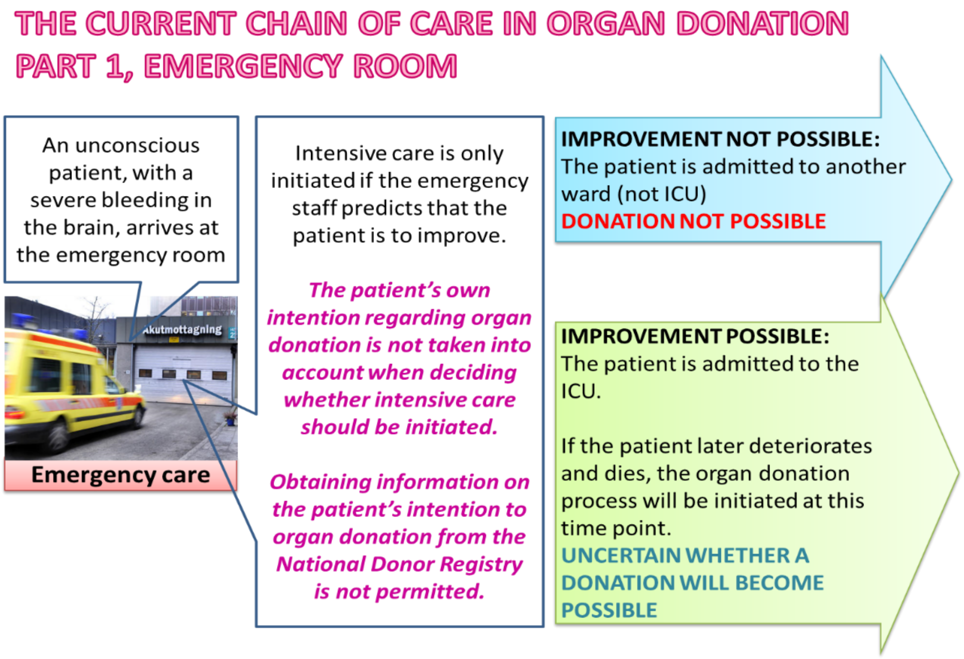
In Sweden the most common donor is a person who unexpectedly suffered a severe spontaneous bleeding in the brain (cerebral haemorrhage, approximately 70%), or, in some cases, was a victim of head trauma caused by for example physical violence or traffic accidents (approximately 15%), or who, for example, was a victim of drowning or who had attempted suicide (approximately 15%) [49, 50]. The person is initially taken to an emergency room and the medical team then makes an initial evaluation of the patient, most often including an x-ray of the brain and an assessment of whether the bleeding is operable. If this first prognosis indicates that the patient cannot be saved even by optimal therapeutic treatment, he/she is provided palliative care. However, if the patient is expected to improve, he/she is admitted to the ICU.

1.6.2 Treatment at an ICU

The subsequent ICU care includes life-sustaining treatment with a ventilator; one reason being that the severe damage to these patients' brains has led to unconsciousness. During ventilator treatment the patients are sedated in order to tolerate the invasive ventilation, as well as to relieve their brains from stress. Furthermore, this enables the medical staff to control the patients' body functions mechanically. Consequently, these patients are not able to express their wishes.

1.6.3 Rapid deterioration

If the patient still is deteriorating in spite of being provided optimal treatment, and in spite of all the efforts made in order to save the patient, and he/she later develops a total brain infarction (all the functions of the brain are totally and irreversibly lost) [11, 22, 51] he/she could possibly donate organs. This progression, from being struck by a life-threatening bleeding in the brain till dying, typically takes a few days, and death is then confirmed according to current legislation and standard protocol [11, 52]. From the time of death the ICU treatment can be prolonged for 24 hours in order to prepare for the organ recovery, and for the transplantation procedures [11]. The chain of care in conjunction with organ donation is illustrated in the flow chart below.



THE CURRENT CHAIN OF CARE IN ORGAN DONATION
PART 1, EMERGENCY ROOM

An unconscious patient, with a severe bleeding in the brain, arrives at the emergency room

Emergency care

Intensive care is only initiated if the emergency staff predicts that the patient is to improve.

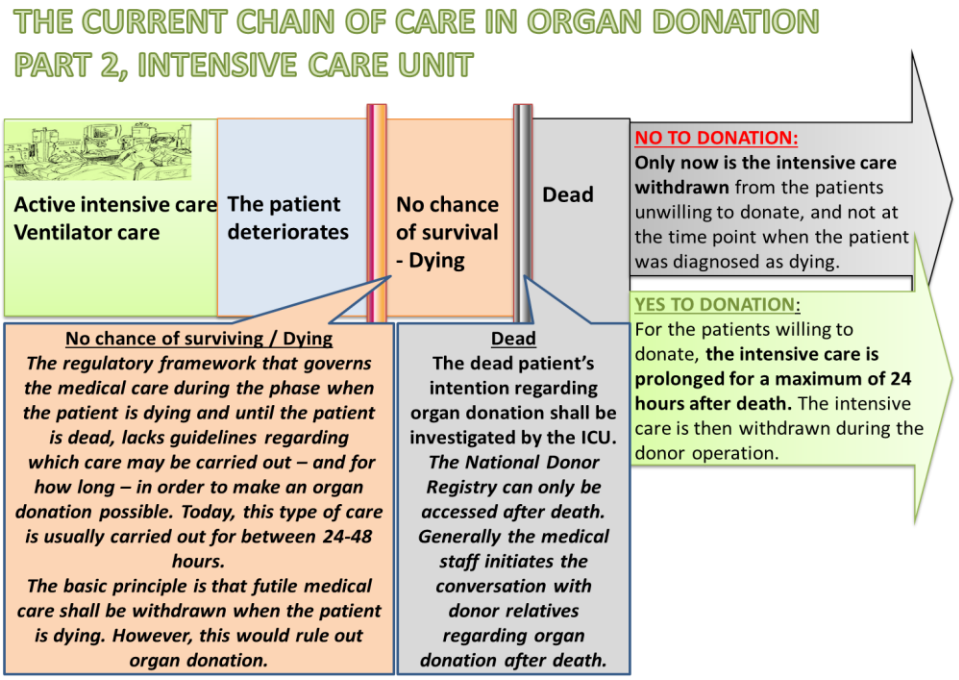
The patient's own intention regarding organ donation is not taken into account when deciding whether intensive care should be initiated.

Obtaining information on the patient's intention to organ donation from the National Donor Registry is not permitted.

IMPROVEMENT NOT POSSIBLE:
The patient is admitted to another ward (not ICU)
DONATION NOT POSSIBLE

IMPROVEMENT POSSIBLE:
The patient is admitted to the ICU.

If the patient later deteriorates and dies, the organ donation process will be initiated at this time point.
UNCERTAIN WHETHER A DONATION WILL BECOME POSSIBLE



THE CURRENT CHAIN OF CARE IN ORGAN DONATION
PART 2, INTENSIVE CARE UNIT

Active intensive care Ventilator care

The patient deteriorates

No chance of survival - Dying

Dead

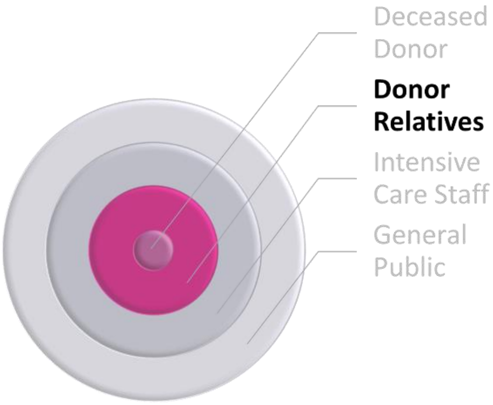
NO TO DONATION:
Only now is the intensive care withdrawn from the patients unwilling to donate, and not at the time point when the patient was diagnosed as dying.

YES TO DONATION:
For the patients willing to donate, **the intensive care is prolonged for a maximum of 24 hours after death.** The intensive care is then withdrawn during the donor operation.

No chance of surviving / Dying
The regulatory framework that governs the medical care during the phase when the patient is dying and until the patient is dead, lacks guidelines regarding which care may be carried out – and for how long – in order to make an organ donation possible. Today, this type of care is usually carried out for between 24-48 hours.
The basic principle is that futile medical care shall be withdrawn when the patient is dying. However, this would rule out organ donation.

Dead
The dead patient's intention regarding organ donation shall be investigated by the ICU.
The National Donor Registry can only be accessed after death. Generally the medical staff initiates the conversation with donor relatives regarding organ donation after death.

1.7 THE DONOR RELATIVES – A COMMON SCENARIO



1.7.1 Being in the ICU environment

For the donor relatives, organ donation is always a consequence of a tragic event – the loss of a family member, partner, relative or friend. This unexpected death often occurs in mid-life, is most often sudden and totally unexpected, as most donors in our country become donors after being struck by a severe spontaneous bleeding in the brain that causes a sudden death [49, 50]. When arriving at the ICU, the donor relatives find their family member with life-sustaining treatment: a ventilator controlling the breathing, technical equipment monitoring the blood pressure and oxygen levels, tubes and cables. The overwhelming visual impression, the sounds produced by the equipment, and the staff's high work pace are all elements of a modern ICU that the donor relatives have to relate to [53]. This environment has proved to be double-edged for the donor relatives: on one hand it signals safety, experience, knowledge and comfort; but on the other hand it signals uncertainty, stress and chaos [54, 55]. It is of the utmost importance for the donor relatives to be able to maintain closeness to their dying family member all through the dying process [54, 55]. However, the physical environment at an ICU often hinders the relatives from obtaining the much needed privacy during end-of-life care [54, 55].

1.7.2 Forced to face the loss within a short period of time

Normally the donor relatives are informed about the severity of the bleeding in the brain shortly after the arrival at the ICU, and in most cases they are informed about the bleak prognosis at an early stage. Within hours or days, they are also informed about the suspected total brain infarction, and about the tests that need to be done in order to confirm the suspicion. Gradually, the donor relatives are forced to take in the harsh truth; they are facing the death of a loved family member [56]. Hence, from sharing a life with an often seemingly healthy person, with no signs of a forthcoming tragedy, they are faced with the fact that their family member has died – all within a very short period of time.

1.7.3 Being dead but still looking alive

A complicating factor is the circumstance that when a patient is treated with a ventilator, the patient looks exactly the same before and after death: the heart is still beating, the chest is still moving as if the patient was breathing, the body is still warm, and the cheeks are rosy. Under these confusing circumstances the sudden death is often hard to understand for relatives and sometimes also for the ICU staff [56-63]. In a thesis based on the experiences of Danish donor relatives the author states that organ donation involves:

> "*… 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.*"[64]

To begin to grasp this situation - that the family member actually is dead though looking alive – and to be able to discuss organ donation, the donor relatives need time and support, as well as continuous well-adjusted information about the situation [64-66]. In one study, nurses point out the need to constantly clarify that the patient is dead, even though the patient looks alive [54]. Yet, what sometimes confuses the donor relatives' understanding of brain death is when the donor relatives hear the medical staff talk to the dead patient as if he/she was still alive [54, 56, 67]. It is perceived by the ICU staff to be a delicate and important – but also somewhat conflicting task – to treat the dead patient with full respect and full medical attention – as if the patient was still alive – and yet not send mixed signals to the donor relatives [54, 64]. Under these circumstances it is important that the staff in every way possible, both in speech and action, convey to the donor relatives that their loved family member really is dead, as this can help them begin to grasp the confusing circumstances surrounding brain death.

1.7.4 The timing of the donation request

The next challenge that the donor relatives face is the donation request. However, at what point in time the donation request is put to the donor relatives varies. In most cases the ICU staff does not initiate the conversation about organ donation until the patient is dead [68]. The donor relatives are then informed about the possibility to donate organs and are asked about the intention of the deceased family member. According to Swedish ICU staff, an increasing number of relatives are aware of the intention of the deceased, but still the intention is often unknown and the relatives are therefore asked to interpret the intention of the dead family member [33]. On some occasions donor relatives wish that the question about organ donation had been raised earlier on during the dying process, giving them more time to process the donation request, while, on the other hand, some relatives find that the request is almost impossible to answer, as they have not yet recognised the loss of the beloved family member [66, 69, 70]. However, a study of Swedish donor relatives indicates that though it is emotionally demanding, most donor relatives are able to discuss organ donation despite the shock and distress caused by the sudden death, and that it is the tragic loss and not organ donation specifically that causes the most distress [71].

1.7.5 The stability of the decision regarding organ donation

During the decision-making process, it has been established that the relatives' psychological reluctance to accept a sudden death and/or the lack of information and time, sometimes lead to a premature *no* to organ donation, which the relatives later tend to regret [59, 72-75]. The donor relatives need to be encouraged to reason about their initial decisions, whether the initial decision is a positive or a negative one, to make sure that the basis for the decision is solid [59, 75]. When the intention of the deceased is unknown, the donor relatives sometimes disagree on what they believe the deceased family member would have wanted [33]. This potentially adds further strain to an already demanding situation. On the other hand, it is often helpful if the decision is already known [70].

Understandably, there is an obvious risk that the relatives do not have the endurance to fully reason about the basis for the decision under the demanding circumstances surrounding the sudden death, unless they are provided guidance and support as well as time and proper information during the decision-making process [59, 61, 65, 67, 73, 76]. However, these complex discussions are often guided by a rather inexperienced physician who only has limited time to spend with the donor relatives (see paragraph 1.8.5, The ICU physicians' role). In addition, the relatives have to come to a conclusion within a limited amount of time, as the organ recovery, according to current regulations, has to be initiated within 24 hours (see paragraph 1.4.3, Regulations after death). This means that the donor relatives have to stay at the hospital until a decision is made, even though they are often emotionally and physically drained. Clearly there are many factors contributing to the delicacy of the decision-making process.

1.7.6 A lengthy and taxing wait in suspense during the donor operation

When the decision is made, the donor relatives face what often is perceived as a long and taxing wait during the donor operation, until the final farewell (clinical experience). However, an area little explored is the donor relatives' thoughts about the actual donor operation during which the organs are removed. The time span between the decision about organ donation and the final farewell after the donor operation is often lengthy. Hence, the donor relatives need to be adequately informed about why the procedure consumes so much time, which most likely would reduce disturbing thoughts.

During this wait, many donor relatives leave the hospital, and they are invited back to the hospital to take a final peaceful farewell of the family member after the donor operation (clinical experience). When someone has died due to brain death – in what sometimes is referred to as "warm death" – death often becomes clearer for the donor relatives once they get to see the "cold death" after the donor operation, because the dead family member then looks the way most people expect a dead person to look [64].

1.7.7 Consequences for the grieving process

When the donor relatives finally leave the hospital, they gradually begin to process the loss of a dear family member. Losing someone in an ICU has sometimes proved to complicate the grieving process [55]. In addition, unanswered questions about the organ-donation procedures further contribute to these complications [76]. However, many donor relatives and ICU staff also point out that an organ donation in itself can give meaning to the donor relatives' sudden loss, and that it can also can provide comfort and be of help during their grieving process [59, 64, 66, 77].

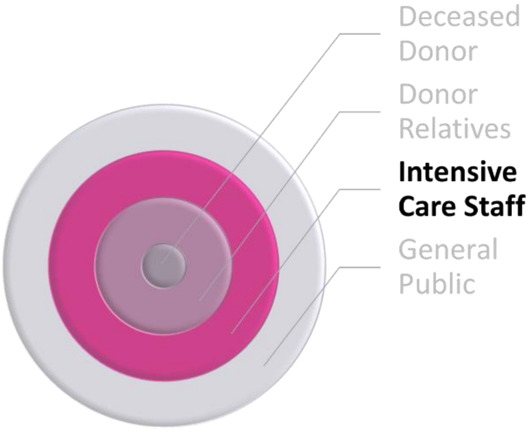
1.7.8 Follow-up with donor relatives

During the first period after the loss, many donor relatives are occupied with funeral arrangements and other practical tasks related to the loss. After some time, however, they often start to reflect upon their time at the ICU [66]. When losing a loved one at an ICU, there is a lot of information to take in, and in cases where organ donation is in question, the information is most often provided within a very short period of time – during which time the donor relatives are under extreme emotional pressure (clinical experience). Under these circumstances, there is an obvious risk for misunderstandings and for questions being left unanswered. Studies indicate that many donor relatives want to be, and benefit from, being invited to a follow-up [64, 66]. This has proved to help relatives better come to terms with the unique circumstances surrounding end-of-life care, and to help them better understand the causes of death [55]. Adding to the importance of providing follow-up to donor relatives are the unique circumstances surrounding brain death and organ donation [64, 67]. In this follow-up, the information on the outcome of the transplantations can also be provided. Many donor relatives hope for a good outcome of the transplantations and they often find comfort and meaning when receiving this feedback [64, 66, 70]. However, it is equally important to offer a follow-up to relatives of potential donors who did not donate organs, but there is evidence indicating that this takes place more rarely [59].

1.7.8.1 The donor relatives – relevance for the papers included

The circumstances surrounding brain death and organ donation are often complicated to understand for the donor relatives, as is the necessary medical treatment provided both before and after death in order to maintain the viability of the organs. Nevertheless, one area little described is the donor relatives' views on the unique medical treatment provided in order to enable organ donation. In article III in this thesis, we wish to elucidate the donor relatives' experiences of the medical treatment enabling organ donation, and thereby contribute to a greater transparency and openness around what becoming a donor really means.

1.8 THE INTENSIVE CARE STAFF



1.8.1 The transition of medical treatment during the donation process

In Sweden the deceased donors are patients with acute devastating brain injuries, treated at an ICU by the ICU staff. In spite of all efforts being made in order to save the patients, the patients sometimes develop a total brain infarction and die (see chapter 1.6). This situation has proved to sometimes provoke feelings of failure among the medical staff, as they were not able to save the patients' lives [57]. Then, after death, the medical treatment shifts from being provided in order to save the patient into being provided in order to maintain a good quality of the organs. Hence, this situation requires that the ICU staff shifts focus, from providing curative treatment to end-of life care and finally to organ-preserving treatment, in order to potentially contribute to saving the lives of others, namely the organ recipients [78].

This transition of care is sometimes perceived as complicated, demanding and even stressful by the ICU staff. Contributing to this is sometimes the fact that the ICU staff is personally affected by the loss of the patients and by the donor relatives' grief [54-57, 71, 79] Nevertheless, the ICU staff is still required to continue to provide medical treatment, even when the patient is dead. This medical treatment is unique, as the ICU staff normally does not provide treatment for a dead patient. This occasionally provokes ambivalent feelings among the ICU staff as it challenges the boundaries between life and death [64].

Fundamental in upholding the ICU staff's acceptance of the donation process, is that the care for the dying and for the dead patient, as well as for the donor relatives, is provided with dignity and respect [54, 57, 67, 79]. Furthermore, it has been established that in order to uphold the staff's acceptance of the donation process, the staff needs to be confident that the medical treatment will not harm the patients during the dying process, and that they can maintain the relatives' trust while continuing to provide medical treatment that is intended to benefit someone other than the patient [55, 58, 80, 81]. It has been established that in this situation the staff benefits from a clearly pronounced declaration that the patient indeed is dying, and that the medical care no longer is provided in order to save the patient's life [55, 58].

1.8.2 Organ donation – possibility or burden

Once the patient is dead, and the possibility of organ donation is a reality, some staff regard organ donation as a positive result of a tragic death, while others regard it as emotionally challenging and as an extra burden for themselves and/or for donor relatives [56, 57, 59, 79, 80]. In fact, an organ donation is quite often perceived by the ICU staff as a complicated process to handle both ethically, emotionally and medically [56-59, 67, 79]. In this situation, a pronounced willingness to donate makes it easier for the staff to feel comfortable with the prolongation of medical treatment in order to make organ donation possible [57, 58]. This care can then be regarded as being in the best interest of the patient [58].

1.8.3 Surrounded by despair

During the donation process, which demands a continuous, thorough and advanced medical monitoring of the donors, the ICU staff is at the same time often surrounded by the donor relatives and face their despair, which contributes to the delicacy of the process [57, 67, 79]. The way the staff then handles this situation and how they relate to and communicate with the donor relatives is known to influence the donor relatives' grieving process [82-84]. The quality of the ICU staff's communication – at any one point during the dying process – is also one of the most important factors for how the relatives perceive the quality of the end-of-life care [55, 85].

1.8.4 The ICU nurses' role during the donation process

The nurses often develop a close relationship with the patient's relatives and therefore play an essential role regarding the important communication with the relatives. This relationship naturally develops as the bedside nurses spend a lot of time interacting with the relatives while monitoring the patients and providing care [55, 61, 67, 85, 86]. Through their unique relationship with the donor relatives, the nurses often gain important knowledge of the dying patient's beliefs and wishes and they also gain an insight into what information seems to be understood by the donor relatives and what does not, during the delicate donation process [54, 55].

1.8.4.1 Nurses feeling moral stress

At times, ICU nurses find that, as a consequence of an insufficient dialogue with the physicians concerning end-of-life decisions, they end up in an unsatisfactory situation which complicates their important interaction with the patient's relatives. Furthermore, they sometimes feel abandoned by the physicians during the delicate donation process [55, 57, 86]. Another source of frustration is when the opinions of the nurses and the physicians differ, concerning the right timing of, and the proper length of time spent on, the specific donation request [55, 59]. Some nurses also think that it would be more appropriate if organ donation was requested by the nurses and not by the physicians, considering their own unique relationship with the donor relatives [61]. Recent studies also indicate that the circumstances surrounding end-of life care and organ donation, sometimes provoke moral stress among nurses [54-57, 79]. Contributing to this stress is most likely the fact that there are nurses who are not confident with the concept of brain death and the procedures undertaken to declare a patient brain dead [57-62, 87].

1.8.5 The ICU physicians' role during the donation process

The physicians are responsible for the demanding medical care provided in a modern ICU and all the medical decisions taken during the patient's stay at the ICU. Furthermore, they have the responsibility to inform the relatives about the patient's diagnosis and prognosis. In most contexts, the physicians are also responsible for the donation request with the donor relatives. This appears to be perceived by the physicians as one of the most difficult tasks during the donation process [61, 71, 88, 89]. Hence, many agree that the requesters need training in order to be comfortable with the situation and in order to handle the request adequately [59, 74, 79, 88, 89].

1.8.5.1 Physicians feeling uncomfortable

There is evidence indicating that the physicians sometimes feel uncomfortable with and ill prepared for requesting for organ donation [71, 74, 90], and that, on one hand, they struggle with their own concerns for the relatives, and with the concerns of the recipients of the organs on the other [59, 71, 90]. In this double-edged situation, the physicians sometimes fail to explore the reasons for a family refusal, which potentially could lead to the decision about organ donation not being in accordance with the wishes of the deceased [59, 71, 75, 88]. During this process, many physicians find that the relatives' trust is crucial and this complicates their position when requesting for organ donation, as they are aiming at maintaining the trust of the relatives while still respecting the wishes of the deceased [58, 59, 90]. During the decision-making process, some physicians are also concerned that the time frame for the process is too limited [74] as a consequence of them being responsible for several more patients. These limitations most likely also add to the complexity of the communication with the relatives.

1.8.6 ICU staff ambivalence of what to tell donor relatives

The regulatory framework surrounding organ donation is considered by many within the Swedish ICUs to be unclear [21, 31]. Furthermore, there is a demand for better guidance regarding what medical treatment is permitted, and when the medical treatment can be introduced or prolonged, in order to enable organ donation [21, 31] (paragraph 1.4.7). This uncertainty regarding the organ donation procedures may well be reflected in the communication with the donor relatives. This assumption has been confirmed by members of the ICU staff in connection with various conferences, educations and workshops, during which the staff have openly talked about their hesitation to address the purpose of the medical treatment provided, with the donor relatives [31]. Adding to the complexity of the communication with the donor relatives is the fact that the ICU staff often considers the possibility of organ donation long before they openly address organ donation with the relatives [57]. This has also been found in a Norwegian study, a country very similar to our own [56]. There are several examples of staff saying that they feel dishonest as they do not openly talk about the possibility of organ donation and the purpose of the treatment provided. This ambiguity contradicts the fact that relatives benefit from the staff being open and honest, from continuously communicating the progress of the patient and from involving the donor relatives in end-of-life care and decisions [55]. Logically, the staff sometimes finds it ethically challenging to not openly describe the purpose of the treatment provided during the dying and donation process [56, 57]. In the UK, this problem has been addressed, and when a dying patient lacks the capacity to make decisions there is a consensus that the ICU staff should be open about the possibility of organ donation, and:

> *"... establish whether taking steps, before death, to facilitate organ donation would be in the patient's best interests"* [91, 92]

Furthermore, the donation process is considered an integral part of end-of-life care, and organ donation should be regarded as a usual and not as an unusual event [93].

1.8.7 Organ donation – an integral part of end-of-life care

Organ donation is a rare event within the Swedish medical health care system [33]. Hence, among the ICU staff the experience and knowledge in this field is sometimes lacking. Logically, the organ donation process is sometimes considered to be complicated and emotionally demanding by many within the ICUs [31, 81]. Currently, the handling of the donation process depends on the knowledge, devotion and attitudes of individual ICU staff, on local guidelines, and on the priorities of the ICU managements [57, 61, 94]. However, there is already a positive development within the Swedish health care system, and more and more ICU staff are starting to consider organ donation as an integral part of end-of-life care (clinical experience). A corresponding tendency has also been evident among ICU staff in the UK and France [31, 58, 61]. In Sweden, this changed sense of ownership of the donation work is most likely one positive effect of the efforts made by the donation responsible physicians and donation responsible nurses (DAL and DAS) [23]. The DAL and DAS responsibilities were clarified and their function strengthened during year 2006 and we are now starting to see the positive effects of their work.

1.8.8 Benefits of specialised staff – Donation Specialised Nurses

The benefits of specialised staff is central to this thesis, and one group of the key actors we addressed is the donation-specialised nurses (Paper II). Several other countries have also reported that the use of specially trained medical staff is an efficient measure towards integrating the work with organ donation in the ordinary ICU remit [95]. The specialised staff has also proved to improve the regular ICU staff's satisfaction with the donation work, as well as improve the care for the donors and their relatives, and to also increase donation rates [75, 96-98].

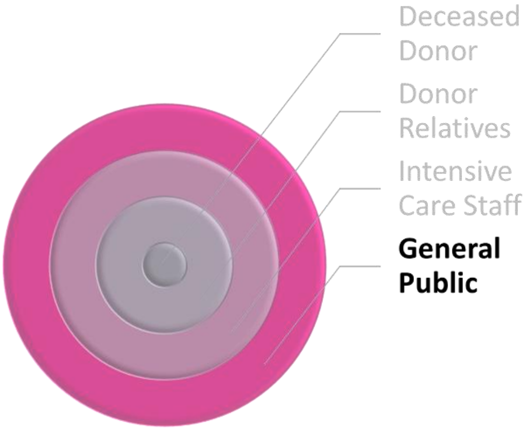
Inspired by this, a unique donation service was established in the Stockholm region in year 2001, offering ICU staff the support of a donation specialised nurse (DOSS). Initially, only one DOSS was appointed, working locally at her own ICU, in her own ICU team. This first involvement of a specialised nurse will be referred to as "the initial DOSS project" in the result in this thesis (see chapter 4.2). Today though, there are 8 DOSSes, constituting a 24/7 on-call service, covering the whole of the Stockholm region. This service, which was established in year 2006, will be referred to as “the permanent DOSS service” in the result in this thesis. When any one of the hospitals treats a potential donor, the ICU staff is offered to contact the DOSS service. The DOSS on call then supports the local team during the donation process.

The DOSSes’ main work tasks – both during the initial DOSS project as well as today in the permanent DOSS service – are: medical care of donors; care for and information to donor relatives; preparation of local routines; education of staff/introduction of new staff; functioning as a source of knowledge, and constituting a relief of workload in the acute donation situation. The main difference, however, is that the initial DOSS knew the staff at her own ICU, and in most cases she had developed a relationship with the donor relatives before the donation request was put to them. Today, the DOSSes support an ICU team at an ICU other than their own, and consequently, in most cases, the DOSSes have no prior relationship with the staff or with the donor relatives.

1.8.8.1 ICU staff – Relevance for the papers included

The attitudes and knowledge regarding organ donation among the ICU staff have proved to be essential for how the donation process is handled. The rare occasion of organ donation most likely contributes to the insecurity some staff feel in connection with organ donation. Nevertheless, in spite of encouraging examples from other countries regarding the involvement of external, specialised staff, there is some hesitation towards the introduction and involvement of donation specialised staff within the Swedish health care system. In Paper II in this thesis, the ICU staff’s acceptance of the involvement of specialised staff, as well as the ICU staff’s views on the impact of specialised staff, are assessed. This study serves as an example for ICUs considering the involvement of specialised staff and it also provides an example of how to optimise the work with organ donation.

1.9 THE SWEDISH GENERAL PUBLIC



1.9.1 Widespread willingness to donate organs

The Swedish general public's trust in the medical health care in general is high, as well as the trust in the specific medical heath care in connection with organ donation [99, 100]. This is also reflected in the widespread willingness to donate organs. As much as 82 percent of the Swedish population claims to be willing to donate, when asked in an opinion poll comparing the willingness in different European countries [100]. As a matter of fact, the Swedish population is more willing to donate organs than any other European population included in the poll. Thus the conditions for obtaining high donation rates ought to be excellent. Nevertheless, in Sweden we are still struggling with poor donation rates (see chapter 1.5) and with the fact that we tend not to tell anyone about our intention regarding organ donation [101].

1.9.2 Failing to communicate about organ donation

In a modern society like ours death seems to be a subject that is not allowed to take up much space in our lives and in discussions, and many Swedes have proved to feel uncomfortable or even reluctant when communicating about death and organ donation [101, 102]. This reluctance may well be a consequence of a lack of knowledge, as the information in society directed towards the general public regarding organ donation is rather scarce [101, 102]. However, private initiatives and patient associations do their best to keep the organ donation issue alive and up-dated [68]. Furthermore, The National Board of Health and Welfare administers a web page called "Livsviktigt" ("Vital") in which they provide information to the general public regarding organ donation [103]. However, no authority or governmental organisation is regularly and actively addressing organ donation within our society.

1.9.3 Information efforts and campaigns

Only temporary information efforts or campaigns have been conducted in order to uphold the knowledge among the general public and to make people talk about organ donation and actively take a stand [101].

The short term campaign assessed in article I, was organised by the Swedish organisation "The Gift of Life" in conjunction with the European Day for Organ Donation in 2001. The main focus of this campaign was on creating a positive attitude to organ donation, as well as on making people share their decision on organ donation with their relatives [101].

The long term campaign assessed in article I, was initiated by the Federation of County Councils in agreement with the Ministry of Health and Social Affairs. This campaign, named "Livsviktigt", conveyed information about organ donation after death. The campaign mainly stressed emotional arguments for donating organs and personified the issue by showing donor families and recipients. The advertisement was carried out over one year, in six campaign periods. The aim was to create a positive attitude to organ donation, to increase the awareness of how to make one's decision known and to inspire people to formally inform about their decision – preferably in the National Donor Registry [101].

A yet unpublished opinion poll carried out in 2014 by the government investigation [21, 102], shows that the general public clearly wants to be informed about organ donation and believes that it has been too long since any information effort was directed towards the general public. The public also states that it wishes that organ donation should be continuously addressed in our society.

1.9.3.1 The Swedish general public – Relevance for the papers included

One of the obstacles to organ donation in our country is that many members of the general public fail to tell anyone about their decisions regarding organ donation during their life time. In Paper I in this thesis we elaborate on the impact on public awareness of the, often costly, information campaigns, and on whether campaigns make people start informing about their decisions on organ donation or not.

1.10 STUDY RATIONALE

The willingness to donate is widespread in our country, yet people are dying while waiting for an organ. One of the obstacles to organ donation is that we tend not to tell anyone about our decision regarding organ donation during our lifetime. Consequently, in the acute situation in connection with an often sudden and tragic death, both donor relatives and ICU staff, frequently face a situation where the intention of the deceased patient is not known. Nevertheless, no authority is continuously informing the public and encouraging the public to take a stand. When considering future information efforts, knowledge is needed regarding the impact of information campaigns on the public's inclination to formally inform about their decision (Paper I).

Adding to the complexity of the donation process is the fact that the ICU staff involved often is rather inexperienced, and sometimes feels unsure of how to handle the process adequately, which can be seen as a consequence of organ donation being such a rare event. Logically, there is a risk that the information about organ donation is not adequate, and that the decision-making process is not properly handled. Experiences from other countries indicate that the involvement of specialised staff has several benefits: for the satisfaction of the ICU staffs and of the donor relatives, as well as for improving the donation rates. However, additional information is needed on how well-functioning work models from other countries can be adjusted to and implemented in our health care system (Paper II).

Finally, further knowledge is needed regarding what people intending to donate comprise in their willingness – do they also comprise organ preserving treatment before and after death in order to be able to donate organs? Previous surveys regarding the general public's decisions regarding organ donation provide little information on the general attitude towards this type of medical treatment. Openness and transparency regarding all the actions taken during the donation process are of the utmost importance in order to increase the public's awareness of organ donation, as well as to allow them to make informed decisions concerning organ donation. This transparency is of equal importance in order to maintain the important trust of the general public in organ donation procedures, as well as that of the ICU staff and the donor relatives (Paper III).

2 GENERAL AIM

The general aim of this thesis is to improve knowledge and understanding of various aspects influencing organ donation after death.

2.1 SPECIFIC AIMS

The specific aims were:

I. To evaluate;
how the attitudes, knowledge and decision-making regarding organ donation were affected by two information campaigns.

II. To evaluate;
- the Donation Specialised Nurses' (DOSSes') effects on donation rates
- the ICU staff's views on the impact of the DOSS function
during the initial DOSS project and during the permanent DOSS service.

III. To explore;
- the donor relatives' experiences of the medical treatment enabling organ donation
- the donor relatives' attitudes towards donating their own organs, and whether or not their experiences have influenced their own inclination to donate.

3 METHODS

To provide a broad knowledge and understanding of different factors influencing, improving and enabling organ donation, both quantitative (Paper I, II) and qualitative (Paper III) methodology was used. The studies have both descriptive and inferential design, and as the specific methods in the three papers included differ, each paper will be described separately.

Table 1. Methodological overview of the papers included

	Study population	Sample	Data collection	Analyses	Outcomes
Paper I	The Swedish general public	3 × 1000	Three telephone surveys / opinion polls	Chi-square test Multiple logistic regression analysis	Attitudes, knowledge and decision making
Paper II	Eligible donors	N=219	Medical record review	Chi-square test ANOVA Post hoc test	Donation rates
	ICU Staff: physicians, nurses and assistant nurses	N=77 N=242	Questionnaire	Descriptive statistics ANOVA Post hoc test Pearson Correlation	Attitudes to the DOSS function
Paper III	Relatives of patients who donated organs	N=21	Individual in-depth interviews	Qualitative and quantitative content analysis	Experiences of the medical treatment enabling organ donation Decision-making regarding donation of their own organs

3.1 QUANTITATIVE PAPER 1: OPINION POLLS TO THE SWEDISH GENERAL PUBLIC

To evaluate the effects of two different information campaigns directed towards the Swedish general public (see paragraph 1.9.3), three opinion polls were made; one in early October 2001 before a short term information campaign that lasted throughout October, one in early November 2001 directly after the short term campaign, and one in September 2005 after a long term campaign that lasted for a year. The State Institute of People's Opinion (SIFO) was commissioned to recruit participants and to perform all the telephone interviews included in the study. SIFO is one of the main market research organisations in Sweden, conducting various national opinion polls, for example those in connection with political elections (for more information about SIFO, see www.sifo.se).

3.1.1 Participants

The study consists of 3000 participants; 1000 participants per opinion poll. The participants all spoke Swedish, were residents of Sweden, and were 15 years of age or older.

Table 2. Participants in Paper I

	Men	**Women**	**N**
Poll 1	472	528	1000
Poll 2	482	519	1001
Poll 3	441	559	1000

3.1.1.1 Sampling methods

When sampling the participants, a probability method – stratified sampling – was used. The study population (the Swedish general public) was initially divided into strata, subsets, and a randomised sample of a beforehand defined size was obtained within each strata.

The sample was nation-wide and stratified by area code of all public household phone numbers. The subsets were proportionally allocated to obtain a geographic balance of the sampled households that corresponded to the official statistics made by Statistics Sweden, SCB [32].

A computer software chose randomly which member of the households to be approached in the telephone interview. If this person was not available, a substitute was randomly chosen.

A post stratification was made with regard to the variables age, gender and occupation. The sample was "calibrated" to represent the Swedish population with respect to the weighting variables.

3.1.2 Data collection

3.1.2.1 Development of questionnaire

A questionnaire with ten questions was developed within the multi-professional research group in collaboration with SIFO (Table 3). These questions derived from previously made opinion polls concerning organ donation. Most questions were quantitative, offering the respondents pre-formulated answers with multiple choices. However, a few questions were open-ended, providing the respondents the opportunity to freely express their thoughts and opinions. In the second poll made in 2001, some of the questions were altered, and the two open-ended questions were excluded and replaced by two new quantitative questions, which were placed at the end of the poll. Six of the questions were asked in all three opinion polls. For poll questions included in the different polls, see Table 3.

Table 3. Poll questions included in the three different opinion polls

	Poll questions	Poll 1	Poll 2	Poll 3
1	If you yourself were struck by a life threatening disease, would you then want to receive an organ?	X	X	X
2	Are you willing to donate one of your own organs after your death, such as kidney, liver or heart, to somebody with a life threatening disease?	X	X	X
3	Have you informed anyone about your decision, and if so, in what way have you informed?	X	X	X
4	What are your primary reasons for not wanting to donate? **	X	—	—
5	Do you know what your closest relative thinks about donating his/her organs after death?	X	X	X
6	If you, as the closest relative, would have to make a decision regarding organ donation for a deceased relative, and he/she had not informed about his/her decision during his/her lifetime, would you then want that his/her organs were used for transplantation?	X	—	—
7	What are your primary reasons for not wanting your closest relative's organs to be used for transplantation? **	X	—	—
8	Would you like to know more about organ donation and transplantation, and if so, what would you like to know? **	X	—	—
9	Are you familiar with the National Donor Registry, and if so, do you know how to register?	X	X	X
10	Are you familiar with the Donor Card, and if so, do you know where to get it?	X	X	X
11	If your closest relative were to die under circumstances that made organ donation possible, would you then expect the doctor to bring up the question of organ donation, or do you not expect the doctor to bring up the question?	—	X	X
12	Not many Swedes have informed about their decision to donate or not donate, how do you think that we can make more people inform about their decision? *	—	X	X

* Open ended question

** Open ended question only asked in the first poll: as we mainly analyse the effects of the long term campaign through comparing results from poll 2 and poll 3, we chose not to include those results.

3.1.2.2 Telephone interviews

All 3000 interviews in the telephone surveys were conducted from SIFO's telephone centre in Ronneby, Sweden, by regular members of SIFO's interviewing corps. Apart from the questions included in the questionnaires (Table 3), all interviews covered standard background questions regarding: age, gender, occupation, household income, education, geographical region, big city/suburb/sparsely-populated areas etc.

3.1.3 Analyses

As the analysis made by SIFO only indicated whether there was a significant difference between subgroups regarding the responses to the questions in the telephone survey, additional analyses were made in the scientific software programme Statistical Package for the Social Sciences (SPSS).

However, as the initial analysis made by SIFO demonstrated that the main differences were found between men and women and between different age groups, the final analysis was performed according to gender and age, using four age groups; the young (15-29 years), the early middle-aged (EMA: 30-49 years old), the late middle-aged (LMA: 50-64 years old), and the elderly (> 65 years old).

In the analysis the responses to the poll questions (Table 3) were the dependent variables, and the independent variables were gender and age.

The differences between the polls, and the differences between the different age groups and gender, within each poll as well as between the polls, were tested using the chi-square exact two-sided test. Subgroups are compared to the rest of the sample if nothing else is indicated in the text.

A p-value of < 0.05 was considered significant.

Multiple logistic regression analyses were made in order to:

- Perform an extra control of the previous findings from the chi-square test
- Adjust for possible confounders
- To guarantee an equal distribution of demographics in the three opinion polls.

3.2 QUANTITATIVE PAPER II: REVIEW OF MEDICAL RECORDS AND QUESTIONNAIRE TO INTENSIVE CARE STAFF

To evaluate the DOSSes' effect on donation rates and the ICU staff's views on the impact of the DOSS function on the medical care of the donors, the care for the donor families and on the working conditions for the staff, a review of medical records was performed and a questionnaire was distributed to ICU staff. The two data-collection methods will be described separately, as will the different analyses.

3.2.1 Data collection – medical records

Donation data from a two-year period prior to the appointment of the initial DOSS were collected and assessed (A) via a review of medical records. To evaluate the effect of the initial DOSS project on donation rates (the conversion of eligible donors to actual donors), the donations over a two-and-a-half-year project period were studied and a comparison was made of the donation rates when the DOSS did not (B) and did (C) take part in the donation process. Data for all ICUs in Stockholm region were collected for a three-year period after the transition, without DOSS participation (D) and with DOSS participation (E). The number of eligible donors in each group is: A: 59; B: 23; C: 26, D: 15, and E: 96 (see page 43, for data-collection scheme). The groups consist of the total number of eligible donors that were identified and reported to the regional organ procurement organisation (OPO) during the study period.

The collected data included: the expressed wishes of the deceased (oral, donor card, and donor registry statement), family vetoes and family consent. Finally a category defined as “no donation for other reasons” included donations that did not take place because of late findings of medical contraindications, together with cases where it could not be established why a donation did not take place.

3.2.2 Data analysis – donation rates

Chi-square exact two-sided test was used for testing the differences between the groups A, B, C, D and E, regarding the number of: donations, family vetoes, non-willing deceased, and donations that were not performed for other reasons. All the p-values are presented in Paper II. In the result section of this thesis (see chapter 4.2) the results are presented somewhat differently, and the p-values are comparisons of donation rates between:

- the *initial DOSS project with DOSS* compared to *before* the initial DOSS project (between groups C and A)

- the *permanent DOSS service with DOSS* and *project period with DOSS* (between groups E and C).

In the analyses, DOSS participation/non-participation were the independent variables, and the dependent variables were: donations, family vetoes, non-willing deceased, and donations that were not performed for other reasons.

A p-value of < 0.05 was considered significant.

The differences in age between the eligible donors in the groups A, B, C, D and E were tested using one-way analysis of variance (ANOVA) and post hoc test with multiple comparisons. Finally, the differences in gender and diagnosis were tested with chi-square test.

3.2.3 Data collection – questionnaire

To evaluate the ICU staffs’ views on the impact of the DOSS function a study-specific questionnaire was distributed to physicians, nurses and assistant nurses at two different time points; during the initial DOSS project (base-line questionnaire) and during the permanent DOSS service (follow-up questionnaire) (see page 43, for data-collection scheme). The follow-up questionnaire was distributed to four different types of hospitals and ICUs: a large university hospital (base-line NICU), a small/ medium-sized emergency hospital, a private emergency hospital, and a children’s hospital. The questionnaire was completed anonymously and was self-administered.

The questionnaire included questions about the respondents’ background such as profession, number of years in the profession, experience of working with organ donation and cooperation with the DOSSes (see Table 11, page 53, for background details). The respondents were asked to rank the importance of five aspects of DOSSes’ work, from 1 to 5 (1 signifying the most essential and 5 the least essential). The staff was also asked to estimate the impact of the

DOSSes on 11 items, using visual analogue scales (VASs) labelled for example “not at all - very much so” or “to the worse - to the better”. Three main areas were covered in the questionnaire: “the medical care of the donors”, “the care for the donor families”, and “the working conditions for the staff” (for questionnaire questions, see Appendix at the end of this thesis).

In the follow-up questionnaire eight additional questions were included, mainly regarding the staffs’ attitudes, and the staffs’ opinions on the differences in the quality of the different DOSSes’ work. These new questions were placed at the end of the questionnaire to avoid influence on the responses to the original questions (see Appendix at the end of this thesis).

Both the base-line questionnaire and the follow-up questionnaire were answered by 75 percent of the staff (77/103 and 242/323 respectively). In the follow-up questionnaire the response rate of the different categories of staff varied: physicians 43 percent, nurses 80 percent and assistant nurses 97 percent.

3.2.4 Data analyses – attitudes of the ICU staff

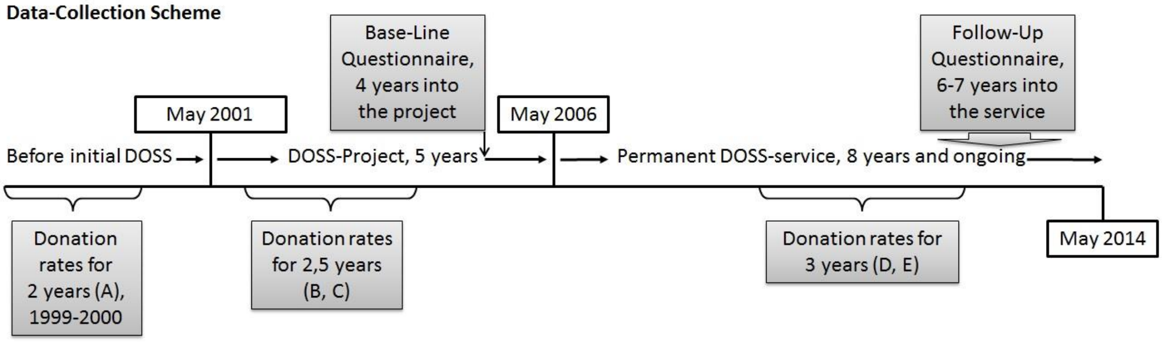
The difference in demographics of the physicians, nurses and assistant nurses was tested with one-way ANOVA and post hoc test with multiple comparisons.

The ranking of the DOSSes’ work tasks is ordered according to mean scores.

The respondents’ answers on the VASs were measured and rounded off to whole millimetres in order to make quantitative estimations and comparison between subgroups. The results are presented on scales of 0.0-10.0 spanning between the labels “to the worse” and “to the better”; a score of < 5 indicates a negative change owing to the DOSS and a score of 5 indicates no change, while > 5 indicates a positive effect. Some VASs span between the labels “not at all” and “very much so”; a score of < 5 indicates no change owing to the DOSS and a score of 5 indicates a moderate change, while > 5 indicates a positive effect. In the result, this will be indicated through the wording of the text.

The results of the VASs are presented as means ± standard deviation (SD). The differences between the groups “physicians”, “nurses” and “assistant nurses”, and between the periods “initial DOSS project” and “permanent DOSS service”, were tested using one-way ANOVA and post hoc test with multiple comparisons.

Correlations between the responses to the follow-up questionnaire and the extent of cooperation with the DOSS as well as the respondents’ levels of experience of organ donation were tested using bivariate correlation (Pearson and Spearman correlations). A p-value < 0.05 was considered significant.



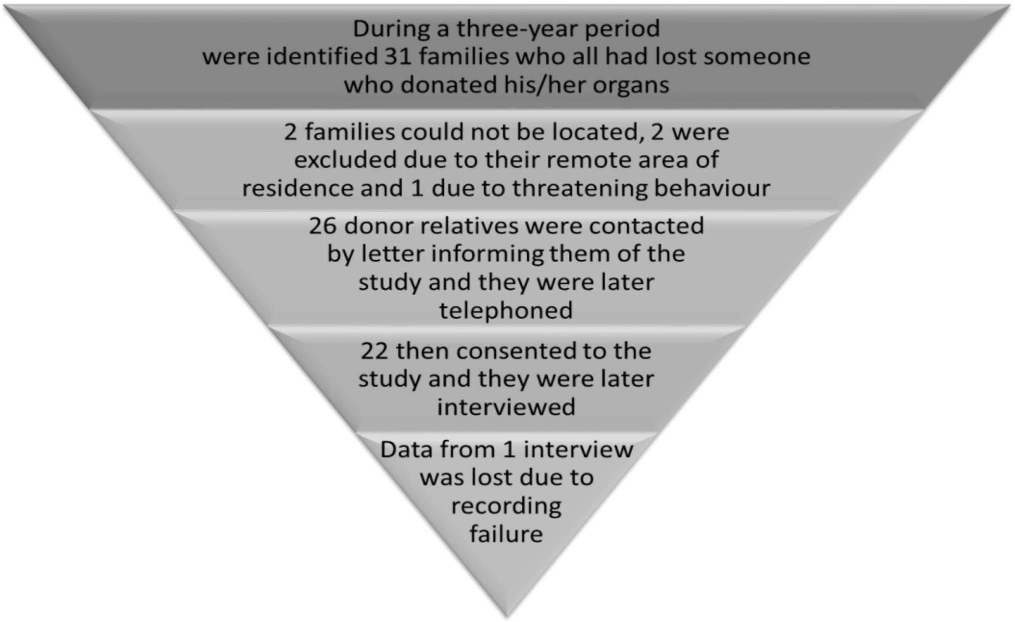
3.3 QUALITATIVE PAPER III: INTERVIEWS WITH DONOR RELATIVES

3.3.1 Participants

3.3.1.1 Inclusion criteria

In order to explore the donor relatives' experiences of the medical treatment enabling organ donation – which is the main focus of this study – we chose to include donor relatives who had experienced the whole donation process: from a family member being struck with a severe bleeding in the brain, till the whole stay at the ICU, till the declaration of brain death, till the donor operation and till the final farewell after the donor operation. Hence, the included donor relatives had all lost a family member who died due to a total brain infarction, and who also donated organs. This inclusion criteria was chosen in order to obtain information-rich participants (purposive sampling) [104]. The participants had all lost a family member at the same neuro intensive care unit at a Swedish University Hospital, spanning a three-year period (see Figure 2, for inclusion of participants) (see Table 4, page 44, for demographics).

Figure 2. Inclusion of participants



3.3.2 Data collection

Data were collected via in-depth interviews [105] , guided by a semi-structured interview guide with open-ended questions covering the whole donation process. In addition, the donor relatives' own decision-making process was covered in all interviews. The first author, an experienced medical social worker specialised in organ donation and transplantation, conducted the interviews. The interviewer had no prior relationship with the participants. The participants chose the location for the interviews – all interviews but three were conducted in the participant's home. The interviews were recorded and transcribed verbatim (see Table 4, for interview information).

Table 4. Participant demographics and interview information

Included relatives	Gender	Age	Lost	Time between donation and interview	Duration of the interviews
N=21	Men: 10	Mean: 55	A partner/spouse: 13	Mean: 3,1 years	Mean: 1h, 7 min
	Women: 11	Median: 55	A child: 4	Median: 2,7 years	Median: 1h, 5 min
		Max: 84	A parent: 3	Max: 6,7 years	Max: 2h, 6 min
		Min: 29	A sibling: 1	Min: 1,4 years	Min: 40 min

3.3.3 Data analyses

In order to serve the aim of the study, both quantitative and qualitative content analysis was applied in the analysis [106]. These analyses will be described separately in the following paragraphs.

3.3.3.1 Qualitative content analysis

When exploring the donor relatives' experiences of the medical treatment enabling organ donation, and their decision-making process regarding the donation of their own organs, latent qualitative content analysis with an inductive approach was used [104, 106, 107]. The qualitative content analysis can be described as a process: from repeatedly reading the entire interviews in order to gain a sense of the whole, to gradually focusing on the content areas that are most essential for the purpose of the study, to dividing these areas into smaller meaning units and coding them with explanatory codes that derive from the text, and sorting the codes into categories and subcategories with internal homogeneity and external heterogeneity. In the result, the headings correspond with the main categories that derived from the analysis, and the subheadings correspond with the subcategories (see Table 5, page 45, for the process of analysis).

Table 5. Example of the process of analysis

Meaning unit	**Condensed meaning unit**	**Code**	**Subcategory**	**Category**
I thought it was so wonderful of her that she made a difference for other fellow human beings when she died. It was so, I was so proud, as I said, over her. So it was natural. Felt a bit ashamed that I had not written a yes before then.	Wonderful of her to make a difference, felt so proud but also ashamed that I had not decided earlier, felt natural to donate afterwards.	Felt natural to donate afterwards	Directly affected by their dead family member's donation	The donor relatives' own decision-making process

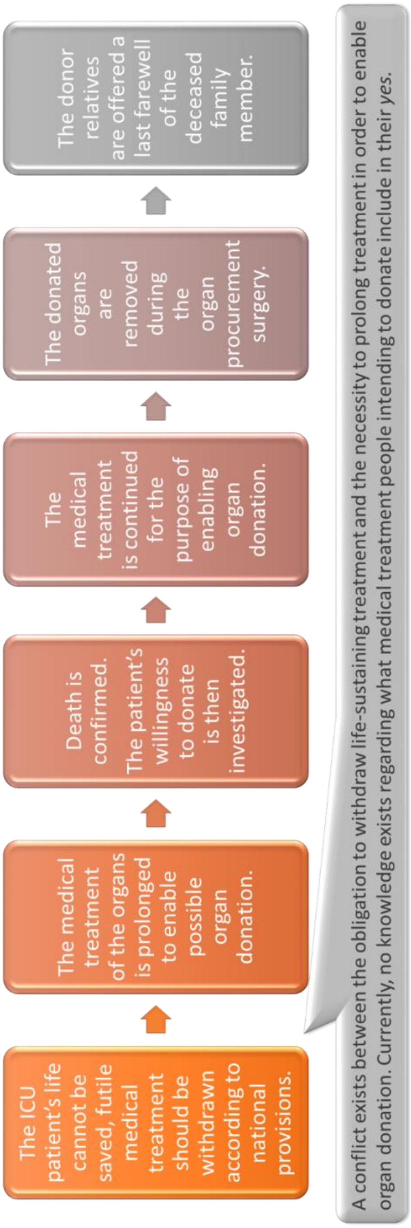


Figure 3: Phases of the donation process included in the analysis

In this study, when we initially explored the donor relatives' statements on the medical treatment enabling organ donation (the main focus of the study), it became clear that several more areas needed to be explored in order to understand the underlying meaning of the donor relatives' experiences of this treatment (see Figure 3, for phases included in the analysis,). The focus was then broadened and the analysis led to the following four main categories: 1) the occurrence of death, 2) the medical treatment enabling organ donation, 3) the donor operation and 4) the donor relatives' own decision-making process.

During the analysis, the qualitative software programme ATLAS.ti [108] was used in order to organise the extensive material. The use of such programmes enhances the possibility to continuously move from parts of the interviews, to the whole, to the context in a specific interview, which is necessary in order to explore the underlying meaning of the donor relatives' statements.

When exploring the donor relatives' statements, this process of constantly moving from parts to the whole and vice versa was continuously applied, in order to validate the interpretations made in the analysis.

3.3.3.2 Quantitative content analysis

In order to also assess the number of donor relatives who were willing/unwilling/indecisive when it comes to donating their own organs, both before and after the loss of a family member who donated organs, a deductive quantitative content analysis was performed [104, 109]. This analysis was based on the donor relatives' retrospective statements in the interviews. When doing this analysis, three pre-set categories were used: willing, unwilling and indecisive. This allowed us to assess changes of the donor relatives' own decisions before and after the loss of the family member who donated organs (see Figure 4, page 59, in the result). In addition, a quantification was made of how many relatives that knew the intention of the deceased: how many felt very unsure, or somewhat unsure, or felt completely confident about the decision that was made regarding organ donation. These data provide information that can be of relevance when considering transferability of the results in this study.

4 RESULTS

In this chapter, the main findings from each included paper will be presented. For all results, see Papers I, II and III. For quotes of the donor relatives' statements that illustrate and support the results, see full Paper III

4.1 PAPER I

FROM WORDS TO ACTION – INFLUENCE OF TWO ORGAN DONATION CAMPAIGNS ON KNOWLEDGE AND FORMAL DECISION MAKING

No significant changes were observed in the study population, regarding the questions included in the opinion polls, before and after the short term campaign. The results presented will therefore be comparisons between the results of the poll performed after the short term campaign (poll 2) and the results of the poll that later was performed after the completion of the long term campaign (poll 3) (see paragraph 1.9.3, page 33, for description of the campaigns).

4.1.1 Maintained widespread willingness to receive and donate organs

After the short term campaign as well as after the long term campaign, a vast majority of the study population claimed to be willing to receive (90% and 89 % respectively, ns) and donate organs (86% and 86 % respectively, ns).

4.1.2 Unchanged tendency to *not* inform about the decision

The proportion of responders who had *not* informed anyone about their decisions was unchanged after the long term campaign (from 56% to 52%, ns). The young and the elderly were the two groups that significantly more often than others did *not* inform anyone about their decision (Young: 62%, p=0.004, Elderly: 61%, p=0.003).

4.1.3 Increased awareness of the National Donor Registry

The general awareness of the National Donor Registry had increased greatly after the long term campaign (from 19% to 40%, $p < 0.001$) and more women than men knew about the registry and how to register (46% vs 34%, $p < 0.001$). The early-middle-aged women had the highest awareness of the registry (from 28% to 52%, $p < 0.001$), while the elderly men had the least awareness and seemed not to have been affected by the national campaign (from 26% to 25%, ns) (Table 6).

Table 6. Awareness of the National Donor Registry, before and after the long term campaign

	Aware of the Registry and how to register		
	Poll 2 (%)	Poll 3 (%)	p-values
All	19	40	<0.001
Men	17	34	<0.001
Women	20	46	<0.001
Men:			
15-29	4	35	<0.001
30-49	17	39	<0.001
50-64	22	31	ns
65-	26	25	ns
Women:			
15-29	8	42	<0.001
30-49	28	52	<0.001
50-64	22	50	<0.001
65-	18	37	0.003

P-value for the changes between poll 1 and poll 2, ns p>0.05

4.1.4 Increased awareness of the Donor Card

Even though the awareness of the Donor Card was not as high as the awareness of the National Donor Registry, the general awareness of the Donor Card had also increased after the long term information campaign (from 24% to 35% $p < 0.001$). Again, more women than men were aware of the card (43% vs 27%, $p < 0.001$) and the early-middle-aged women seem to be the group most affected by the campaign (from 34% to 51%, $p=0.001$). Furthermore, the elderly women's awareness of the Donor Card had increased significantly (from 22% to 41%, $p=0.010$) (Table 7).

Table 7. Awareness of the Donor Card, before and after the long term campaign

	Aware of the Card and where to get it		
	Poll 2 (%)	Poll 3 (%)	p-values
All	24	35	<0.001
Men	19	27	0.005
Women	29	43	<0.001
Men:			
15-29	14	27	0.026
30-49	17	25	ns
50-64	23	28	ns
65-	25	28	ns
Women:			
15-29	22	26	ns
30-49	34	51	0.001
50-64	35	48	0.028
65-	22	41	0.010

P-values for the changes between poll 1 and poll 2, ns p>0.05

4.1.5 Women started informing about their decision

When the changes in the ways of informing about the decision were analysed – before and after the long term information campaign (poll 2, poll 3) – significant changes were only observed among women. No changes were observed among men.

After the long term campaign, there were fewer women who had *not* informed anybody about their decision (from 53% to 44%, p=0.003): the analysis of different age-groups proved that fewer early-middle-aged (EMA) women and late-middle-aged (LMA) women had *not* informed anyone about their decision, compared to before the long term campaign (EMA: from 43% to 29%, p=0.003) (LMA: from 51% to 36%, p=0.014) (Table 8).

Furthermore, more women had registered in the National Donor Registry than before the campaign (from 11% to 16%, p=0.020): the analysis of the subgroups indicated that young and EMA women to a higher degree had registered in the national donor registry than before the campaign (Young: from 3% to 12%, p=0.010, EMA: from 16% to 24%, p=0.051) (Table 8).

Moreover, LMA women had to a significantly higher degree started informing their relatives about their decisions than before the campaign (from 22% to 36%, p=0.012) (Table 8).

And finally, more women in general were aware of their closest relative's intention (from 50% to 58%, p=0.010) (Table 8).

Table 8. Ways of stating the decision, before and after the long term campaign

	Not informed anybody			**Donor Card**			**Donor Registry**			**Informed a relative**			**Aware of closest relative's intention**		
	Poll 2 (%)	Poll 3 (%)	p	Poll 2 (%)	Poll 3 (%)	p	Poll 2 (%)	Poll 3 (%)	p	Poll 2 (%)	Poll 3 (%)	p	Poll 2 (%)	Poll 3 (%)	p
All	56	52	ns	14	15	ns	11	14	0.043	20	23	ns	48	53	0.025
Men	59	60	ns	12	12	ns	10	11	ns	17	18	ns	47	48	ns
Women	53	44	0.003	15	19	ns	11	16	0.020	23	28	ns	50	58	0.010
Men:															
15-29	70	69	ns	11	8	ns	7	8	ns	12	16	ns	44	38	ns
30-49	53	56	ns	15	15	ns	7	14	ns	24	19	ns	50	56	ns
50-64	56	58	ns	12	12	ns	16	11	ns	17	18	ns	52	50	ns
65-	64	60	ns	8	12	ns	10	9	ns	12	18	ns	38	43	ns
Women:															
15-29	59	54	ns	14	10	ns	3	12	0.010	24	25	ns	51	59	ns
30-49	43	29	0.003	21	23	ns	16	24	0.051	30	35	ns	58	66	ns
50-64	51	36	0.014	19	24	ns	15	16	ns	22	36	0.012	51	63	ns
65-	65	62	ns	7	15	ns	9	8	ns	12	14	ns	37	40	ns

P-value for the changes between Poll 2 and Poll 3
ns p>0.05

4.1.6 Increased expectation for the organ donation request

After the long term campaign, more individuals in the study population would expect the physician to bring up the question of organ donation, if a relative were to die under circumstances that made organ donation possible (from 73% to 79%, p=0.002). The greatest increase regarding this expectation was seen among young women (from 81% to 93 percent, p=0.013).

4.1.7 Early-middle-aged and late-middle-aged women stood out

When subgroups were compared, i.e. men and women in different age groups, within the poll performed after the long term campaign (poll 3) early-middle-aged and late-middle-aged women distinguished themselves repeatedly: significantly more EMA and LMA women had signed a donor card (EMA: 23%, p=0.001, LMA: 24%, p=0.001), and they had also informed a relative of their decision to a significantly higher degree (EMA: 35%, $p < 0.001$, LMA: 36%, $p < 0.001$), and they were significantly more often aware of their closest relative's intention than others (EMA: 66%, $p < 0.001$, LMA: 63%, p=0.012).

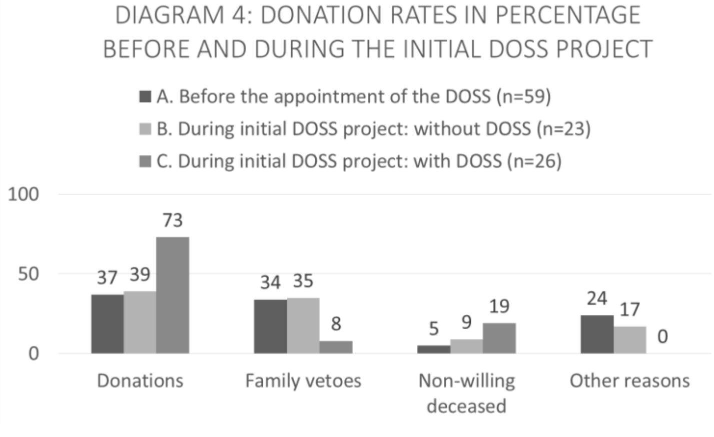
4.2 PAPER II

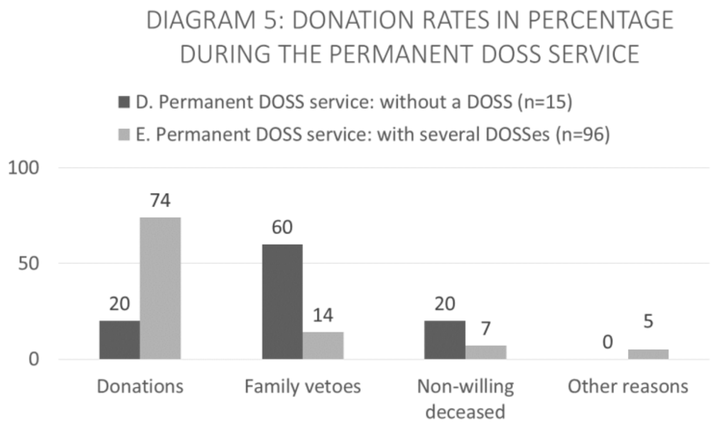
FROM HESITATION TO APPRECIATION: THE TRANSFORMATION OF A SINGLE, LOCAL DONATION-NURSE PROJECT INTO AN ESTABLISHED ORGAN-DONATION SERVICE

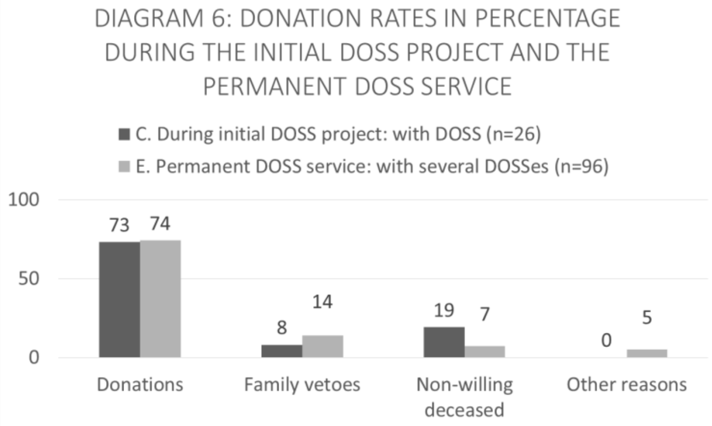
DONATION RATES

4.2.1 Increased donation rates

After the appointment of the first DOSS, the donation rate (conversion of eligible donors to actual donors) increases significantly from 37 to 73 percent (p=0.002) when the DOSS was involved in the donation process (Diagram 4). Both during the initial DOSS project as well as during the permanent DOSS service, the donation rate was much higher when a DOSS participated in the donation process than when the anaesthesiologist or neurosurgeon working in the ICU handled the donation process independently (DOSS project: 73 vs 39 percent; DOSS service: 74 vs 20 percent) (Diagram 4, Diagram 5). To involve a DOSS from the permanent DOSS service proved to be as promising as was the involvement of the initial local DOSS, with 74 and 73 percent respectively, of eligible donors becoming donors (ns) (Diagram 6). Although the DOSS from the permanent DOSS service in most cases was not known by the local ICU team or by the donor relatives the donation rate was maintained high.







4.2.2 A decrease of family vetoes

One of the factors that has an impact on the donation rate is the donor families' inclination to use their right to veto when the intention of the deceased is not known. After the appointment of the first DOSS the number of families using their right to veto decreased significantly from 34 to 8 percent ($p=0.011$). However, when the local physician handled the donation process independently, the number of donor families using their veto was much higher, during the initial DOSS project as well as during the permanent DOSS service (DOSS project: physician 35 percent, DOSS 8 percent; DOSS service: physician 60 percent, DOSS 14 percent) (Diagram 4, Diagram 5). Finally, the involvement of one of the DOSSes from the permanent DOSS service proved to be as promising as was the involvement of the initial DOSS considering the family vetoes (DOSS project: 8 percent; DOSS service: 14 percent, ns) (Diagram 6).

4.2.3 Variation in the number of deceased donors being non-willing

One of the main focuses of the DOSSes is to make sure that the decision made for the deceased is in accordance with the intention of the deceased. The percentage of eligible donors being reported to be non-willing to donate varied between 5 and 20 percent in the different groups (Diagrams 4, 5 and 6). The only significant difference, however, was the one observed between "before the initial DOSS project" and "during the DOSS project" when the DOSS did take part in the donation process: the number of donors being reported to be non-willing then increased from 5 percent to 19 percent ($p=0.04$) (Diagram 4).

4.2.4 A decrease of donors that did not become donors "for other reasons"

Sometimes it is not possible to proceed with a donation because of late findings of medical contraindications. These cases, together with cases where the reasons for not proceeding could not be established through the medical records, are defined as *no donation for other reasons*. A significant decrease of these cases was seen when the initial DOSS was involved: 0 percent of the eligible donors did then not become donors for *other reasons*, compared to 24 percent before the initial DOSS project (p=0.007) (Diagram 4). When the physician handled the donation process independently during the initial DOSS project, the corresponding percentage was 17. During the permanent DOSS service, however, the fraction of donors not becoming donors for *other reason* was equally low when a DOSS was involved and when the physician handled the donation process independently (5 and 0 percent respectively, ns) (Diagram 5).

ATTITUDES OF THE ICU STAFF

4.2.5 Changed ranking of the DOSS' work tasks

When the ICU staff was asked to rank the various work tasks of the DOSSes, one work task was given a higher ranking during the permanent DOSS service than during the initial DOSS project: "source of knowledge in the acute donation process." This work task was then considered to be the most important work task for the DOSSes in the permanent DOSS service (from ranked 3rd to ranked 1st, Table 9).

Table 9. The staff's ranking of the DOSS' work tasks during the Initial DOSS project and the Permanent DOSS service

Initial DOSS Project		**Mean Score**	**Permanent DOSS Service**		**Mean Score**
1.	Care for and information to donor families	1.61	**1.**	Source of knowledge in the acute donation process	2.29
2	Medical care of potential donors	2.74	**2.**	Care for and information to donor families	2.37
3.	Source of knowledge in the acute donation process	2.98	**3.**	Medical care of potential donors	2.75
4.	Relief of workload for the staff	3.43	**4.**	Relief of workload for the staff	3.29
5.	Development of local routines/education of staff	3.73	**5.**	Development of local routines/education of staff	4.08

Ranking from 1-5, 1=most essential, 5=least essential work task

4.2.6 Improvements owing to the DOSS

The results of the questionnaires – both during the initial DOSS project and during the permanent DOSS service – indicate that all aspects included had improved greatly owing to the DOSS function (Table 10). However, two aspect of the DOSSes work was given somewhat lower mean scores during the permanent DOSS service than during the initial DOSS project:

the care for donor families (from mean score 9.0 to mean score 8.4, p=0.005), and the education and introduction of new staff (from mean score 7.2 to mean score 5.5, p=0.000). The total effect of the DOSSes was considered to be equally high during the initial DOSS project and during the permanent DOSS service (DOSS project: 8.9; DOSS service: 8.8, ns) (Table 10).

Table 10. Overall changes between the two periods; Initial DOSS project and Permanent DOSS service

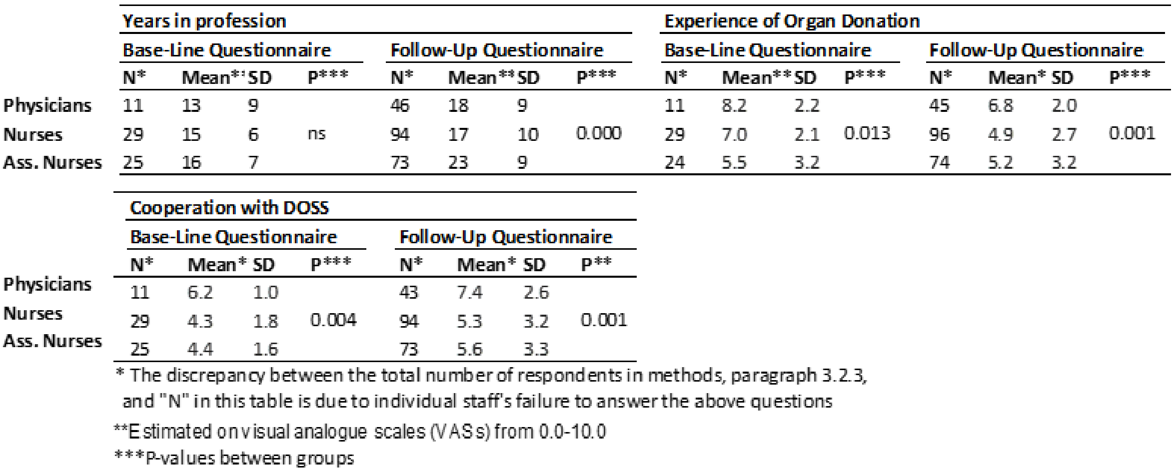
	Initial DOSS project, N=77		**Permanent DOSS service, N=241**		
	Mean*	**SD**	**Mean***	**SD**	**p-values****
Care for donor families	9.0	1.0	8.4	1.4	0.005
Information to donor families	8.4	1.4	8.2	1.5	ns
Follow-up with donor families	8.8	1.2	8.6	1.5	ns
Identification of potential donors	7.7	1.7	7.3	1.4	ns
Medical care of potential donors	8.3	1.6	8.2	1.3	ns
Relief of workload for the staff	8.8	1.4	8.6	1.4	ns
Source of knowledge and support for the staff	7.9	1.7	8.0	1.6	ns
Sense of confidence among staff	8.0	1.8	8.3	1.5	ns
Development of local routines	6.8	1.6	6.5	2.5	ns
Education of staff and introduction of new staff	7.2	1.8	5.5	2.7	0.000
The total effect of the DOSS/DOSSes	**8.9**	**1.4**	**8.8**	**1.2**	**ns**

*Estimated on visual analogue scales (VASs) from 0.0-10.0.
Score 5 = no change owing to the DOSS/DOSSes, >5 = positive effect, <5 negative effect
**P-values for the changes between the initial DOSS project and the permanent DOSS service, ns = p>0.05

4.2.7 Differences between the three categories of ICU staff

The background of the ICU staff in the three categories somewhat differs, both during the initial DOSS project as well as during the permanent DOSS service: e.g. the responding physicians had more extensive experience of working with organ donation, as well as had cooperated with a DOSS to a higher degree than the nurses and assistant nurses (Table 11).

Table 11. Background details of the respondents of the questionnaires



	Years in profession								**Experience of Organ Donation**							
	Base-Line Questionnaire				**Follow-Up Questionnaire**				**Base-Line Questionnaire**				**Follow-Up Questionnaire**			
	N*	**Mean****	**SD**	**P*****	**N***	**Mean****	**SD**	**P*****	**N***	**Mean****	**SD**	**P*****	**N***	**Mean***	**SD**	**P*****
Physicians	11	13	9		46	18	9		11	8.2	2.2		45	6.8	2.0	
Nurses	29	15	6	ns	94	17	10	0.000	29	7.0	2.1	0.013	96	4.9	2.7	0.001
Ass. Nurses	25	16	7		73	23	9		24	5.5	3.2		74	5.2	3.2	

	Cooperation with DOSS							
	Base-Line Questionnaire				**Follow-Up Questionnaire**			
	N*	**Mean***	**SD**	**P*****	**N***	**Mean***	**SD**	**P****
Physicians	11	6.2	1.0		43	7.4	2.6	
Nurses	29	4.3	1.8	0.004	94	5.3	3.2	0.001
Ass. Nurses	25	4.4	1.6		73	5.6	3.3	

* The discrepancy between the total number of respondents in methods, paragraph 3.2.3, and "N" in this table is due to individual staff's failure to answer the above questions
**Estimated on visual analogue scales (VASs) from 0.0-10.0
***P-values between groups

A comparison of the answers from the three categories of ICU staff regarding the permanent DOSS service shows that the physicians found that the impact of the DOSSes on the information to donor families (physicians' mean score: 7.4, p=0.001) and the identification of potential donors (physicians' mean score: 6.9, p=0.044) was less positive than did the nurses and assistant nurses (Table 12). Nevertheless, all three categories of ICU staff stated that all areas evaluated in the questionnaire had improved owing to the permanent DOSS service (Table 12).

Table 12. Permanent DOSS service; Differences between subgroups

	Physicians, N=46		**Nurses, N=98**		**Ass. nurses, N=76**		
	Mean*	**SD**	**Mean***	**SD**	**Mean***	**SD**	**p-values****
Care for donor families	8.4	1.3	8.4	1.4	8.3	1.6	ns
Information to donor families	7.4	1.6	8.4	1.2	8.4	1.6	0.001
Follow-up with donor families	8.3	1.6	8.8	1.2	8.3	1.7	ns
Identification of potential donors	6.9	1.5	7.3	1.4	7.7	1.5	0.044
Medical care of potential donors	8.1	1.5	8.3	1.2	8.1	1.4	ns
Relief of workload for the staff	8.4	1.6	8.8	1.2	8.5	1.6	ns
Source of knowledge and support for the staff	7.8	1.8	8.3	1.4	8.0	1.9	ns
Sense of confidence among the staff	7.9	1.8	8.5	1.3	8.4	1.7	ns
Development of local routines	5.9	2.9	6.6	2.3	6.7	2.7	ns
Education of staff and introduction of new staff	5.6	2.7	5.3	2.9	5.8	2.6	ns
The total effect of the DOSS/DOSSes	**5.6**	**1.3**	**9.0**	**1.1**	**8.9**	**1.3**	**0.009**

*Estimated on visual analogue scales (VASs) from 0.0-10.0.
Score 5 = no change owing to the DOSS/DOSSes, >5 = positive effect, <5 negative effect
**P-values for the changes between the initial DOSS project and the permanent DOSS service, ns = p>0.05

In the follow-up questionnaire evaluating the permanent DOSS service, some additional questions were added, mainly regarding the DOSSes' influence on the ICU staff's attitudes, feelings and sense of responsibility. The ICU staff stated that the DOSS service had contributed to an increased willingness to learn about organ donation (mean: 6.1, SD ± 2.7) as well as to a strengthened sense of responsibility for the donation work at the department (mean: 7.2, SD ± 2.4). Furthermore, the ICU staff felt more confident when caring for a donor (mean: 7.7, SD ± 1.7) and they were more willing to donate their own organs (mean: 7.0, SD ± 2.0). In addition, the working conditions had improved greatly according to the ICU staff (mean: 7.9, SD ± 1.7). Finally, there were only small differences in the quality of the different DOSSes' work (mean: 4.4, SD ± 3.0) (please note that a low score equals little differences in quality).

Again, there were some differences in the responses to these additional questions between the three categories of ICU staff (Table 13).

Table 13. Permanent DOSS service, additional questions: differences between subgroups

	Physicians N=46		Nurses N=98		Ass. Nurses N=76		
	Mean*	SD	Mean*	SD	Mean*	SD	p-values**
DOSSes' influence on the staff's personal commitment in donation work	3.4	3.0	5.7	2.8	6.4	2.5	0.000
DOSSes' influence on the staff's willingness to learn about organ donation	4.3	2.9	6.4	2.5	6.9	2.5	0.000
The staff's sense of responsibility for the donation work at the department	7.9	1.9	7.4	2.2	6.6	2.7	0.021
DOSSes' influence on the staff's feelings in connection with organ donation	7.0	1.9	7.9	1.6	7.9	1.7	0.010
DOSSes' influence on the staff's working conditions during donor care	7.8	1.6	8.1	1.4	7.6	2.0	ns
DOSSes' influence on the staff's own willingness to donate organs	5.5	1.0	7.2	2.0	7.7	2.0	0.000
Cooperated with one single DOSS only: quality of that DOSS's work	8.1	1.2	8.3	1.7	8.6	1.7	ns
Cooperated with more than one DOSS: differences in quality of the DOSSes' work***	3.9	3.0	4.9	3.0	4.3	3.2	ns

*Estimated on visual analogue scales (VASs) from 0.0-10.0 - from “no influence” to “major influence”
** P-values for differences between professions, ns = p>0.05
*** Please note that a low score equals a positive result on this specific question: 0.0=no differences, 10.0=major differences

4.2.7.1 Physicians feeling responsible for the donation work

Of the three categories of ICU staff, the physicians felt the greatest responsibility for the donation activities at their departments (Table 13). This was also supported by the correlations that showed that staff with extensive experience of organ donation, which in this study were the physicians (Table 11), felt a greater responsibility for the donation work at the ICU (correlation coefficient [cc]: 0.407, $p < 0.001$). Furthermore, staff that more frequently cooperated with the DOSS service, again the physicians (Table 11), felt a greater responsibility for the donation work (cc: 0.254, $p < 0.001$).

However, the physicians’ personal commitment in donation work (physicians’ mean score: 3.4, p=0.000) or willingness to learn about organ donation (physicians’ mean score: 4.3, p=0.000) had not been influenced by the DOSS service, to the same extent as in the other categories (Table 13).

4.2.7.2 Physicians’ willingness to donate was less impacted

Moreover, the physicians’ willingness to donate organs was significantly less impacted than was the willingness in the other categories of ICU staff (physicians’ mean score: 5.5, p=0.000) (Table 13). This result was also supported by the correlations indicating that staff with less experience (nurses and assistant nurses) had increased their willingness to donate their own organs to a higher extent than staff with extensive experience (cc: -0.233, p=0.002).

4.2.7.3 Agreement on improved working conditions, and on the high quality of the DOSSes' work

The physicians, as well as the nurses and assistant nurses, found that their working conditions in connection with the care of an organ donor had improved greatly (mean scores: 7.8, 8.1, 7.6 respectively, ns) (Table 13). Staff that more frequently cooperated with the DOSS service saw a greater improvement of the working conditions in connection with an organ donation (cc: 0.285, $p < 0.001$) than did staff that more seldom cooperated with the DOSS service.

Finally, all three categories of the ICU staff agreed that there were only small differences in the quality of the different DOSSes' work (mean scores: 3.9, 4.9, 4.3, ns) (Table 13).

4.3 PAPER III

WHAT DO PEOPLE AGREE TO WHEN STATING WILLINGNESS TO DONATE? ON THE MEDICAL TREATMENT ENABLING ORGAN DONATION AFTER DEATH

QUALITATIVE RESULTS

The following four main categories are a result of the qualitative content analysis of the interviews with the donor relatives: 1) The occurrence of death, 2) The medical treatment enabling organ donation, 3) The donor operation and 4) The donor relatives' own decision-making process. Together these categories provide an understanding of the donor relatives' experiences of the medical treatment enabling organ donation.

4.3.1 The occurrence of death

To comprehend death when the dead family member still looks alive despite being dead, was sometimes hard for the donor relatives. Hence, the point in time at which the relatives perceived their family member to have died varied widely, following a time line from the family member initially collapsed till the actual donor operation (when the family member first collapsed; during brain death being determined; when receiving formal information about death; at the donation request; during the donor operation).

There were also relatives who were uncertain of the time of death or who talked about it in a contradictory manner. Contributing to this uncertainty may well be that staff, according to the donor relatives, sometimes communicated with the dead patient as if the patient was still alive.

Among the relatives in this study, there was only one relative who did not completely trust the reliability of the procedures to declare death. Finally, some donor relatives stated that they received vague information about the declaration of death, e.g. staff trying to explain death without using the word *dead*. Finally, the psychological difficulties some relatives had in accepting the sudden loss contributed to their difficulties in comprehending death.

4.3.2 The medical treatment enabling organ donation

4.3.2.1 Being on a ventilator

The only aspect commented on by almost all relatives regarding the medical treatment necessary for organ donation, was the ventilator treatment. The understanding, however, of the purpose of the ventilator varied widely; from those donor relatives who clearly understood that the ventilator treatment was prolonged after death in order to maintain organ viability by providing oxygen to the organs, to those who misinterpreted the purpose of the ventilator and actually believed that the ventilator kept their family member alive until the actual organ removal. Hence, the ventilator treatment sometimes made it hard to fully grasp the concept of death. Nevertheless, most relatives put forward that they understood that there was no hope for recovery despite the use of the ventilator.

In most cases the prolonged ventilator treatment was not commented on as something that caused discomfort – only two relatives indicated some discomfort due to changes in their dead family member's body (swollen) and due to all the technical equipment that was still supporting the body functions (cables everywhere).

4.3.2.2 Other medical treatment given and preparations made in order to maintain organ viability

Hardly any medical treatment given in order to enable organ donation other than the ventilator care was mentioned by the donor relatives. Instead, the vast majority of the donor relatives put forward that they were very pleased with the overall medical care. However, the analysis proved that it was hard for most donor relatives to distinguish between which treatment aimed at recovery and which treatment aimed at enabling organ donation.

4.3.2.3 Suspicion of less good medical treatment

Three of the donor relatives in this study feared that their family member was not provided optimal medical treatment so that a possibility of organ donation would be generated. These relatives suspected that the staff did not do their best to save the dying family member, as the staff thought that there were others who needed the organs better (recipients). One of these relatives saw a programme on TV which stated that the need of organs far exceeds the organs available for transplantation, which contributed to her suspicions.

4.3.3 The donor operation

4.3.3.1 Information about the donor operation

According to the donor relatives, the information provided by the ICU staff regarding the procedures surrounding the donor operation, was often vague. However, some stated that they did not need any more information as they were pleased with the knowledge they already had concerning organ donation. Others clearly stressed that they did not want to discuss the operation, not in the acute situation nor during the interviews. This was communicated in a manner to indicate that the operation was something they would rather not think about. Among these relatives we found those who expressed uneasiness when considering the operation and who also said that they had felt uncomfortable seeing the body after the surgery.

When the relatives referred to more specific information about the donor operation, it mainly concerned which organs could be donated. Some relatives had also received information about the specialised surgeons involved and about the comprehensive logistic planning that the operation required.

4.3.3.2 The surgical procedure

The donor relatives' reflections on the donor operation can be described in three distinct positions; as something *positive and/or respectful* – like in any surgery; or something *neutral and/or with an emotional distance* – the procedure was not considered a surgery, the surgeons were just going to fetch the organs; and finally as something *negative and/or connected with uneasiness* – these relatives had thoughts about the donor still being able to feel, and about molestation of the body.

4.3.3.3 The state of the body after the operation

Thirteen of the twenty-one donor relatives chose to take a final farewell of their family member after the donor operation. The reflections of these donor relatives on the state of the body can be described in the three following positions; *a positive view* of the body post operation – no signs of the organ recovery; *a neutral view* of the body post operation – not good or bad, just something one is supposed to do, and finally; *a negative view* of the body post operation – discomfort caused by the state of the body, which was perceived as collapsed.

4.3.4 The donor relatives' own decision-making process

Of the donor relatives who described their own willingness to donate as directly influenced by their dead family member's donation, all but one indicated that their intention had been positively influenced; some had even changed a previously negative decision to a positive one. The fact that the experience of the donation process often made the donor relatives more knowledgeable about organ donation, and also made many of them realise that they themselves were not too old or too sick to donate, contributed to this positive change. Some donor relatives had also been inspired by knowing that many recipients had been helped thanks to their dead family member's donation, and for some, the pride they felt at their dead family member's donation had inspired or reinforced their own willingness to donate. One relative, however, was negatively affected, which made her change her previously positive decision in protest against a chain of events during her husband's stay at the ICU, including mistakes made by one of the ICU physicians, which she believed to have contributed to her husband's death. She also thought that her husband's arm had been exposed in a TV-news report about organ donation, which reinforced her unwillingness to donate.

However, most decisions made by the relatives regarding organ donation were not directly influenced by their dead family member's donation. Instead, the basis for their decision was related to a willingness to help others in need, or to a belief that it was the right thing to do. The minds of these relatives had often been made up long before their loss of a family member who donated organs. Furthermore, they held the opinion that if you are willing to receive an organ, you should also be willing to donate. Some donor relatives were aware of the fact that the need for organs by far exceeds the number of organs available, or they were aware of other facts concerning organ donation through their employment within medical health care.

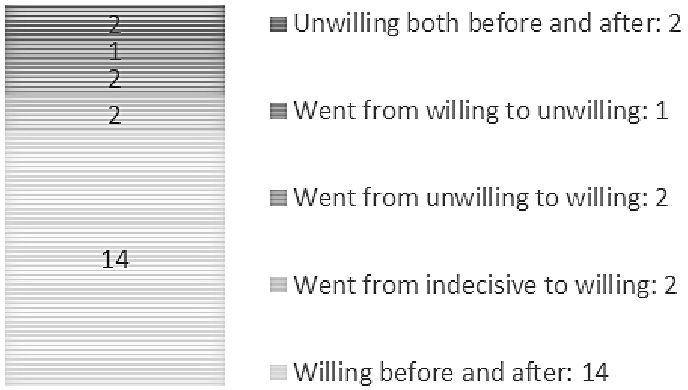
After having experienced the loss of a family member who donated organ, most of the relatives remained willing to donate, and many were also strengthened in their willingness. Still, two donor relatives remained unwilling to donate; one feared that his organs would be taken before death and the other wanted his burial according to old traditions, with the body intact.

QUANTITATIVE RESULTS

4.3.5 The donor relatives’ own standpoints on organ donation before and after having lost a family member who donated organs

In order to further explore the donor relatives’ decisions, a quantification of their decisions was made. This quantification could be made as the donor relatives’ retrospective descriptions of their decision-making process always included their initial decision as well as their decision today. These results demonstrate that the inclination to donate held by most of the relatives was influenced or reinforced by their dead family member donating organs (Figure 4).

FIGURE 4: DONOR RELATIVES’ OWN STANDPOINTS ON ORGAN DONATION BEFORE AND AFTER HAVING LOST A FAMILY MEMBER WHO DONATED ORGANS



Finally, the quantitative results demonstrate that most of the donor relatives (n=18) felt very confident with the decision that had been made for the deceased. However, two felt somewhat unsure and one felt very unsure as a consequence of having had to interpret the intention of the deceased. Of the three feeling unsure, none took farewell of their family member after the organ removal surgery.

At the time of the family member’s passing, most of the donor relatives (n=12) knew that the deceased family member wanted to donate. However, two relatives decided to donate the deceased family member’s organs based on their own positive view on organ donation and not on the interpreted or explicit wishes of the deceased. One of the above stated that she had actually gone against the wishes of the deceased.

5 DISCUSSION

This chapter begins with a discussion of the results from the papers included, followed by a discussion of the methods used in each paper, and finally the chapter ends with a discussion of the ethical consideration regarding the three papers included.

5.1 DISCUSSION OF RESULTS

In the result discussion, the results from each paper included will be discussed in relation to the others, and in relation to other relevant publications within the field. Another starting point is the experience I have gained through working with the organ donation issue in various contexts over the last ten years.

5.1.1 Information to the general public

5.1.1.1 What use is information to the public?

A society that offers transplantation as a therapeutic treatment relies on its members to donate their organs. It is worth considering that during our lifetime all of us are potential donors as well as potential recipients – but currently, the risk for an individual ending up in need of an organ is much greater than ending up in a situation that enables us to donate organs. In Sweden, the willingness to donate is very widespread (Paper I). However, this willingness has proved insufficient to provide with organs those members of our society who are in need of organs [110]. Hence, the possibilities of organ donation and transplantation need further and equal attention in our society. In Sweden, "*The role of The National Council for Organ and Tissue Donation is to support and advise the National Board of Health and Welfare regarding the donation promoting work"*[111]. Initially, the role of the council was not only to give advice, but to independently promote organ donation towards the general public as well as within the medical health care. Today, though, there is rarely any visible public information on the subject of organ donation conveyed by authorities or state agencies.

One may argue that costly campaigns are not the best way to influence attitudes, increase awareness and make people inform about their decision, considering the limited effect of the campaigns shown in Paper I. However, one of the main goals of the long term campaign was to make people aware of, and register in, the National Donor Registry – and the general awareness of the registry did increase – nevertheless there was only a small increase of registrants. However, the fact that more people claimed to expect to be requested about organ donation, if ending up in a situation where organ donation could be an option, is an important finding. This, as an increased expectancy for the question on organ donation most likely makes it easier for everyone involved in the donation process – staff as well as donor relatives. What would make this situation even easier, is if the decision of the deceased were known. However, the campaigns had very limited effect on people's inclination to inform about their decision. Still though, according to assessments made by the campaign office, the long term campaign was noticed by as many as 78 percent of the general public [112] – hence, the conditions for further reaching the public would most likely have been good, had the campaign continued. The donation rates also increased during the campaign periods, from a nadir of 12.1 donors PMI in 2001 to 14.2 in year 2005 [34].

5.1.1.2 Modern media landscape provides good but challenging opportunities for information

Since the last public campaign assessed in Paper I, the media landscape has rapidly evolved, and today there are numerous ways to reach the public with information. However, people face a constant flow of information which makes it hard to ensure that the citizens really take part of the information. In Sweden, the patient founded organisation ‘MOD’ [113], Mer Organdonation (More Organ Donation), act via; a web page, social media, volunteers’ visits to schools, and an expert panel responding to questions via internet, etc. Since the establishment in October 2012, the number of registrants in the National Donor Registry has increased from 33.987 in year 2012, to 62 799 in year 2013, to 106 000 in 2014 [68, 113]. MOD is most likely one important factor contributing to this increase of registrants, as no other organisation or authority has actively conveyed information to the general public. This indicates that carefully designed information can influence public behaviour. MOD was partly inspired by the Norwegian organisation ‘Stiftelsen Organdonasjon’ (The Foundation for Organ Donation) who claim that their information to the Norwegian public has had an impact on the donation rate [114]. In connection with a documentary series called ‘Livet på vent’ (Life on hold) the number of donations increased dramatically in Norway: the foundation later concluded that public information efforts need to be continuous as the donation rate gradually decreased after the television series ended [114]. This clearly shows that media exposure can be very valuable, provided that the donation issue is handled correctly by the media.

5.1.1.3 Interaction with the media

In Sweden, there is no clear media policy or strategy within the organ donation field. However, one important component is how organ donation is portrayed in the media. There are good examples of how organisations working with organ donation can interact with the media in order to promote organ donation: in Spain the ‘Organización Nacional de Trasplantes’ (ONT) [115] works in accordance with a communication policy which aims at creating a positive climate and trust among the inhabitants, concerning organ donation. This policy states that the organisation should pay close attention to the media, and not only promote organ donation but also respond to existing information provided in various media [116]. The professionals within the organisation have direct communication with journalists through dedicated meetings, which allows messages to be delivered with no intermediaries. According to the authors, this policy has contributed to the media handling information about organ donation and transplantation more appropriately [116].

5.1.1.4 What is written about the impact of information campaigns?

There are several organisations promoting organ donation worldwide, often via web pages informing about organ donation [114, 115, 117, 118]. However, besides our publication (Paper II), very little has been published about the impact of specific information campaigns on the general public. An older Swedish publication, however, shows that the distribution of information brochures with donor cards enclosed had a positive, though limited, impact on the public's inclination to inform their relatives about their decision [119]. There are also studies establishing that various information can increase willingness to donate as well as make people inform about their intention on organ donation. This can e.g. be done via education programmes in schools [120], via video narratives, and the authors of the latter publication state that "*brief, one-min videos can have a very dramatic and positive impact on willingness to consider donation and behavioural intentions to register as an organ donor*" [121]. Another study also states that "*public exposure to information is key"* and that having seen public information, within 30 days, has a positive impact on a person's willingness to donate [122]. This supports our conclusion in Paper I; that information needs to be continuous and to be promoted via different media.

5.1.1.5 We are all a part of the general public

Even though we all are a part of the general public, we seem to respond differently to information. Hence, the information needs to be carefully designed to target different subgroups within society in order to reach as many as possible. The campaigns assessed in Paper I primarily promoted emotional arguments for organ donation and transplantation, which seem to mainly have influenced women. It has been suggested that women still are more inclined to talk about emotional issues [123, 124], which is also indicated by our results. Another possible explanation for women being more influenced by the campaign than men, is that women tend to search health care information via the internet more often [125], and to more regularly visit the pharmacy [126] than men – these are places where the campaign was displayed. What yet needs to be explored is how to reach men with information about organ donation; the campaigns assessed in Paper I most certainly did not succeed in doing so.

Worth considering is also that medical staff as well as future potential donors and their relatives, all are members of the general public, and all these categories of the general public are most likely affected by the information – or lack of information – provided in a society. We also know that staff bring in their attitudes to the hospitals [81, 127, 128] as do, most likely, donor relatives. When considering future information efforts it is worth bearing in mind that the priority/lack of priority of the donation issue, from politicians, authorities and hospital managements, also conveys a message of the importance/unimportance of the organ donation issue.

Finally, countries applying presumed consent, like Sweden, in situations where the intention of the deceased is unknown, have a particular obligation to offer the public continuous and transparent information about organ donation and to promote and offer various easily accessible ways of declaring one's decision.

5.1.2 Does specialised staff really make a difference?

Besides organ donation being a rather invisible topic in our society, the individual ICU staff is rarely confronted with a donation process in practice. For example, the ICUs in Central Sweden consulted the regional OPO regarding patients that were considered for organ donation, on average 7-8 times per ICU during year 2014, which was an increase by approximately one third from the previous year. The number of donors (actual and utilised) per ICU outside the university hospitals was approximately 3 [50]. As also mentioned in the introduction (chapter 1.5), only 4,8 percent of the patients dying in an ICU during year 2014 became donors. Hence, organ donation is a rare event in the Swedish ICUs and for each individual staff an organ donation is even rarer. This may well complicate the handling of a donation process, and studies have indeed shown that the handling of the potential donors very much depends on the staff's experience, knowledge and also on their attitudes [57, 61, 94]. Adding to the complexity of this situation is the circumstance that the intention of the potential donors often is unknown (Paper I). In this situation our results clearly indicate that the involvement of specialised staff such as the DOSSes is beneficial to the staff as well as to the donor relatives, and the DOSSes also have an impact on the donation rates (Paper II). This has also been established in other countries that involve various sorts of specialised staff in the donation process [57, 61, 94]. However, besides the benefits of specialised staff on donation rates, there are ethical benefits of equal importance – sometimes not sufficiently mentioned – which consist of the specialised staff striving to ensure that the wish of the deceased is respected [75]. Furthermore, the specialised staff help donor relatives come to a well-founded decision which – in the long run – they will be content with. To help donor relatives thoroughly deliberate and discuss the basis for the decision is of great importance, especially as a premature *no* to organ donation is often regretted [74, 75].

5.1.2.1 The DOSSes' impact on donation rates

The involvement of the DOSSes in the donation process seem to have a significant impact on donation rates (Paper II). One possible reason for their success in comparison with that of the physicians, is that though the physicians have the ultimate responsibility for the handling of a donation process, it is hard for them to gain the same knowledge and experience as the DOSSes have, as physicians do not have time designated for organ donation work. The amount of training and the profound knowledge of all the steps taken during a donation process that the DOSSes have gained over the years, is unique. This, together with the fact that some physicians feel uncomfortable when requesting for organ donation [57, 61, 94], most likely explains why the donation rate is significantly lower, and why the rate of family vetoes is significantly higher, when the physicians handle the donation process independently (Paper II). Another possible explanation for the high veto rate when the physicians request for organ donation, is that they tend not to ask about the reasons behind an initial refusal of organ donation [59, 71, 75, 88].

5.1.2.2 The DOSSes' impact on support and information

The DOSSes' positive impact on donation rates underlines the value of the support and information provided by them (Paper II). Others have also pointed out that the initial reluctance some donor relatives feel when being asked about organ donation, often disappears when receiving clear information and discussing organ donation with specialised staff, like the DOSSes [129]. Nevertheless, the initial uneasiness some donor relatives feel can understandably discourage some staff from proceeding with the conversation about organ donation. However, this initial reluctance has proved often to be a consequence of the donor relatives' reluctance to accept a sudden loss, rather than a reaction to the actual donation request [71, 129].

The ICU staffs in our study confirm the importance of specialised staff and they put forward that the support provided for the ordinary ICU staff, followed by the information provided for the donor families, are the most important work tasks of the DOSS service. Even so, the physicians are not as positive regarding the information provided by the DOSSes as are the nurses and assistant nurses. One possible explanation is that the nurses stay with the donor relatives, while the physicians often leave the conversation with donor relatives soon after having requested for organ donation, as they have other urgent tasks to tend to. Thus, they do not spend as much time with the relatives as do the nurses [71, 75] – consequently they do not have the same insight regarding the information provided by the DOSSes.

5.1.2.3 The DOSSes' influence on different categories of staff

The influence of the DOSSes on the attitudes and feelings of the physicians, nurses and assistant nurses, varies (Paper II). Of the three categories, the physicians felt the most responsible for the work with organ donation, but still the DOSSes had less impact on their willingness to learn about organ donation, on their willingness to donate organs, and on their feelings in connection with an organ donation. This can be interpreted in numerous ways, one being that the physicians – as the staff category responsible for the donation process – find it hard to be influenced by another category of staff, such as the DOSSes. Another possible explanation is that the physicians' willingness to donate, to learn, etc. initially was higher than was the willingness among the staff in the other categories, resulting in the physicians not being as influenced by the DOSSes. However, the fact that the physicians – who are and also feel responsible for the donation activities – regularly involve a DOSS in the donation process, clearly demonstrates a great appreciation for the DOSSes' work.

Nevertheless, regardless of the DOSSes' impact on the ICU staffs' attitudes and feelings, it is of importance to consider how the ICU staffs' attitudes influence the donation process: ICU staff that question organ donation, or are unwilling to donate their own organs, may well be less suited to handling the donation process [81]. Not all ICU staff need to be willing to donate their organs. It is of importance, however, to reflect on who is best suited to handling a donation process. This, as we know that a positive attitude and approach when requesting for organ donation has an impact on the outcome of the donation request and on the donor relatives' satisfaction [130, 131]. The positive impact of the DOSSes shown in our study, is most likely not only a result of their profound knowledge – but an equal result of their positive approach and attitude.

5.1.2.4 A successful transformation of the DOSS project into the permanent DOSS service

Initially there was some hesitation at the introduction of the DOSS function, though there were inspiring examples of the use of designated staff from other countries like Spain [95, 132]. What was sometimes questioned was the involvement of external staff that solely focused on organ donation, which included the medical treatment of the donors as well as the interaction with donor relatives. There are ethical guidelines underlining the importance of a clear distinction between staff involved in transplantation procedures at one end, and staff responsible for the donor care and the donation request at the other [39, 133]. In some countries, like the US, organ procurement organisations have been established in order to act in the interface between the ICU and the transplant department. In Sweden, though, the transplant coordinators have usually been a part of the transplant department. In contrast to this, the DOSSes are positioned as a regional support to the ICUs, and their belonging to the donor team is underlined by their combined employment as both a DOSS and as an ordinary ICU nurse. In spite of the initial hesitation to the DOSS function, the ICU staff in our study found valuable improvements in many areas, thanks to the DOSS service (Paper II).

Since the initial DOSS project was transformed into the permanent DOSS service, the individual DOSS involved in the donation process varies, which was one of the concerns when expanding the service. Fortunately, the ICU staff in our study found very small differences in the quality of the different DOSSes' work (Paper II) – which is a testament to the DOSS service as a whole. Another concern in connection with the said transformation, was that in most cases the individual DOSS would be unknown by both ICU staff and donor relatives, and the DOSS would also be introduced at a rather late stage of the donation process. This could potentially complicate the involvement of the DOSSes. Nevertheless, the rate of family vetoes remained low, which indicates that the DOSSes in the permanent service have the ability to build a trusting relationship with the donor relatives within a very short time frame, and in an emotionally very demanding situation.

Furthermore, though it is not mandatory for the ICU staff to involve a DOSS, the DOSS service was contacted in 86 percent of the cases, which suggests that the initial hesitation towards cooperating with specialised and external staff has turned into appreciation (Paper II). Another indicator of the success of the permanent DOSS service is that the donation rates in the whole Stockholm region have increased since the establishment [50].

5.1.2.5 Changed priorities of the work tasks of the DOSS functions

During the permanent DOSS service, when the staff was asked to rank the DOSSes' work tasks, one work task was given a higher ranking than during the initial DOSS project: "source of knowledge in the acute donation process". This task was then regarded as the most important work task of the DOSS service, followed by the "care for and information to donor relatives".

The latter task had been seen during the initial DOSS project as the most important work task (see Table 9, page 52, for ranking of the work tasks).

A reasonable explanation for this change in ranking of the DOSSes’ work tasks may well be that the DOSSes take part in the donation process at a rather late stage, and have no prior relationship with the donor relatives. Therefore the involvement of the DOSSes is primarily considered to be a support for the staff – and the nurses from the ordinary team are most likely considered to be the most important staff when it comes to the care and emotional support for the donor relatives. Another contributing factor to this change in ranking may well be that the initial DOSS worked at a neuro ICU where organ donation was a rather frequent event. Today, though, the DOSSes take part in the donation process even at ICUs that very rarely treat a potential donor. Hence, the support for the staff has become an even more important work task for the DOSSes.

However, though the work task “care for and information to donor relatives” (combined in one work task in the ranking) was given a lower ranking during the permanent DOSS service, a different picture was presented when the staff scored the impact of the DOSSes on family care and on family information separately on the VASs. What then became clear was that the information provided by the DOSSes was given equally high scores both during the initial DOSS project and during the permanent DOSS service. Hence, the information was considered to be of equally good quality during the permanent DOSS service as during the initial DOSS project. This finding is essential as the quality of the information provided to donor relatives is of key importance. The care for the donor families, however, was scored significantly lower during the permanent DOSS service, which supports the reasoning above about the bedside nurse being of greater importance when it comes to family care. However, the care provided to the donor families by the DOSSes was still given a high score of 8.4 out of 10.0.

5.1.2.6 Education and introduction of ICU staff need further attention

Though, according to the ICU staff, many aspects of the donation process have been improved thanks to the DOSS service, there is one area that could be further improved; education and introduction of staff. This area was given significantly lower scores during the permanent DOSS service than during the initial DOSS project. One logical explanation for this is that the focus on and responsibility for staff education today mainly lies with the donation responsible nurses and physicians [24]. The work tasks and responsibilities of this category of staff had not yet been clearly defined when the initial DOSS project was ongoing, and the initial DOSS also took great pride in educating staff. Today however, the DOSSes are mostly involved in the acute donation process. By improving the collaboration between the DOSSes and the donation responsible nurses and physicians, the important sharing of knowledge and the joint planning of educations may further optimise the organ donation process. By prioritising education of staff and introduction of new staff, the risk of hollowing out the ordinary ICU staffs’ knowledge on organ donation is most likely minimised – which otherwise could be a consequence of relying on specialised staff.

5.1.2.7 The overall value of the DOSS function

In the introduction (see chapter 1.8) the ambivalence and uncertainty some ICU staff feel during the donation process is described. The chapter illustrates how the staff is surrounded by the donor relatives' despair and that some staff then consider the introduction of organ donation an extra burden for the donor relatives, and how some staff subsequently fail to request for organ donation. During the transition of treatment, from life sustaining to organ preserving treatment, many also put forward that they do feel ambivalent regarding what information should be given to the donor relatives, and that they sometimes feel dishonest when not explaining why the medical treatment is prolonged. Taken together, there are several circumstances that sometimes cause emotional stress among nurses and some also find it ethically challenging to care for a potential donor and his/her relatives. The physicians on their part describe discomfort when requesting for organ donation, which sometimes is caused by inexperience, and by the fact that they find it hard to balance their concern for the recipients of the organs on one hand, and their concern for the donor relatives on the other. Some of these issues can most likely be resolved by the involvement of specialised staff, offering the ICU staff relief both emotionally and practically during the delicate donation process.

Finally, though the ICU staff initially displayed some hesitation concerning the involvement of specialised staff, the fact that the ICU staff scored the DOSS service 8.8 on a scale from 0.0-10.0, clearly indicates a true appreciation for the cooperation with specialised staff.

5.1.3 Is there acceptance of the organ preserving treatment?

During some years now there has been a discussion among professionals working with organ donation regarding what medical treatment is acceptable and appropriate in order to enable organ donation, and how this medical treatment should be presented to the general public and, in the acute situation, to the donor relatives (see introduction, paragraph 1.4.7). As mentioned earlier, the regulations regarding this treatment are also perceived as unclear. In a democracy, the regulations ought to reflect the opinions of the inhabitants. Nevertheless, the circumstances surrounding an organ donation are complex and hard to comprehend for the common man. However, donor relatives constitute an informed group of the general public. We therefore chose to turn to donor relatives – a group with unique experiences and insight – in the search for what medical treatment is perceived as acceptable in order to enable organ donation.

5.1.3.1 The understanding of death proved to be central

The donor relatives' understanding of death proved to be central in order to gain a better understanding of the main focus of this study, namely: the acceptance of the medical treatment enabling organ donation. This, as the prerequisite for understanding what medical treatment was life-sustaining and what treatment was organ-preserving, was knowing when the dying family member no longer could be saved, and when death had actually occurred. What complicated the understanding of brain death for some of the donor relatives in our study were the psychological difficulties in accepting their loss. These difficulties are most likely a consequence of the fact that the donor relatives are forced to face the loss of a dear family member or friend within a very short time period – the threat of losing a loved one is actually often perceived as the most stressful part of the donation process [134].

5.1.3.2 The time point for the occurrence of death

Concerning the time point for the occurrence of death, we found major differences between the donor relatives – some believed very early on that death had occurred while others thought that their family member was alive until during the donor operation. The lack of information on organ donation in our society, which was discussed earlier (see paragraph 5.1.1), most likely contributes to donor relatives being unprepared and ignorant when ending up in a real situation where organ donation may be an option [96, 135].

5.1.3.3 To agree to donate the organs of a loved one despite not being certain of death

To agree to donate a loved one’s organs though not being certain of death, may seem strange. Nevertheless, others have also found that even though some donor relatives doubt that their family member is dead, they still do agree to organ donation [136]. An American study also points out that the concept of brain death is unclear to many, and that some people actually are willing to donate the organs of a loved one even though they do not perceive that person to be dead [135]. This confusion about death which leads people to think that the ‘dead donor rule’ may be violated, could potentially cause distress and discomfort. A Swedish study stated that the most common discomfort (in connection with organ donation) is the *‘‘Illusion of lingering life, which means that it is difficult to imagine a difference between the living and the dead body and that procedures with a corpse are perceived as conducted on a living body”* [137].

5.1.3.4 The importance of realising that there is no hope for recovery

However, the donor relatives in our study who believed that their family member was still alive at the organ recovery, did not display these feelings of discomfort. In general, what seems to be central in this context is that the donor relatives realised that there was no hope of recovery and that their family member was beyond saving. Another study also points out that it is of importance for the ICU staff to make an assessment of whether the donor relatives find that their family member is beyond recovery, and whether they have accepted the inevitable death, rather than for the ICU staff to make sure that the donor relatives define brain death correctly [62]. Furthermore, the trust the donor relatives in our study felt in the medical interventions ensuring that their family member did not suffer, helped them to be at ease with the donation procedures.

5.1.3.5 Farewell ceremony before the donor operation

Nevertheless, it has also been established that the donor relatives’ confidence in the brain death diagnosis has an impact on their grieving reactions and depression symptoms [138]. In our study we find that what may have complicated this important confidence – as well as the donor relatives’ comprehension of death – is the fact that the dead family member still looked alive even though he/she was dead. In order to better understand death under these circumstances it has been suggested that the donor relatives may well benefit from the ICU staff offering a farewell ceremony, before the donor operation, when the family member is actually declared dead. Instead, however, the ICU staff sometimes contributed to the donor relatives' uncertainty about death by being vague when communicating about death – sometimes by failing to use the word *dead,* and sometimes by communicating with the dead patient in the same manner as when the patient was alive.

5.1.3.6 How to reach a greater professionalism when caring for a donor

In order to reach a greater professionalism when caring for a donor, a Swedish thesis suggests recruiting an extra ICU nurse to perform professional after-death care [139]. By doing this, the nurse previously responsible for the living patient is freed from caring for the brain dead person, and from participating in the preparations that need to be made before the organ procurement surgery [139]. This partly is what is actually practiced in the Stockholm region when the support from the DOSS service is utilised, which has proved to be valuable for both the ICU staff and donor relatives. As pointed out in the introduction of this thesis, ICU staff is often inexperienced and feels insecure when communicating about death and organ donation, and there are also nurses that do not completely trust the diagnostics of brain death – hence, this may well contribute to the donor relatives' vague perception of death [57-62, 87]. The feeling of failure some staff experience when they are not able to save a patient [57], may also serve as an explanation of why the staff feels uncomfortable when communicating with the donor relatives. Taken together there are several possible explanations for ICU staff lacking clarity and transparency when explaining death in connection with organ donation, which could be helped by introducing staff like the DOSSes.

5.1.3.7 The importance of being responsive to the individual donor relative

However, most certainly some ICU staff informed the relatives in our study adequately about death and organ donation, and many relatives put forward that they did receive information, but that they cannot recall much of it. In this emotionally demanding situation, when faced with the threat of loss, some relatives were not able to take in information. Hence, the staff needs to be responsive to the individual donor relative, in order to adjust accordingly the information and the timing of the different actions taken during the donation process.

5.1.3.8 The importance of providing the donor relatives with time

Worth considering in this context is that the only possibility for giving the donor relatives time to start processing the situation is before death, as the organ recovery has to begin within 24 hours after death has been diagnosed – hence the time is very limited. During this delicate phase the support of specialised staff, such as the DOSSes assessed in Paper II, can be of great value. This is also supported by others, pointing out that death and organ donation need to be made understandable by providing the donor relatives time and comprehensible information – both early on during the donation process and after the decision has been made [66]. One study also claims that the number of organs available for donation will not increase until *"bereaved family members approached to donate the organs of their deceased relative have a better* *understanding of what these diagnoses mean"* [62]. The DOSSes' impact on donation rates found in Paper II clearly supports this statement.

5.1.3.9 Fears of sub-optimal treatment in order to make organ donation possible

Organ donation is depending on the public's trust in the medical health care and in the physicians' and other medical staff's efforts to primarily save patients' lives [78]. However, what sometimes threatens this trust – as well as the understanding of the concept of brain death – is the fact that the media occasionally portray people's deepest fears – that doctors would deliberately remove a patient's organs before death, or that life-saving medical care is withheld so that patients become eligible for organ donation [63]. In our study, we found very little suspicion of less good medical treatment in order to "generate a donor". Nevertheless, one relative who was very strongly pro-donation before the loss of her husband, changed her decision into a negative one as a consequence of mistrust in the medical care provided to her husband and suspicions of neglect in order to "produce a donor". In general, however, we found very little evidence of fear of the dying patient not receiving optimal treatment in order to speed up the dying process and "produce a donor" – on the contrary; the donor relatives were very pleased with the overall medical care.

What may be helpful when communicating with the donor relatives, is to clarify that in order for the organs to be transplantable, the medical treatment provided all through the dying and donation process needs to be optimal and that the medical treatment will be optimal, regardless of organ donation. In this communication, the entire sequence of events during the stay at the ICU ought to be summarised and discussed, in order to identify and clarify possible concerns and misconceptions of the donor relatives. In addition, written information about brain death and the process of organ donation may be provided. This can be of value for the donor relatives as they can read the information after the said conversation and after they have left the ICU. The donor relatives' narratives in Paper III show very clearly that the relatives wish for, as well as benefit from, honesty and transparency – which most likely minimises suspicions and concerns of sub-optimal treatment during the donation process.

5.1.3.10 Awareness of the medical treatment in order to make organ donation possible

The findings in our study show that the donor relatives had very limited understanding of what medical treatment was aimed at saving the patient and what treatment was provided in order to make organ donation possible. This may well be a consequence of what was discussed earlier; the donor relatives' difficulties in understanding death. However, this was most likely also a consequence of ICU staff not openly describing the purpose of the medical treatment during the donation process.

Nevertheless, what most donor relatives understood was that the ventilator was essential in order to be able to donate organs. However, the donor relatives' understanding in the *function* of the ventilator varied widely. This impacted their understanding/misunderstanding of death, as well as their understanding of the aim of the medical treatment. The ventilator actually led some relatives to mistakenly believe that their family member was alive after death, while others understood that the sole purpose of the ventilator was to maintain organ viability. Hence, the donor relatives would most likely be helped by a thorough explanation of the function of the ventilator, and the changed purpose of the ventilator before and after death.

Many suggest that it is appropriate to prolong ventilator treatment even though there is no hope for recovery, in order to enable organ donation – provided that the dying patient is pronounced willing to donate [58, 140, 141]. However, the unclear framework regulating this phase of the donation process most likely contributes to the Swedish ICU staffs being vague regarding this prolonged treatment, which in turn may lead to uncertainty among donor relatives. This needs to be addressed and the pros and cons of the prolonged medical treatment need to be discussed and clarified among the medical health care providers [141].

5.1.3.11 What about the donor operation?

Our results, along with the results in a Danish thesis [64], point out that there is a risk that the donor relatives are left with disturbing fantasies about the actual organ procurement surgery. After having analysed the donor relatives' narratives, this seems to be a consequence of the staff not sufficiently addressing the operation with the donor relatives. In our study, the information that the donor relatives recalled regarding the donor operation mainly concerned which organs could be recovered. In our country, the ICU staff is obligated to seek consent for each organ that can be donated. Hence, it is logical that this is the main subject that the relatives recall from the conversation about the operation. Nevertheless, there is further information which could be helpful in order for the donor relatives to better cope with the organ recovery surgery.

However, it seems like the donor operation is an area that has been somewhat neglected. When we turn to previous publications, we can see that little has been written about the donor relatives' feelings and thoughts about the operation. Our analysis of the interviews also showed that the information provided to the donor relatives about the operation was often scarce. Also, when educating ICU staff the question "should we really talk about the donor operation with the door relatives?" has sometimes been raised.

In the interviews some relatives clearly conveyed, in words, with body language and in tone of voice, that they did not want any information about the donor operation – not in the acute situation at the ICU, and not during the interviews. It is also a well-known fact regarding other surgical procedures within the medical health care; some people do not want detailed information about the surgical procedure. Still though, one may wonder if these relatives in our study would have benefitted from being appropriately informed about the procedures, as the impression they gave during the interviews was that the thought of the operation was very emotionally challenging for them. Behind these relatives' resistance there may well be disturbing feelings and thoughts surrounding the organ removal surgery – which some relatives also openly addressed in the interviews.

5.1.3.12 What information should be provided about the donor operation?

Carefully thought-out information would most likely reduce some donor relatives' fears of molestation and dismemberment of the deceased family member's body – fears that were found in our study as well as in a Danish thesis [64] – and reduce disturbing thoughts and nightmares. Proper information may also prevent donor relatives from opposing organ donation, due to misconceptions of the procurement surgery [64]. However, as a consequence of the low frequency of organ donation, the ICU staff may lack insight regarding the donor operation. Before communicating with donor relatives, the ICU staff then ought to prepare and to learn about the procedure.

There are important circumstances which, if communicated, could provide donor relatives with a clearer picture of what is happening before and during the organ removal surgery, while they wait for the final farewell: the fact that there are medical preparations that need to be made in order to maximise the quality of the organs; that there are several tests that need to be made in order to evaluate the medical suitability of the donor; that each organ needs to be matched with a specific recipient; that the recipients need to be located and prepared for the transplantation surgery; that specific surgeons need to be assembled, and finally – and importantly – that the operating procedure consumes a lot of time as the organs need to be removed very carefully in order not to be destroyed during surgery.

5.1.3.13 The donor relatives' own decision was positively influenced

The idea for this study (Paper III) arose during an ethics seminar addressing what treatment is appropriate in order to enable organ donation. The initial idea was solely to assess the donor relatives' own decisions before and after having lost a family member who donated organs. This, as the donor relatives' decisions were considered to be a good indicator of the general acceptance of the medical treatment enabling organ donation. Most certainly, the donor relatives would not want to donate their organs if they had perceived the donation process as inappropriate or objectionable. Hence, the number of donors being positively or negatively influenced by their experiences of the donation process is naturally of interest. The quantification of their decisions, as displayed in Figure 4 in the result chapter (page 59), showed that most donor relatives either remained willing or became willing to donate their own organs after having experienced the donation process. However, when we were doing this quantification, it became clear that the reasoning behind their decisions was of equal interest. Hence, a qualitative analysis was made of the donor relatives' decision-making process. This showed that the basis for some relatives' decisions was actually the specific experience of losing a close family member who donated organs, while most had made up their mind a long time previously. Still, though, the latter category of donor relatives did not change their already positive attitude after having experienced the loss of a family member who donated organs, and many were reinforced in their willingness. This also indicates an acceptance of the procedures undertaken during the donation process.

5.2 DISCUSSION OF METHODS

As the methods in the three papers in this thesis differ, they will be discussed separately in consecutive order. For quantitative Papers I and II, the chapter will cover measures taken to obtain validity and reliability.

For qualitative Paper III, the chapter will cover ways to achieve rigour and trustworthiness in terms of credibility, transferability, dependability and confirmability.

5.3 QUANTITATIVE PAPER I – OPINION POLLS TO THE SWEDISH GENERAL PUBLIC

5.3.1 Validity and Reliability in Paper I

Internal validity: *"The degree to which it can be inferred that the independent variables, rather than uncontrolled, caused the observed effects or relationships."* [104]

In order to establish if the differences between the three opinion polls remained after controlling for independent variables like age and gender, a multiple logistic regression analysis was made of each poll question. This analysis supported our previous findings from the chi-square test, regarding the differences (non-differences) between the polls. Hence, the conclusion made in Paper I regarding the differences between the different polls is well supported.

In the three polls, we asked about the respondents' willingness to both receive and donate organs. The question about receiving an organ may have influenced the answers concerning the willingness to donate, which should be considered when comparing our data with that of others. On the other hand, by addressing both donation and transplantation, the questions in the polls were put in a relevant context.

External validity: *"The degree to which the findings can be generalised to settings or samples other than the one studied."* [104]

In order to reach as many as 3×1000 participants for a telephone interview, we chose to collaborate with SIFO. SIFO's stratification of the sample made it possible to achieve the same precision of estimates, in smaller groups, as in completely randomised larger groups. This was important as we aimed at making inferences about the Swedish general public's attitudes and knowledge concerning different issues covered in the opinion polls, such as the willingness to donate organs.

The stratification also ensured a geographical balance of the sample, resulting in all parts of Sweden being represented. Hence, the geographical stratification ensured representation of remote areas which may well have been less represented if a completely randomised sample had been used. The post-stratification also ensured that the sample represented the Swedish general public regarding age, gender and occupation.

Construct validity: *"The degree to which an instrument measures the construct under investigation."* [104]

The questions included in the telephone interviews were worked out by the multi-professional research group, in collaboration with representatives of patient organisations and SIFO. SIFO has extensive experience of constructing valid interview questions and conducting telephone interviews. SIFO therefore contributed with valuable input to the included questions. However, logically SIFO had very limited knowledge on organ donation, therefore the research group accounted for the subject knowledge, and contributed with information of the construction of similar surveys concerning organ donation. The research group had the final say of how the questions were formulated and of how the questionnaire was constructed.

Two of the "constructs under investigation" were the information campaigns directed towards the general public (see paragraph 1.9.3, page 33). The three opinion polls offered an opportunity to compare the different aspects included in the polls, before and after the two information campaigns. However, no question was included regarding whether the respondents actually had noticed the campaigns. This would have made additional analyses possible, making more inferences about the impact of the campaigns.

However, no other positive or negative media exposure, or information efforts regarding organ donation took place during the intervening periods. The campaign office made an estimation of how many Swedes had noticed the long term campaign, and as much as 78 percent of the general public claimed to have noticed the campaign [112]. Hence, we draw the conclusion that the observed changes between the polls were a consequence of the information targeted at the general public.

Reliability: *"The degree of consistency with which an instrument measures an attribute."* [104]

SIFO offers standardised procedures for data collection, has major experience of doing similar opinion polls, offers trained staff and a safe computerised system for data collection and storage of data.

However, to check the use of the questionnaire as well as the interviewers, random checks on about 10 percent of the interviews were carried out by phoning the respondents who had participated in the survey. A number of check items were then covered, which included the quality of the interviewer, verification of household data, correct use of the questionnaire, etc. Hence, the consistency during the data collection is considered high.

5.4 QUANTITATIVE PAPER II – REVIEW OF MEDICAL RECORDS AND QUESTIONNAIRE TO INTENSIVE CARE STAFF

Paper II consists of two different data collections and analyses. In the following paragraphs the methods in the two different parts of the paper will be discussed separately, starting with a methodological discussion about the donation rates followed by a discussion about the questionnaire to the ICU staff.

5.4.1 Validity and Reliability in Paper II

REVIEW OF MEDICAL RECORDS

Internal validity: *"The degree to which it can be inferred that the independent variables (DOSS), rather than uncontrolled, caused the observed effects or relationships."* [104]

5.4.1.1 Could the selection of donors cause the increase of donation rates?

Due to the retrospective study design the research group had no influence on which cases were referred to the DOSS and which were not. Hence, the research group could not deliberately or unconsciously select easily manageable cases to the DOSS, which otherwise could have contributed to the increased donation rates when a DOSS participated.

During the initial DOSS project, the donors in the different subgroups were included according to the DOSS' work schedule; the potential donors during a DOSS shift were included in group B, and the potential donors at other times were included in group C. During the permanent DOSS service the inclusion of donors in group D and E was depending on the local ICU staff's choice to contact the DOSS service or not. This could potentially lead to a bias of what donation processes the ICU staff chose to involve a DOSS in or not. However, the staff contacted the DOSS service in as many as 86 percent of the cases. It also seems reasonable to infer that the staff chose to contact the DOSS service when having complicated donation cases, considering that the staff, due to the rarity of organ donation, often lacks experience of how to handle a donation process.

5.4.1.2 Could there be differences in demographics among the donors which caused the increased donation rates?

In order to establish if there were other variables than the DOSS participation which caused the increase of donation rates, the differences in demographics among the donors in the different subgroups were also tested. There were no significant differences in age, gender or diagnosis between the subgroups that could explain the difference in donation rates (Table 14). Hence, the differences in donation rates between the subgroups are, to our knowledge, a consequence of the DOSS participation.

Table 14. Organ donor demographics of groups A, B, C, D and E

	Before initial DOSS Project No DOSS (A)	***DOSS Project without DOSS (B)***	***DOSS Project with DOSS (C)***	***DOSS Service without a DOSS (D)***	***DOSS Service with a DOSS (E)***
Number of suitable donors (n)	59	23	26	15*	96**
Gender, female/male (n)	27/32	15/8	16/10	6/8	50/44
Age, mean (yrs)	53	53	52	47	49
Age, median (yrs)	54	55	53	52	54
Diagnosis (n)	Trauma: 6 No trauma: 53	Trauma: 4 No trauma: 19	Trauma: 2 No trauma: 24	Trauma: 3 No trauma: 11	Trauma: 10 No trauma: 84

Age, gender and diagnosis: No significant differences between the groups were observed
*Demographics for one donor in group D are missing, only age could be found
**All demographics for two donors in group E are missing

5.4.1.3 *Could there be other developments within society that had an impact on the donation rates?*

During the initial DOSS project, the information campaign "Livsviktigt", which is discussed in Paper I, took place. Over the last decades social media have also evolved rapidly and people can easily share their personal stories of organ donation and transplantation in various media. The developments in society may have had an impact on the donation rates. However, the impact ought to be equal, regardless of who handled the donation process (DOSS or physician). Hence, it is not logical that the developments in society should be interpreted to explain the significant difference in donation rates when the DOSS participated in the donation process and when the physician handled the donation process independently.

External validity: *"The degree to which the findings can be generalised to settings or samples other than the one studied."* [104]

The findings can most likely be generalised to other groups of donors with similar demographics (age, gender and diagnosis, see Table 14). When considering generalisation of the results, the Swedish ICU context and the function of the DOSSes need to be considered.

Construct validity: *"The degree to which an instrument measures the construct under investigation."* [104]

5.4.1.4 *How accurate was the information in the medical records about the donation rates?*

The subgroups in Paper II consist of the total number of eligible donors that were identified and reported to the regional organ procurement organisation (OPO) by the local ICU staff during the study period. There may well be cases which the local ICU staff failed to identify. Hence, this study does not cover unidentified donors, also an essential topic, considering the often low donation rates.

The transplant coordinators within the OPO record all data according to pre-standardised definitions of variables of interest for Paper II, such as the expressed wishes of the deceased (oral, donor card, and donor registry statement), family vetoes, family consent, and the involvement of DOSS, followed by an explanatory text about each donor, making a review of the records possible. When reviewing the data for Paper II, in case of ambiguity of how to interpret the data, an investigation was made through medical records and documentation made by the OPO, by a senior transplant coordinator in order to make clarifications. Hence, the information gained from the records kept by OPO concerning donation rates is considered valid.

Reliability: *"The degree of consistency with which an instrument measures an attribute."* [104]

The design of the record administered by the OPO was the same during the whole study period and the record had previously been used for many years. All OPO staff registers information in the same digitalised version of the record within a short time frame after the completion of a donation process, according to standard definitions and routines. However, as in any medical records 'the human factor' could potentially have an impact on the registered data. Nevertheless, the consistency of the records is considered to be reasonably high.

QUESTIONNAIRE

Internal validity: *"The degree to which it can be inferred that the independent variables, rather than uncontrolled, caused the observed effects or relationships."* [104]

5.4.1.5 Did the response rate have an effect on the result?

The general response rate was high, both in the base-line questionnaire and in the follow-up questionnaire; 75 percent respectively. However, the response rate of the physicians in the follow-up questionnaire was low (physicians 43 percent, nurses 80 percent and assistant nurses 97 percent). Consequently, there could be opposing opinions regarding the DOSS function among non-respondents. However, the fact that the DOSS service was contacted by the local staff in 86 percent of the cases, and that the physicians were responsible for the actions taken during the donation process, indicates a true appreciation for the DOSS service.

In our analyses (ANOVA and post hoc test with multiple comparisons) the physicians that answered the questionnaire proved to have more extensive experience of working with organ donation as well as having cooperated with a DOSS to a greater extent than the nurses and assistant nurses. Hence, the physicians who responded the questionnaire had experiences that were of great interest for the study. However, the low response rate as well as the extensive experience among the physicians that responded, need to be considered when interpreting the results.

5.4.1.6 What can be concluded from VAS?

To use VAS results for statistical analysis is sometimes debated, as the VAS is an ordinal scale without equidistant increments. When using a VAS, it cannot be stated that score 10 is twice as much as score 5 – but only that 10 is more than five. Furthermore, if strictly using the VAS as an ordinal scale, mean scores should not be calculated. Nevertheless, VAS is sometimes used as a ratio scale with equidistant increments. In the result in Paper II, however, the mean scores on the VAS labelled “to the worse” and “to the better” simply indicate that a score of < 5 corresponds to *a negative impact of the DOSS*, and a score of 5 corresponds to *no impact* owing to the DOSS, and > 5 corresponds to *a positive impact*. On VAS labelled “not at all” and “very much so”, a score of < 5 indicates *no impact* owing to the DOSS, and a score of 5 indicates *moderate impact*, while > 5 indicates a *positive impact*.

In order to make comparisons between independent groups (physicians, nurses and assistant nurses, during initial DOSS project and permanent DOSS service) and in order to make statistical inferences through analyses which include several factors, and which allow more powerful conclusions to be made, a parametric test can be applied instead of a non-parametric test, in spite of the latter being customary for VAS results. The condition for doing so is that the mean scores and the median scores are similar, that the sample is reasonably large, and that the standard deviation does not differ much between groups. In Paper II these conditions were met, indicating a normal distribution making parametric test applicable. Hence, the VAS results are presented as mean scores ± standard deviation (SD).

External validity: *“The degree to which the findings can be generalised to settings or samples other than the one studied.”* [104]

The questionnaire was distributed at two different time points and to three different categories of medical staff (physicians, nurses and assistant nurses) and to four different types of hospitals and ICUs (university hospital, small hospital, private hospital and children’s hospital) in order to provide a broad spectrum of opinions regarding the involvement of specialised staff. The findings in the study can likely be generalised to the whole of Stockholm County and to many other regions in Sweden, given that they introduce specialised staff similar to the DOSSes. However, the study does not aim at generalisation, but at serving as a valuable example of a gradual introduction of specialised staff, which can be of importance for other regions or countries considering new work models.

Construct validity: *“The degree to which an instrument measures the construct under investigation.”* [104]

To capture the various effects of the DOSSes’ work, the questionnaire included questions reflecting the various work tasks of the DOSSes (see Appendix at the end of this thesis). The DOSS function primarily focuses on three different areas; the potential organ donors, the donor relatives, and the ICU staff. In order to assess the impact of the DOSSes on these areas, several questions were included in the questionnaire for each area. The project group responsible for the development of the DOSS function took part in the construction of the questions.

Reliability: *"The degree of consistency with which an instrument measures an attribute."* [104]

The questionnaire was tested on a small group of ICU staff, some content was then slightly altered and the questionnaire was then standardised. What could be regarded as a weakness considering the reliability is that the questionnaire was not tested by letting some members of staff fill it in at two different time points, in order to assess the consistency of how the staff answered the questions. However, the main author participated in staff meetings at all included ICUs, introducing the questionnaire in order to clarify how to answer it.

All distributed questionnaires were delivered by the main author directly to the ICUs in question, in the post box of each individual staff with a stamped return envelope enclosed. When receiving the completed questionnaires, the responses on the VAS were carefully measured by the same person, and the scores were recorded in one result file. In total, the consistency of the questionnaire is considered reasonably high.

Finally, in order to ensure the validity of the statistical analyses made in Papers I and II, a statistic consultant participated in the analyses. All the statistical analyses were performed with IBM SPSS Statistics.

5.5 QUALITATIVE PAPER III – INTERVIEWS WITH DONOR RELATIVES

5.5.1 Trustworthiness and rigour in Paper III

In qualitative research the transparency of all the phases in a study is essential for assessing the trustworthiness and rigour of a study. The researchers need to provide the reader with information that allows the reader to make judgements of the credibility, transferability, dependability and confirmability of a study. Hence, the following paragraphs will describe the measures taken in order to achieve trustworthiness and rigour in Paper III.

Credibility: *"...referring to confidence in the truth of the data; analogous to internal validity in quantitative research."* [104]

5.5.1.1 Is the focus of the study clearly described?

When considering the credibility of a study, the focus of the study needs to be clear in order to be able to determine how well data and the process of analysis address the intended focus [107]. We have therefore thoroughly described the focus in the method (see chapter 3.3, page 43) and how/why the focus was revised and gradually expanded during the process of analysis (see paragraph 3.3.3.1, page 44). For example, it became clear that we also needed to know when the donor relatives perceived their family member to be dead, in order to understand what medical treatment they believed was provided in order to save lives and what medical treatment they believed was provided in order to maintain organ viability.

5.5.1.2 Is the coding process clearly described?

To enhance the understanding of the coding process, this process is illustrated with a code scheme (see Table 5, page 45, for the process of analysis). To exemplify the origin of our findings, we have also chosen to include quotations from the interviews in the result (see full Paper III), providing support for the interpretations made from the analysis.

5.5.1.3 Was the selection of participants in accordance with the aim of the study?

One aspect of importance for the credibility is the selection of participants [107]. In order to elucidate the donor relatives' experiences of the whole donation process and what people intending to donate actually comprise in their willingness to donate, we chose to include donor relatives and not members of the general public. This choice was made with regard to the experiences – unique to the donor relatives – of the complex procedures taking place during an organ donation process. In order to explore the *whole* process surrounding an organ donation, we chose to only include relatives of patients who actually donated organs, and not relatives of patients where the donation process – for various reasons – did not proceed into a donation. Logically, the knowledge and understanding gained through these experiences cannot be found among the general public. The donor relatives most likely internalise these unique experiences in their own standpoints on organ donation – this benefits the study, as one purpose is to explore whether the donor relatives' experiences of having lost a family member who donated organs had an impact on the their own willingness to donate.

5.5.1.4 Was the interviewing procedure reliable?

In order to gain a deeper understanding of the delicate and complex issues covered in this paper, we chose to collect data through in-depth interviews [105]. To create as favourable conditions as possible for the interviews, we encouraged the participants to choose a place where they felt at ease, and where they could talk about the delicate issues covered in the interviews in private and without being interrupted.

Furthermore, the interviews did not only cover the main focus of the study (medical treatment enabling organ donation), but the donor relatives' spontaneous narratives of the whole donation process. This allowed us to make an analysis based on the context surrounding the entire organ donation process, which provided us with a profound and nuanced picture of our main focus.

5.5.1.5 Do the results really mirror the content in the interviews?

All the interviews were transcribed verbatim, by one and the same professional transcriber. The interviewer also listened to the recorded interviews while reading the transcribed interviews in order to make an extra check-up of the quality of the transcriptions. This was done also in order to include non-verbal communication such as laughter or crying, and to get a sense of the whole.

To minimise the risk of misinterpreting the donor relatives' statements, these were always interpreted in relation to the whole context in the interview in which they were given [142]. A constant process of moving from parts to the whole and vice versa, took place during the analysis to make sure that the interpretation made was not contradicted by the rest of the material. Hence, the interpretation made should reflect the essence of the whole material. In some cases, the non-verbal communication, such as tone of voice, was also considered when the findings were interpreted.

Transferability: *"The extent to which qualitative findings can be transferred to other settings or groups; analogous to generalisability"* [104]

5.5.1.6 Similarities and differences regarding organ donation in different countries

When considering the transferability of the findings in the study several factors need to be taken into account. The procedures during end-of-life care and organ donation differ between countries. The role of the relatives and of the physicians also differs: in our country the physicians decide when the medical treatment no longer is considered to benefit the patient and therefore should be withdrawn; in other countries the decision about ending treatment lies with the patient's relatives. In spite of these differences, there are a lot of similarities between all countries with well-established systems for deceased organ donation. For instance, the medical treatment necessary in order to maintain organ viability, which this study focuses on, is a prerequisite for organ donation regardless of country.

5.5.1.7 Circumstances concerning the donor relatives in this study

For the reader to be able to assess if the findings in a study can be transferred to their own context, the context of a study as well as the participants included need to be thoroughly described. In Paper III, the demographics of the donor relatives and some quantitative data are therefore provided (see Table 4, page 44 and paragraph 4.3.5, page 59). These data describe circumstances of the specific group of relatives included in the study, which can be of importance when considering transferability.

Hence, the findings in Paper III can most likely be transferred to other settings where organ donation after brain death is practised; at ICUs, in countries or cultures that resemble Sweden. However, this is to be decided by the reader when comparing the context surrounding the donor relatives in this study to their own.

Dependability: *"…referring to the stability of data over time and over conditions; analogous to reliability in quantitative research."* [104]

5.5.1.8 Was the interviewer consistent all through the interview series?

In order to reduce the risk of inconsistency during data collection, one and the same interviewer conducted all the interviews. In addition, an interview guide was used which ensured that the interviewer covered the same areas with all participants, but still allowing follow-up questions. The interviewer initially conducted three interviews that were not included in the study. These interviews were recorded and the interviewer and an experienced qualitative researcher listened to the interviews and assessed the quality of both the interviewer and the interview guide. Some alterations were then made. The topics in the interviews – sudden death and organ donation also, logically, put an emotional strain on the interviewer. In order to maintain the same empathy, responsiveness, and energy that was needed in order to uphold a high quality of the interviews, the interviewer did not conduct more than one interview a day.

5.5.1.9 Was there consistency in the codes and categories, and in the interpretation made?

The codes and categories were carefully defined during the process of analysis in order to uphold consistency. In some cases it became clear that some codes or categories needed to be redefined. All the interviews were then re-read and assessed according to the new definitions. Inter-coder reliability was also applied, meaning that more than one coder independently coded the interviews [143]. A comparison of the coded interviews was then made, followed by a discussion of differences – when necessary the codes were redefined and data were re-coded.

Confirmability: *"…referring to the objectivity or neutrality of the data and interpretations."* [104]

The first author/interviewer had worked within the organ donation field for some years before conducting the analysis of the interviews. These experiences could potentially both benefit and damage the trustworthiness of the study. In order to take into consideration the main author's pre-understanding, and to make sure that this understanding did not compromise the confirmability of the analysis and interpretations made in the study, a continuous dialogue of what the donor relatives really expressed in the interviews took place between the interviewer and one of the co-authors during the whole process of analysis [104, 107, 144]. The co-author – an experienced qualitative researcher, PhD and social worker – had no previous experience of working with deceased organ donation. Furthermore, the co-author read the interviews and made an independent analysis. A comparison of the co-author's and the interviewer's coding of the interviews was then made, followed by a discussion of how to organise the codes in logical categories. On a few occasions, when the analyses differed, a discussion of how to interpret the findings took place until a shared understanding was reached and both authors felt satisfied with the interpretation deriving from the discussion [104, 107, 144].

5.6 ETHICAL CONSIDERATIONS – STUDY I, II AND III

The included studies all concern organ donation after death. To ask people to consider conditions regarding their own death or that of a close family member naturally requires both psychological and ethical considerations.

In Study I, members of the general public were telephoned, in their own homes, and asked about organ donation, which can be perceived as a sensitive topic. Hence, it was important that the participants were clearly informed that the participation in the telephone interview was voluntary and that they could end the interview at any time. Concerning anonymity, the research group did not have access to any personal information about the participants.

In Study II, regarding the DOSSes' impact on donation rates, the study covers data concerning deceased patients and no personal data are provided in the published paper. Hence, there is no risk of harming these patients or of exposing their relatives. Nor does the included questionnaire answered by the ICU staff contain personal data, and answering the questionnaire was optional. What potentially could be considered sensitive would be a comparison between hospitals, both considering the donation rates and considering the opinions among the ICU staff concerning the DOSS service. Hence, these data are not provided in the publication.

In Study III, donor relatives were interviewed about the death of a close family member which naturally brought up emotions in many. Hence, the interviewer chosen to conduct the interviews was chosen on the basis of having many years' professional experience of talking to people under emotionally difficult life circumstances. In order not to force the interview situation the interviewer had plenty of time for each interview, allowing the donor relatives to talk at their own pace. The relatives were also informed about the possibility of ending the interview at any time.

A follow-up phone call was made by the interviewer to all participants in order to ask about the wellbeing of the donor relatives after the interview situation. In addition, all participants were offered to see a medical social worker, if further support was needed. However, no relatives took this offer, but instead put forward that it had done them good to talk about the circumstances that surrounded their loss and the organ donation. When needed, the donor relatives were helped to establish contact with staff at the ICU where their family member had died, in order to get some answers to questions that still remained.

When considering the ethics of involving donor relatives in a study like this, in total, it seems that the participation can have a positive effect, rather than put emotional strain on the relatives, though the specific interview situation was emotionally demanding for many. Finally, the result of the study cannot be deduced to any specific relative as no personal data are provided in the publication.

Summarising, organ donation can be an emotionally challenging subject to address in research as the participants are asked to reason about death. However, this should not hinder researchers from exploring the subject in various ways, given that ethical and emotional considerations are made. If we as a society have chosen to provide transplantation as a therapeutic treatment, organ donation and transplantation deserve equal attention in order to respect the intentions and attitudes that prevail within this society.

5.6.1 Ethical approval of the studies included

All papers included were approved by or received recommendations by the local ethics committee.

Decision on Study I, From words to action - influence of two organ donation campaigns on knowledge and formal decision making – *approved: 276/03*

Decision on Study II, From Hesitation to Appreciation: the transformation of a single, local donation-nurse project into an established organ-donation service – *approved: 04-099/2*, additional application *approved: 2012/1589-32*

Decision on Study III, What do people agree to when stating willingness to donate? On the prolongation of the medical treatment enabling organ donation after death – *received recommendation: 04-615/5*. The ethics committee stated that the data in the study did not fall under the Ethics Review Act, therefore the application was not reviewed in detail by the board. However, the ethics board stated that it did not find any obstacles for the study to be carried out.

6 CONCLUSIONS

One may think that there is a straight answer to why the donation rate in our country is low, but, as illustrated in this thesis, the reasons behind the low donation rate are multifactorial. Nevertheless, this thesis also highlights the fact that various aspects indeed influence and also increase organ donation after death:

Firstly, information campaigns can influence the general public's inclination to inform about their decision on organ donation, provided that these are long term and designed to target different subgroups. This conclusion was drawn as two of the most important observations made were: that the short term campaign had no impact on the general public, and that the long term campaign – essentially conveying emotional aspects of donation and transplantation – mainly attracted the attention of women. Thus future information efforts ought to be continuous and carefully designed to reach different subgroups of the general public in order to make people inform about their decision on organ donation and finally go – From Words to Action (Paper I).

Secondly, the rarity of organ donation within the ICUs makes the involvement of specialised staff – such as the DOSSes – of great value considering donation rates as well as the quality of the handling of the acute donation process and the situation for donor relatives. This conclusion was drawn as the assessment of the DOSS function clearly proved that the involvement of a DOSS increased donation rates and, according to the ICU staff, also optimised the acute donation process for both staff and donor relatives. The positive influence of the DOSS function was also maintained after the transition from the local initial project to the permanent county-based service. Thus, inviting various DOSSes from different ICUs to take part in the acute donation process at hospitals other than their own did not interfere with donation rates or with the situation for ICU staff and/or donor relatives. Hence, these results provide an illuminating and encouraging example of how the work with organ donation can be optimised – and despite some initial reluctance to the introduction of the DOSS function, the ICU staff gradually went – From Hesitation to Appreciation (Paper II).

Thirdly, the donor relatives' own inclination to donate is partly influenced by their experiences of the loss of a close family member who donated organs. It is often hard, however, for donor relatives to understand the donation process including the purpose of the medical treatment enabling organ donation. To help donor relatives better understand this process, there are several areas that ought to be improved and clarified, such as: the time of death, the ventilator and organ-preserving treatment and the donor operation. Despite the fact that these areas were unclear to many donor relatives, and though the misconceptions concerning some aspects of the donation process potentially could have caused the donor relatives immense distress, most of the relatives in this study were either inspired to - or strengthened in their willingness to - donate their own organs. Thus, having experienced the donation process closely did not discourage the donor relatives from donating their own organs – but rather encouraged a willingness to donate. Hence, there seems to be an acceptance of the transition – From Life Sustaining to Organ Preserving Treatment (Paper III).

Summarising, there are various ways to influence and also optimise organ donation after death, e.g. via continuous and well-designed information campaigns, careful introduction of specialised staff and finally through greater openness and transparency towards the donor relatives as well as the general public of all the procedures included in a donation process.

7 RECOMMENDATIONS

The recommendations in this chapter are primarily based on the findings of the papers included, but also on research done by others, which is referenced and discussed in this thesis. Moreover, the clinical experience I have gained over the years while working with organ donation, as well as the unpublished data that I refer to in this thesis, provide an additional basis for the following recommendations.

Firstly, our results indicate that the information to the general public needs to be continuous and carefully designed. Hence, the responsibility for the information ought to be formalised and prioritised. In a country applying presumed consent, the whole general public should be continuously informed about organ donation, and the various ways of declaring one's decision ought to be promoted. One way to declare the decision is by registration in the National Donor registry, however, the future existence of the registry has sometimes been discussed. Nevertheless, new unpublished data suggest that the members of our society consider registration in the registry the most reliable and secure way of stating the decision [102, 145]. Hence, the National Donor Registry ought to be preserved. Furthermore, the responsibility for public information about organ donation needs to be not solely entrusted to non-governmental organisations or individual counties. Instead, a clear national information and communication strategy needs to be developed, ensuring that the information is equal across the country, yet differentiated relative to target groups.

Secondly, hopefully other regions will be inspired by the DOSS service and adjust this work model to function in their own regions, in order to optimise the handling of the organ donation process, and in order to enhance the understanding of the complex circumstances in connection with an organ donation – both among donor relatives and ordinary ICU staff. The use of specialised staff would most likely also make the donation process less dependent on the experience/inexperience of individual staff. The introduction of specialised staff should be possible in many parts of the country, as was the emergence and organisation of the transplant coordinators during the 1980s.

Thirdly, the initial intensity of the debate during the introduction of brain death has subsided. Nevertheless, the comprehension of brain death and the circumstances surrounding an organ donation seem to be low among many. There also seems to be a discrepancy between the intellectual and emotional aspects of brain death and organ donation within the general public, as well as among donor relatives, and occasionally also among medical health care staff. This needs to be considered by the ICU staff, both personally and when they meet donor relatives in the acute situation.

Fourthly, the relatively low understanding of death and of the medical circumstances surrounding an organ donation displayed among the donor relatives in our study, is an indication of the necessity to provide clear and transparent information to donor relatives. The regulations of the donation process therefore need to be clarified in order for the practice to be standardised. This would enable the ICU staff to be more confident with their acting space, which in turn, most likely, would make the staff more comfortable with being transparent towards the donor relatives.

Fifthly, the important transparency mentioned above would be enhanced by clarifying the breaking point – when there is no hope for survival and the medical treatment no longer is benefitting the patient and therefore should be withdrawn. In this decisive moment, the decision on organ donation ought to be investigated – this would then enable the ICU staff and the donor relatives to really respect the wishes of the dying patient, and only prolong the medical treatment aiming at enabling organ donation for those actually willing to donate. The purpose of the subsequent treatment would then be to maintain organ viability and thus save other patients in need of organs. Both ICU staff and donor relatives would most likely benefit from this being openly addressed. Finally, this policy should minimise the secrecy and ambivalence that sometimes surround the handling of a potential organ donor.

8 SWEDISH SUMMARY/SVENSK SAMMANFATTNING

I detta kapitel presenteras en sammanfattning av de tre inkluderade studierna i denna avhandling var för sig.

Först en studie om huruvida allmänhetens attityder och benägenhet att förmedla sitt personliga beslut kring organdonation, påverkats av de informationsinsatser som riktats mot allmänheten.

Därefter en studie som belyser donationsspecialiserade sjuksköterskors (DOSS) påverkan på donationsfrekvensen, samt hur intensivvårdspersonal uppfattar DOSS påverkan på donationsprocessen.

Slutligen en studie som belyser donatorsanhörigas upplevelser av den medicinska behandling som är nödvändig för att möjliggöra organdonation, och huruvida de anhörigas egna beslut kring donation påverkats av att ha förlorat någon nära som donerat organ.

Slutsatserna presenteras dock gemensamt i slutat av kapitlet. Kapitlet inleds med en generell introduktion som beskriver en avliden donator, en kunskap som är nödvändig för att förstå de inkluderade studierna.

ÖVERGRIPANDE SYFTE

Det övergripande syftet med denna avhandling är att öka kunskapen om och förståelsen för de aspekter som påverkar organdonation efter döden.

Generell introduktion: Samtliga i avhandlingen inkluderade studier berör donation efter döden. För att kunna donera organ krävs att en individ dör i total hjärninfarkt (hjärndöd) – vilket innebär att hjärnans samtliga funktioner totalt och oåterkalleligen har upphört – på en intensivvårdsavdelning medan denne/denna vårdas i en respirator. Respiratorn syresätter kroppen och därigenom organen även efter döden, vilket är en förutsättning för att dessa organ ska kunna fungera i de patienter som transplanteras. Syretillförseln till hjärnan har dock helt upphört, trots den mekaniska syretillförseln till kroppen, på grund av att det syre som transporteras via blodet inte kan nå fram till hjärnan, till följd av att hjärnan svullnat så mycket att blodet inte längre kan tränga fram. Detta är det som orsakar döden under dessa omständigheter. De flesta som dör på detta sätt har drabbats av en plötslig, spontan hjärnblödning. Under år 2014 donerade 166 personer organ i Sverige, samtidigt väntade 756 personer på att bli transplanterade med ett eller flera organ.

Studie I, Informationsinsatsers påverkan på allmänheten

Bakgrund: Donationsviljan är mycket utbredd bland den svenska befolkningen. Cirka 80-90 procent av befolkningen säger sig vara villiga att donera organ i olika undersökningar. Dock är det få som kommunicerar sitt beslut till någon närstående, alternativt formellt registrerar beslutet i donationsregistret. En konsekvens av detta är att många anhöriga till patienter som dör på ett sådant sätt att en donation är möjlig, ställs inför uppgiften att uttolka den avlidnes vilja. Detta innebär att de anhöriga involveras i en beslutsprocess i en känslomässigt mycket krävande situation, då de precis har drabbats av en plötslig och tragisk förlust. Att den avlidnes vilja ofta är okänd försvårar självfallet även för intensivvårdspersonalen som guidar de anhöriga genom beslutsprocessen.

De informationsinsatser som bedrivits i Sverige gentemot allmänheten har främst syftat till att få befolkningen att förmedla sitt beslut, snarare än att ytterligare öka donationsviljan. Detta, då donationsviljan redan är mycket utbredd i vårt land. Denna studie utvärderar två olika kampanjer: en kortare intensiv kampanj som varade under en månads tid och en längre som förmedlade information till allmänheten via olika media under ett års tid.

Syfte: Syftet med studien är att utvärdera hur attityder, kunskap och beslutsfattande angående organdonation påverkats av två olika informationskampanjer.

Metod: För att öka förståelsen för vilken påverkan olika typer av donationskampanjer har på allmänheten, genomfördes tre opinionsundersökningar med hjälp av SIFO. Den första, före den korta intensiva informationsinsatsen; den andra, direkt efter avslutad insats. Den tredje opinionsundersökningen genomfördes efter avslutandet av den längre informationskampanjen. I varje undersökning genomfördes telefonintervjuer med 1000 anonyma frivillig deltagare som utgjorde ett representativt urval av Sveriges vuxna befolkning (15 år och äldre).

I opinionsundersökningarna inkluderades frågor kring huruvida de intervjuade var villiga att ta emot organ, var villiga att donera organ, hade kunskap om sin närmsta anhörigas beslut och formellt hade meddelat sitt eget beslut. Några frågor var öppna, vilket medgav att de intervjuade kunde svara mer fritt.

Resultat: Den höga donationsviljan var lika utbredd i alla tre opinionsundersökningarna, cirka 85 procent var villiga att donera organ – viljan var således oförändrad före och efter de olika kampanjerna. Resultaten visar också att den kortare informationsinsatsen inte hade någon effekt på befolkningens benägenhet att formellt förmedla sitt beslut. Efter den längre kampanjen återfanns dock vissa förändringar hos framförallt medelålders kvinnor, som i högre utsträckning hade börjat förmedla sitt beslut. Bland kvinnor i åldrarna 30-49 år var det nu endast 29 procent som *inte* hade förmedlat sitt beslut på något sätt. Bland kvinnor i åldrarna 50-64 år var motsvarade andel 36 procent. Andelen kvinnor i dessa kategorier som *inte* hade informerat om sitt beslut var signifikant lägre efter avslutandet av den längre kampanjen. Motsvarande sänkning återfanns inte bland kvinnor i de andra ålderskategorierna och inte heller bland män i någon ålderskategori.

Studie II, Donationsspecialiserade sjuksköterskors påverkan på donationsfrekvensen samt situationen för intensivvårdspersonal och donatorsanhöriga

Bakgrund: Erfarenheter från andra länder visar att involveringen av donationsspecialiserad personal i donationsprocessen bidrar till en högre donationsfrekvens samt leder till ett mer optimalt omhändertagande av donatorsanhöriga. Inom svensk intensivvård är organdonation sällan förekommande, som en följd av den låga donationsfrekvensen som råder i landet. Detta leder till att intensivvårdspersonalen ofta är oerfaren, har bristande kunskap och ibland känner olust inför att hantera donationsprocessen och inför att samtala med donatorsanhöriga kring organdonation. Involveringen av specialiserad personal torde således betraktas som ett positivt stöd av intensivvårdspersonalen. Dock har introduktionen av specialiserad personal upplevts som kontroversiell av vissa inom svensk intensivvård.

Ett projekt initierades som ett första försök att involvera donationsspecialiserad personal inom svensk intensivvård, och en donationsspecialiserad sjuksköterska (DOSS) tillsattes på ett av Stockholms sjukhus. Syftet var att optimera donationsprocessen och höja donationsfrekvensen. Idag består verksamheten, som är unik för Stockholms läns landsting (SLL), av åtta (8) DOSS:ar som tillsammans bemannar en dygnet-runt-jourlinje som svarar mot samtliga sjukhus inom SLL, där en möjlig donator vårdas. Intensivvårdspersonalen på det aktuella sjukhuset har möjlighet att ringa in en DOSS då de har identifierat en möjlig donator. DOSS:en deltar då i vården av donatorn samt i utredningen av den avlidnes inställning till donation med patientens anhöriga.

De främsta skillnaderna mellan det ursprungliga DOSS-projektet och dagens permanenta DOSS-verksamhet är att den ursprungliga DOSS:en enkom arbetade lokalt på sitt eget sjukhus med sina ordinarie kollegor, och därmed samtalade med donatorsanhöriga som hon ofta tidigare hade haft kontakt med och hade en relation till – medan dagens DOSS:ar samverkar med främmande personal på främmande sjukhus och således möter donatorsanhöriga som de inte har en relation till. Hur detta påverkar donationsfrekvensen samt personalens syn på samverkan med denna specialiserade personal är av intresse för framtida utformning av uppdrag likt DOSS-funktionen.

Syfte: Syftet med studien är att utvärdera DOSS-funktionens effekter på donationsfrekvensen samt utvärdera intensivvårdspersonalens syn på effekterna av DOSS; dels under initialt DOSS-projekt, dels under permanent DOSS-verksamhet.

Metod: En journalgranskning av möjliga donatorer genomfördes för tre olika tidsperioder:
- en 2-årsperiod före den första DOSS:en tillsattes (A)
- en 2,5-årsperiod under initialt DOSS-projekt (B)
- en 3-årsperiod under permanent DOSS-verksamhet (C)

Statistiken i studien baseras på de möjliga donatorer som vårdades under de tre olika perioderna och som rapporterades till de regionala transplantationskoordinatorerna: A: 59 donatorer, B: 49 donatorer, C: 111 donatorer. En analys genomfördes av skillnaderna mellan antalet faktiska donatorer, antalet donatoranhöriga som nyttjade sin vetorätt då den avlidnes vilja var okänd, antalet avlidna som själva hade uttryckt sin vilja mot donation och antalet möjliga donatorer som inte donerat av andra skäl (medicinska kontraindikationer, samt oklara fall) under de tre olika perioderna. En jämförelse gjordes också av utfallet av just nämnda kategorier, när en DOSS var involverad i donationsprocessen och när ordinarie personal självständigt ansvarade för processen.

För att ytterligare utvärdera DOSS-funktionen genomfördes en enkätundersökning vid två olika tillfällen: under initialt DOSS-projekt och under permanent DOSS-verksamhet. Enkäten riktade sig till intensivvårdspersonal: läkare, sköterskor och undersköterskor. Enkäten innefattade frågor kring personalens syn på DOSS-funktionens påverkan på olika delarna av donationsprocessen: såsom vården av donatorn, omhändertagandet av donatorsanhöriga, arbetssituationen för personalen etc.

Resultat: Resultaten visar att DOSS:ens medverkan ledde till en kraftig ökning av antalet möjliga donatorer som faktisk blev donatorer (från 37 procent före tillsättandet av den initiala DOSS:en till 73 procent under DOSS-projektet när DOSS:en handlade donationsprocessen, och till motsvarande 74 procent under permanent DOSS-verksamhet). Resultaten visar även att färre donatorsanhöriga nyttjade sin vetorätt då den avlidnes vilja var okänd, både under det initiala DOSS-projektet (innan projektet 34 procent, under projektet 8 procent) och under den permanenta DOSS-verksamheten (14 procent) då en DOSS var involverad.

När ordinarie personal handlade donationsprocessen – före initialt DOSS-projekt, under initialt DOSS-projekt och under permanent DOSS-verksamhet – var antalet donatorer signifikant färre (37, 39 och 20 procent respektive).

Resultaten från enkäten visar att intensivvårdspersonalen ansåg att DOSS:ens medverkan under donationsprocessen starkt bidrog till en förbättrad och tryggare arbetssituation för personalen, samt till förbättrad information till donatorsanhöriga och förbättrat stöd av de anhöriga under beslutsprocessen.

Studie III, Donatorsanhörigas erfarenheter av den medicinska behandlingen som är nödvändig för att möjliggöra organdonation

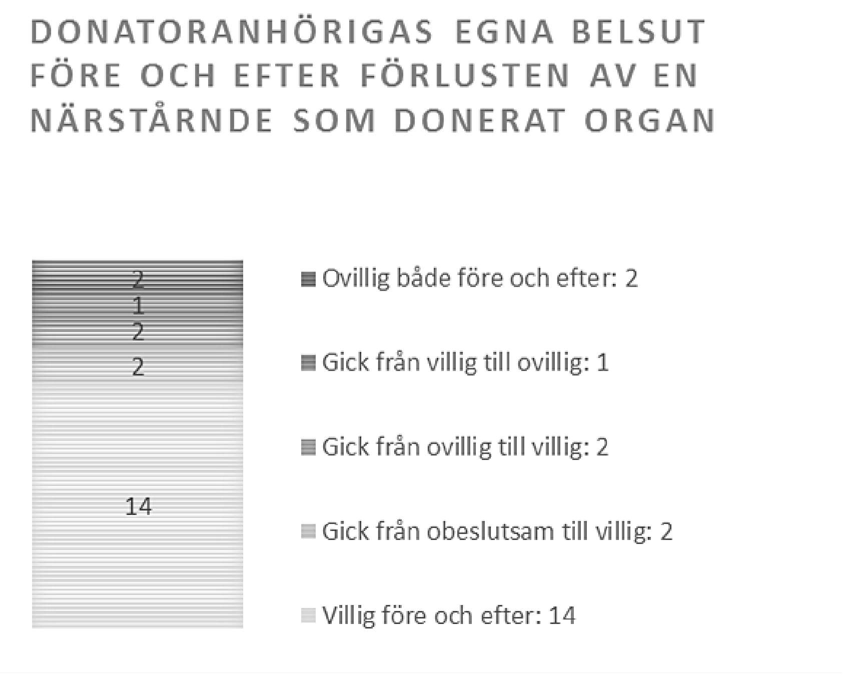
Bakgrund: De senaste åren har arbetet med organdonation inom svensk intensivvård präglats av viss oro. Detta då många menar att rådande regelverk inte uttryckligen stödjer behandlingen – före döden – som syftar till att möjliggöra organdonation. Denna behandling är dock nödvändig för att upprätthålla en god kvalité på organen under döendet. Dock inverkar behandlingen inte menligt på patienternas tillstånd; för att kunna donera organ, behöver kvalitén på den behandling och vård som bedrivs vara optimal. Denna fas – från det att den livsuppehållande behandlingen inte lägre gynnar patienten och därför egentligen enligt rådande regelverk bör avbrytas, och fram tills att döden faktiskt är fastställd – behöver tydliggöras enligt många inom svensk intensivvård. En tydlighet och transparens kring den behandling som bedrivs för att möjliggöra organdonation är också av stor vikt för att upprätthålla förtroendet för donationsverksamheten. Regeringen har tillsatt en utredning, bland annat som gensvar på det missnöje som uttryckts inom intensivvården. Det regelverk som reglerar donationsprocessen bör återspegla den vård som de invånare som önskar donera organ ser som adekvat i samband med en donation. Dock är donationsprocessen komplex och svår att förstå för gemene man. Denna studie vänder sig därför till en mer informerad grupp av allmänheten – donators-anhöriga.

Syfte: Syftet med studien är att utforska donatorsanhörigas erfarenheter av behandlingen som möjliggör organdonation – samt utforska de anhörigas egna inställning till att donera organ och huruvida deras benägenhet att donera organ påverkats av deras erfarenheter.

Metod: För att öka kunskapen kring acceptansen för den behandling som bedrivs i syfte att möjliggöra organdonation vände vi oss till donatorsanhöriga. Detta är sannolikt den grupp av allmänheten (förutom IVA-personalen) som har den bästa insikten om hur vården bedrivs i samband med organdonation, då de på nära håll bevittnat denna. Studien bygger därför på djupintervjuer med 21 donatorsanhöriga som alla förlorat någon närstående som donerat organ på en och samma intensivvårdsavdelning. Analysen av intervjuerna gjordes huvudsakligen med kvalitativ innehållsanalys men också till viss del med kvantitativ innehållsanalys.

Resultat: Analysen av intervjuerna ledde fram till fyra huvudkategorier: 1) dödens infinnande, 2) den medicinska behandlingen som möjliggör organdonation, 3) donationsoperationen, och 4) donatorsanhörigas egen beslutsprocess. Tillsammans utgör dessa kategorier en god grund för förståelsen av donatorsanhörigas upplevelser av den medicinska behandlingen som är nödvändig för att en person skall kunna donera organ. Resultaten visar att de anhörigas acceptans och förtroende för vården som bedrevs i samband med organdonation, generellt sett var hög. Detta trots att omständigheterna kring hjärndöd och organdonation var svåra att förstå för många donatorsanhöriga, och trots att kunskapen kring den behandling som bedrevs för att möjliggöra organdonation var förhållandevis låg. Det faktum att många anhöriga inte hade någon förståelse för när döden faktiskt inträffade, ledde till att det var svårt för dem att avgöra vilken behandling som egentligen bedrevs för patientens egen skull och vilken behandling som syftade till att upprätthålla en god kvalitet på organen. Något som starkt bidrog till svårigheterna att förstå döden, var oklarheterna kring respiratorns funktion som de anhöriga beskrev i intervjuerna. Vad som ofta ytterligare komplicerade förståelsen för döden, är det faktum att en person som vårdas med respirator ser ut på samma sätt – före och efter döden. Slutligen bidrog det faktum att omständigheterna kring donationsoperationen ofta var oklara till att vissa anhöriga hyste olustkänslor och störande tankar kring operationen.

Beträffande de anhörigas egna beslut kring att donera sina organ, så fattades det beslutet ofta långt innan hon/han förlorade någon närstående som donerade. Dock vidmakthöll de flesta anhöriga sin tidigare positiva inställning och många stärktes dessutom i sin vilja att donera, efter att personligen ha erfarit en närståendes donation. Endast en anhörig ändrade sitt positiva beslut till ett negativt, medan flera andra för första gången beslutade sig för att donera.



Vissa uppgav också att det just var erfarenheterna i samband med förlusten av en närstående som donerade organ, som ledde fram till deras egen önskan att donera. Sammantaget var majoriteten anhöriga villiga att donera sina organ efter att ha erfarit förlusten av en närstående som donerat.

SLUTSATSER

Studie I: En ökad kunskap om vilken effekt olika typer av donationskampanjer har på olika subgrupper i befolkningen är av vikt vid valet av utformningen av framtida kampanjer. För närvarande finns det dock ingen instans i Sverige som kontinuerligt informerar befolkningen om organdonation, vilket är fallet i många andra länder. Konsekvenserna av detta, är något som den av regeringen initierade donationsutredningen, utvärderar. En kontinuerlig och för olika målgrupper välanpassad information, skulle förhoppningsvis leda till att fler människor uppmärksammade donationsfrågan och tog ställning. Detta skulle i sin tur innebära att donatorsanhöriga i det akuta läget i högre grad kunde luta sig mot ett redan fattat beslut och att intensivvårdspersonalen kunde avlastas uppgiften att guida donatorsanhöriga igenom en ofta mödosam beslutsprocess. En mer välinformerad befolkning, och en befolkning som i högre grad förmedlar sitt beslut, skulle också i förlängningen kunna innebära att fler patienter får möjligheten att bli transplanterade.

Studie II: Det faktum att organdonation är så sällan förekommande inom svensk intensivvård gör involveringen av specialiserad personal – såsom exempelvis DOSS – värdefull beträffande donationsfrekvensen, men även värdefull för både personal och anhöriga under den akuta donationsprocessen. Vår studie visar också att DOSS-funktionens positiva påverkan på donationsprocessen, även vidmakthölls efter övergången från lokalt DOSS-projekt till permanent landstingsövergripande verksamhet. Att involvera olika DOSS:ar, från DOSS-verksamheten, i handläggningen av den akuta donationsprocessen på andra sjukhus än deras egna, hade således inte en negativ påverkan på donationsfrekvensen eller på situationen för personal och donatorsanhöriga. Dessa resultat utgör klargörande och uppmuntrande fakta kring hur arbetet med organdonation kan optimeras.

Studie III: Samtidigt som studien påvisar ett flertal förbättringsområden, så visar den att förtroendet för vården i livets slutskede i samband med organdonation är högt bland de inkluderade donatorsanhöriga. Dock framgår det att förståelsen för donationsprocessen och den behandling som är nödvändig för att möjliggöra organdonation ofta är låg bland de anhöriga. Det finns flera områden som med fördel kunde förbättras och förtydligas för att hjälpa donatorsanhöriga att bättre förstå denna process, såsom: tidpunkten för dödsfallet, respiratorns funktion, den organbevarande behandlingen samt donatorsoperationen. Trots det faktum att dessa områden var oklara för många anhöriga, och trots att missuppfattningarna kring vissa delar av donationsprocessen skulle ha kunnat orsaka stor olust, så blev de flesta anhöriga i denna studie antingen inspirerade till, eller förstärkta i sin vilja att donera organ. Att ha upplevt donationsprocessen på nära håll avskräckte sålunda inte de anhöriga från att donera sina egna organ, utan det snarare uppmuntrade en önskan att donera. Sammantaget tyder resultaten således på att det finnas en acceptans för den behandling som bedrivs i samband med organdonation.

Sammanfattningsvis så förefaller det finnas åtskilliga sätt att påverka och optimera organdonation efter döden; via t.ex. kontinuerliga och noggrant utformade informations-insatser, via införandet av donationsspecialiserad personal och slutligen via en större öppenhet och transparens kring donationsprocessen gentemot donatorsanhöriga så väl som gentemot allmänheten.

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