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# The Role of Relatives in Decision Making on Organ Donation

## – an Ethical Analysis

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Version 2

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## Abstract

**Introduction:** The three ways of making a wish for organ donation known are donor registration, donation card and telling the relatives. The relatives always have to be consulted to know the last expressed wish. If the wish was unknown there is a presumed consent, but the relatives have veto and can refuse organ donation. A new proposal suggests that the veto should be removed.

**Aim:** To identify and analyse the ethical considerations concerning decision making on organ donation with an emphasis on the role of relatives.

**Methods:** A search for literature was made. Scientific articles, debate articles, constitutional texts, reports and other texts were selected. The selection of sources was performed on the basis of relevance for the aim of the study which means for answering the research questions.

**Results:** Recurrent themes were identified in studies with an emphasis on the experiences of relatives who have been part of decision making on organ donation. The themes identified were: “incompetence to decide”, “disagreement”, “lack of information and support”, “comprehension of brain death” and “protection”. The themes, together with the reading of debate articles and other texts, formed the basis of arguments in favour of and against relatives’ right to veto.

**Conclusions:** There are many factors influencing relatives in their decision concerning organ donation. There are strong arguments against the relatives’ right to veto. Donor registration and a sensitive approach in the conversation with relatives are important factors to increase the consent rate and fulfil the wish of the deceased.

**Key words:** organ donation, relatives, ethics, decision making, veto

## 1. Introduction

According to Swedish law (1987:269) a human being can be declared dead when the functions of the brain completely and irreversibly have ceased. This declaration can take place when breathing and circulation have stopped for a time long enough to be sure that there are no brain functions left, or if breathing and circulation are maintained artificially and an examination of the brain function has shown that there are no functions left. When death has been declared intensive care can be continued for 24 hours if needed to enable organ donation [1]. In Sweden organ donation is possible when a patient with a primary severe brain injury develops complete brain infarction while treated with a ventilator [2]. This is called DBD – Donation after Brain Death [3].

When death occurs and organ donation could be possible, first, it is the wish of the deceased that should be requested. This is done by searching in the donation register, checking for donation card and talking to relatives.<sup>1</sup> Even if the wish is expressed in the register or on a donation card the relatives have to be consulted since it is the last expressed wish that is valid [4]. In cases where the wish was unknown there is a presumed consent and we assume a positive attitude, but the relatives have veto and can refuse organ donation. The operation can also not be done before the relatives have been informed about it and their right to veto (1995:831) [5]. If there are disagreements among the relatives there will be no donation [4].

In Sweden 80 % of the people are willing to donate their organs which is the highest rate in Europe [6]. At the same time Sweden has a donation rate below the European median [7]. In 2018 there were 182 organ donors in Sweden who enabled 640 organ transplantations. There were also 144 kidney transplantations from living donors which makes a total of 784 organ transplantations. Despite this there are over 800 patients waiting for organ transplantation [2] and during the last year 38 patients died on the waiting list [8].

Trying to increase the number of organ donors a change in the regulation was made in May 2018. According to this new regulation qualified personnel get access directly to the donation register and can start searching for the patient's will on organ donation not only after the declaration of death, but also after the breaking point, when the decision has been made that no more life-sustaining treatments will continue or be started [9]. There is also a national project called the DCD-project (Donation after

<sup>1</sup> There is an awareness that the word "relatives" might be problematic since the people close to the deceased do not have to be related by blood or marriage. In this paper the word "relatives" refer to the people close to the deceased.

Circulatory Death) to enable organ donation not only when complete brain infarction primarily occurs but also when the brain functions pass away as a consequence of cardiac arrest. The project started in January 2018 [10] and the results of the donations are comparable with DBD [11].<sup>2</sup>

In June 2019 a report (SOU 2019:26) was given to the government with several proposals for a change in the regulation to further increase the number of organ donors and to clarify what can and cannot be done before a possible donation. The report proposes that organ preservative treatment can be given after the breaking point to enable organ donation. This is only if the treatment cannot wait until death has occurred and causes no more than modest pain and suffering. At the breaking point the patients wish on organ donation can be requested and from that moment organ preservative treatment can go on for 72 hours. Another proposal is to remove the relatives' right to veto. They do have an important role when it comes to clarifying the patient's preference but according to this proposal, they should not be able to refuse donation if the wish of the patient was unknown. The duty to inform the relatives about the operation will remain, but if the relatives cannot be reached in time, that will not prevent organ donation if the deceased has given his/her consent [12].<sup>3</sup>

The relatives are of great importance when it comes to decision making on organ donation. They have an important role in identifying the wish of the deceased, but the question can be asked if it really is ethically acceptable that they have a veto and that a wish in the donation register can be overruled. Another consideration is that the relatives have to make a decision of such importance when they recently have found out that they have lost a family member.

## 2. Material and Methods

### 2.1. Aim

The aim of this study was to identify and analyse the ethical considerations concerning decision making on organ donation with an emphasis on the role of relatives.

<sup>2</sup> The pilot project of DCD was successful, and the pilot hospitals are free to continue with DCD according to the protocol. In March 2020 a final report and a strategy of how to implement DCD in the Swedish healthcare will be presented. (<http://vavnad.se/dcd-projektet/>)

<sup>3</sup> The proposal was referred from the government to several agencies. A majority (36/42) of the responding agencies has a positive attitude towards the removal of relatives' right to veto. (<https://www.regeringen.se/remisser/2019/08/remiss-av-sou-201926-organbevarande-behandling-for-donation/>)

## 2.2. Research questions

Which factors influence relatives' decision concerning organ donation?

Which are the arguments in favour of and against relatives' right to veto?

What dilemmas would remain if relatives' right to veto was removed?

## 2.3. Method

This work was a study in medical humanities which made the methodological basis different from that of biomedical sciences. The basic approach was qualitative, not quantitative. The aim was to search for meaning, intention and context and to find concepts, descriptions, arguments and interpretations to analyse the relatives' role in decision making on organ donation.

There is an inevitable subjective element in this kind of analysis. The author will inevitably bring her preunderstanding into the study. It was therefore of great importance to distinguish between interpretations from other references and the interpretations from the author herself and to be conscious about these different perspectives. There was also an intention to be as objective as possible by selecting sources and arguments with different perspectives that not always were coherent with the opinion of the author.

## 2.4. Sources

A comprehensive search for literature was made. Scientific articles, debate articles, constitutional texts, reports and other texts were selected. The selection of sources was performed on the basis of relevance for the aim of the study which means for answering the research questions. A systematic review was therefore not applicable. An inclusion criterion was that the articles were published during the last 10 years.

A search in PubMed was made with words as "relatives", "influential factors", "decision making" and "organ donation". Based on the title of the article abstracts were read, and one article included. A similar search was made in ScienceDirect which gave other results and inclusion of at least four articles. Another search in PubMed was made with "organ donation", "family" and "decision making/ethics" as

MeSH terms and two articles were included. Further articles were found as “Similar articles” and then as references to included articles. Google search was used to find debate articles and other texts, using similar keywords as mentioned above, including “debate” and “veto”.

Table 1. Type and number of sources included.

<b>Type of source</b>	<b>N</b>
Scientific articles	20
Debate articles	4
Other journal articles	2
Reports	5
Constitutional texts	3
Texts from web pages	9

## 2.5. Delimitations

There is a limited number of articles which have been included since it is a master thesis with specific limitations of time and space. The search was made as long as the findings contributed to the result and discussion, but there could still be other studies that emphasize other influential factors or arguments that have not been found and accordingly not included in this study.

## 3. Results

There were 14 scientific articles, about what influences the relatives in their decision and relatives’ feelings and difficulties during the decision making, selected. The studies were often qualitative and based on interviews with relatives or healthcare professionals. The articles were initially read to get an overview, and in this process recurrent themes based on influential factors were identified. The identified themes were: “incompetence to decide”, “disagreement”, “lack of information and support”, “comprehension of brain death” and “protection”. There is some overlap between the themes, but the description of each theme aims to be as specific as possible.

### 3.1. Incompetence to decide

Some relatives felt incompetent to make that decision for someone else and knowing what the deceased would have wanted made the decision easier. The study of Morais et al., who asked family members that

previously had refused organ donation if they would have made another decision today, points out lack of knowledge what the deceased would have wanted as one of the main reasons for refusal [13].

According to de Groot et al. many of the relatives, mostly those who refused donation, said that they did not feel competent to make that decision in such crisis. The majority of the families who refused donation did not know the wish of the deceased. The families who gave consent to organ donation and knew what their family member would have wanted did not report much distress about the decision making. They knew what to do and could honour the deceased. The authors also mention the importance of donor registration since it could prevent dilemmas in the decision making. Most of the families who gave consent to donation had support in the donor register. If the deceased had not expressed his/her wish in the register the family was more likely to hesitate in the decision making [14]. Further research of de Groot et al. shows that families that do not know the wish of the deceased are more likely to refuse donation [15].

Bramstedt reports that when relatives know the preference of the deceased on organ donation, they feel obligated to fulfil that wish, and this can reduce the emotional burden of families in such crisis. It can make the decision easier since it is in honour to their loved one and the decision was already made [16]. According to Hulme et al. knowledge of what the deceased would have wanted has the most significant effect on the family's decision making. Knowledge of a wish to donate gives high consent rate [17]. The study of Can and Hovardaoglu shows that if the wish of the deceased is known the family do respect that wish and if the wish is unknown it is likely to affect the family's decision negatively [18].

### 3.2. Disagreement

Another important reason for donation refusal, according to Morais et al., is disagreement among relatives [13]. To reach agreement whether to donate or not was mentioned as a dilemma within both donor families and non-donor families in the study of de Groot et al. [14].

The study of Ghorbani et al. showed that two reasons for refusing organ donation was unstable family mood and fear of objection by other family members [19]. The follow-up study that was made six years later by Mojtabae et al. showed no significant change of these causes [20].

de Groot et al. reported that some relatives did not feel supported by each other. They describe some cases where the decision-maker experienced lack of support from the family; they refused donation, they

did not give any directive, or they had to take care of other family members. Disagreement among the relatives led to refusal [15]. In the study of Anker and Feeley organ procurement coordinators identified disagreement among relatives as a problem in the decision making. Some of the families did not give consent to donation because the decision was not unanimous [21].

In Sweden, if there is a disagreement among the relatives there will be no organ donation [4].

### 3.3. Lack of information and support

Lack of information about the process is another consideration identified in several studies. More information and support to the relatives engaged in decision making could encourage organ donation.

According to the study of Michaut et al. healthcare professionals think that an advance relatives approach, which is a systematic way of bringing up the question about organ donation with the family and giving them time to process and understand, can help the relatives to come to a decision based on what the deceased would have wanted. They also state that since the nurses are often closer to the family, their attendance in the advance relatives approach seems necessary to enable optimal support to the families in this situation [22].

Morais et al. suggest that disagreement among relatives is associated with lack of information about organ donation. There was also a question in the study about what should be done to increase the organ donations and many of the study participants stated that more information should be offered to the population about the subject [13].

The study of Hulme et al. shows that presence of a specialist nurse on organ donation in the approach has a positive impact on the family to give consent to organ donation. Further, the study shows that a reason for greater consent rate could be how the family approach is performed. If the healthcare professionals are trained on how to ask the question the family is more likely to consent. It is also important to have a positive climate for donation, to generate trust in the donation system and increase the number of people making their donation wish known [17].

According to de Groot et al. some of the relatives look back at the situation and think of making another decision. They are also justifying their decision by, for example, lack of time and need for support in the decision making, especially those who refused donation [14]. In the other study of de Groot et al. some

of the families assign poor care for the relatives and not getting empathy from the requestor as reasons for refusal of organ donation [15].

Can and Hovardaoglu emphasize the importance of the attitudes of the healthcare professionals. Almost 22 % of the family members stated that they refused donation because of negative attitudes from personnel. Many of the study participants clarified that empathic, sensitive, understanding and informative communication from personnel made the decision making easier and if they experienced lack of support they were more likely to refuse donation [18].

According to Sque et al. relatives describe many different emotional reactions to the question about organ donation: anticipation, shock, surprise. They describe the importance of a sensitive approach from the requestor, appreciation of them being kind, gentle, polite, neutral, calm. Most of the participants were satisfied with the hospital care and highly valued good communication. Some of them also suggest that the support from personnel was important for their decision to donate [23].

### 3.4. Comprehension of brain death

Studies have shown that there can be difficulties in understanding that a person is considered dead when there are still machines that make it possible for the heart to go on beating.

In the study of Berntzen and Bjork many relatives found it difficult to understand when their family member actually died. “It was explained that the circulation of blood to her head had stopped, but her face was warm, so there was blood in her head”, a quote from one of the interviews. A mother described that leaving her son when he was warm and the chest was moving up and down was very difficult, and she would have wanted more information about what was going to happen. Another woman said that it would feel improper to light a candle as you use to when someone dies since her husband, who were going to be an organ donor, was not really dead [24].

In the study of Gyllström Krekula et al. the relatives expressed different experiences of when death had occurred. Some of them thought it was when the family member collapsed and some of them when the doctors declared the family member brain dead. Other donor relatives believed that death really occurred during the donor operation, when the heart stopped beating. Some of the relatives thought they did not get enough information about the declaration of death and did not completely trust the procedures. Most of the study participants understood the concept of organ preserving interventions and that their family

member was dead despite the ventilator. However, some of them thought that the machines were keeping their family member alive [25].

de Groot et al. report that some relatives that refused donation wanted more proof that their family member was really dead and some of them entirely rejected the concept of brain death [15]. In the study of Morais et al. some of the participants indicated that they refused donation because they did not really believe that their family member was dead and they thought that he/she would get better [13].

According to Can and Hovardaoglu, more than one fourth of the non-donor relatives stated that they were suspicious about the concept of brain death. They did not really believe that their family member was dead since the body was warm and heart was beating [18].

### 3.5. Protection

According to Sque et al. some relatives that were involved in decision making on organ donation describe that initially they did not want anyone to touch the body and they felt very protective. Although they gave consent to donation, they were affected by their own beliefs, fears and concerns which made them refuse donation of specific organs or tissues, most often the eyes [23].

In the study of de Groot et al. family members identified the ethical dilemma of either helping others or protecting the body of the deceased. Donor families often thought of the body parts as useless after death and thought of it as a way of comfort that the organs can live in another body and that their loved one saved other people's lives. They often wanted to honour the wish of the deceased. Non-donor families were protective of the body and emphasized the integrity of the body. They also thought that they had more right to decide about organ donation than the deceased since they had to live with the decision [14].

Sque and Galasinski suggest that one of the main reasons for family refusal of organ donation is the wish to keep the body of the deceased "whole". Some of the participants in the study suggested that they did not want the body to be "cut up" and that they would not be able to live with that decision. It is obvious that some relatives have their own feelings and interests in mind when making the decision. Others state that they did not want their family member to go through another surgery, that "they have been through enough". One relative justified her decision by "saving her loved one from mutilation" [26].

In the study of Can and Hovardaoglu 7 % of the donor family members and 25 % of the non-donor family members stated that brain death contradicts with their religious beliefs and moral values. A religious belief of protecting the integrity of the body after death was associated with a lower consent rate to organ donation. Some said that they protected the body for life after death [18]. In the study of Mojtabae et al. religious beliefs were the most common cause for donation refusal of families [20].

Anker and Feeley reported that a barrier for consent to donation was that the family did not want the body to be “cut up” and they expressed concerns about “bodily wholeness”. Another common barrier against donation was that the families’ religious beliefs did not support organ donation [21].

## 4. Discussion

Vincent and Logan made a review of literature to understand why families refuse organ donation. The most common identified causes were: protection of the body of the deceased, lack of knowledge about the deceased wishes, disagreement among family members, lack of support from healthcare staff, religious/cultural reasons and lack of understanding brain death or accepting death [27]. This is coherent with the findings in this study.

The themes identified in this study, together with debate articles and other texts, formed the basis of arguments in favour of and against relatives’ right to veto.

### 4.1. Arguments in favour of relatives’ right to veto

The three ways of making one’s preference about organ donation known are the donation register, a donation card and telling the relatives [4]. The relatives are important to find out what the deceased would have wanted and for donor characterising [28]. To donate the organs a characterising of the deceased has to be done to know if donation is medically suitable. Some answers could be found in the medical record, but to answer some of the questions help from relatives is needed [29,30].<sup>4</sup> If the relatives are strongly against the donation, it would be hard to go against them and they might not be willing to cooperate in the donor characterising which could make proceeding with the process harder. For this reason, it can be argued that relatives should have a right to veto [28].

<sup>4</sup> One part of the medical investigation is a form about the patients’ medical history, diseases, medications, vaccinations, possible tattoos and piercings, alcohol or drug abuse, smoking, exposure of specific materials, hepatitis or HIV.

Research shows that protection of the body and integrity are key factors influencing relatives' decision making on organ donation [14,18,20,21,23,26]. In some of the studies they especially emphasize religious reasons and that the practice of the religion does not coincide with organ donation, for example protecting the body for life after death or specific burial rituals [18,20,21]. There are also cases where the relatives want to protect the body and refuse donation overall or of specific tissues or organs due to their own fears and concerns, without any religious influences [14,23,26]. Relatives have claimed that they do not want the body to be "cut up" and that the deceased have been through enough. This could represent the principle of non-maleficence. There is a diversity of religions, cultures and traditions in our country. In some, the family has a stronger position than in others [31] and the family makes the decision in difficult situations. We should respect and honour the diversity and therefore, it is argued, keep the relatives' right to veto.

It is the relatives who have to live with the decision and it can be argued that they should have more right to decide [14]. It can also be argued that the family has a relational claim on the body since they have invested it with care and the body does not lose value after death. It might be in the family's interest what happens to the body [32]. Removing the veto would strengthen the position of the individual and it can be claimed that we should pay closer attention to the consequences for the people around us by our actions in this individualistic society. A decision about organ donation may be made by one individual but influenced by others that will also be affected by the decision [28]. For this reason, the veto should remain.

Another argument in favour of the relatives' right to veto is that the relatives are more likely to make an informed decision [32]. In other situations where we use informed consent the patient gets information about different options, the medical status at the moment and what the different treatments will entail [33]. It can be questioned if putting a mark in a box can be defined as informed consent. The relatives, that can get all the information in the specific situation, have a greater chance to make an informed decision about organ donation.

#### 4.2. Arguments against relatives' right to veto

According to the principle of respect for autonomy the wish of the deceased should always be fulfilled. What should happen to the body, in life and after, is up to each individual. This is a strong argument against the relatives' right to veto [28,34,35]. It can be argued, since there is a presumed consent, that the

right for relatives to refuse organ donation only because there is no expressed wish is actually going against the principle of autonomy. Also, relatives do not have veto in other medical situations. They are a part of care and treatment of the family member, but do not have their own right of decision [12]. Current regulations say that the donor operation cannot be done before the relatives have been informed (1995:831) [5]. A situation can appear where the deceased have expressed in the register or donation card that he/she wants to be an organ donor, but it will not be possible. This will also go against the principle of autonomy. Accordingly, this is an argument in favour of removing the veto and to enable donation even if the relatives cannot be reached, as long as the deceased has given his/her consent.

Relatives describe that knowing the wish of the deceased on organ donation makes their decision easier and that if the wish is unknown they sometimes feel incompetent to decide [13–18]. Considering that most of the people have a positive mind to donate their organs in Sweden [6] and there actually is a presumed consent, if a person has not expressed their specific opinion of donation refusal, maybe it would make more sense to assume consent instead of burdening the relatives with the decision making [34].

It can be considered unfair that the relatives should make a decision on organ donation when they have recently lost their loved one [28]. Studies claim that it might be difficult for relatives to understand when death occurs and that brain death equals death since the ventilator makes the deceased breath, the heart beats and the skin is warm [13,15,18,24,25]. Relatives being a part of a donation process said that their family member looked alive and some of them mistrusted the healthcare professionals [24,25]. Studies report that a reason for refusal of donation was rejecting the concept of brain death and believing that the deceased would wake up [13,15,18]. It is perfectly understandable to refuse organ donation while believing that your loved one will get better. When organ donation is possible it has most often been preceded by a sudden brain bleeding or traumatic head injury. The relatives are often in chock and not in their best emotional state of mind for a discussion about organ donation [35]. One of the ethical dilemmas mentioned by relatives in studies is choosing between the possibility to save lives and to honour the wish of the deceased [36]. When the wish was unknown the relatives identified a dilemma of helping other people or protect the body of the deceased [14]. Whether the wish is known or not, there can always be a difficult situation if the relatives have to make a decision. Another reason for relatives' refusal of donation is disagreement among relatives [13–15,19–21]. While mourning a loved one the relatives need support from each other, not having an argument about something that already could have been decided. Removing the relatives' right to veto would lift the burden of decision making off their shoulders.

There is a risk that the relatives regret their decision to refuse later on. A study shows that more than 50 % of the families who refused donation would make another decision in a new situation [13].

Accordingly, this can be seen as an argument against the relatives' right to veto [28].

As earlier mentioned, 38 patients died waiting for organ transplantation in Sweden 2018 [8]. In 37 cases (24 % of the cases where the deceased person's wish was unknown) where organ donation could have been possible the relatives used their right to veto and refused donation [2]. From a utilitarian point of view this is an argument against the relatives' right to veto. The terrible event of a sudden death of one person can through organ donation save several other people's lives. Removing the veto could prevent avoidable suffering and death of patients on the transplant list [28].

### 4.3. Analysis

The relatives are an important source of information about the deceased, but it might be hard for them to make a decision when they have just found out that their loved one has passed away. Also, making a decision on organ donation while still thinking that your family member is going to wake up is not fair and that should not be a reason for refusal. We should respect different cultures, religions and different reasons for wanting to protect the body, but still it should be up to every single person to make that decision for themselves. There are also arguments about relational autonomy and relatives having claims on the body [32], but that should not overrule the autonomy of the deceased. The relatives are more likely to make an informed decision, but on the other hand they do not have their own right of decision in any other medical situation. Some relatives argued that they should have more to say since they are the ones that have to live with the decision, while others stated that they wanted to honour the wish of the deceased. An ethical dilemma that relatives have identified is to protect the body of the deceased or to help other people by donating organs [14]. This could be seen as a dilemma between the principle of non-maleficence and the principle of beneficence. Since the relatives' right to veto decreases the number of organ donations that possibly could save several lives it can be considered going against the principle of beneficence. Accordingly, there are arguments both in favour of and against the veto, but the principle of autonomy, the difficulty for relatives to make a decision in that situation and the fact that organ donation can save several other lives indicate removal of the relatives' right to veto.

As earlier mentioned, the relatives are being consulted only to learn the wish of the deceased, but it is probable that they also include their personal beliefs, fears or concerns in the decision making

[14,21,23,26]. This can be done intentionally or unintentionally, but we cannot prove what actually is the wish of the deceased. Accordingly, this is a dilemma that will not go away even if the veto is removed. On the other hand it is the relatives who knew the person best and they are most likely to figure out his/her attitude towards organ donation [12]. Also, as several studies show that relatives find the decision easier if they knew the wish of the deceased, most relatives would probably try to make a decision based on the preference of the deceased.

Even if the veto would be removed it would still be hard for the healthcare professionals to talk about organ donation with the relatives. On the other hand, in theory, it could be easier to the relatives. It could be more like only information that organ donation can be possible and that there will be an investigation of the deceased person's wish. If there is a consent the process will proceed, otherwise it will not. Since the relatives do not have their own right of decision in either organ donation or other situations maybe donation will be a more "natural" part. Obviously, this would not be as easy in practice.

Imagine the scenario of a woman who has just lost her partner. Her loved one has not expressed a wish on organ donation which means there is a presumed consent, but she does not want the organs to be donated. She is screaming that nobody can touch the body and is literally standing in the way. It would not be easy for the healthcare staff to just go against her and take the body away. It does not seem fair either to the staff or to the woman who has recently become a widow. A difficulty that would remain even if the veto would be removed is, accordingly, a psychological aspect for healthcare professionals. Even if there is a change in the law, the question can be asked if it really will be a change in reality.

The relatives can refuse donation even if there is a registered wish to donate, if they claim that the deceased changed his/her mind. At the same time, if there was a registered objection to donate no one would probably try to reach consent from the relatives. That would be considered unethical and disrespectful of the deceased person's wish and integrity. Maybe it should be as obvious that the relatives could not refuse donation if the deceased gave his/her consent since overruling a "yes" is also disrespectful to the deceased. If there is a registered wish the relatives may not be consulted at all. The donor register could be compared to a testament, but that would not be overruled. It can be discussed for how long an autonomous decision is valid and that relatives can claim that they believe that the deceased would have made another decision during current circumstances. That is, yet again, not a possibility when it comes to testaments.

Maybe the register should have greater impact in the question about organ donation (provided that the number of registrations increases since only 17 % of the people in Sweden have registered a wish [37]). Just as inheritance law, where it is decided who gets what if there was not a testament, this could be the case also for organ donation. This presupposes that if a wish is registered that is valid, otherwise it is a presumed consent. Another suggestion is to have more like an opt-out system where everyone is included as donors when they turn 18 and have to register a refusal if they do not want to donate the organs [38]. It would be of great importance that everyone knows that they are included as donors, what it means to be a in the register and how to opt-out of the register. Accordingly, this system would not be without ethical difficulties. Considered that an unknown wish can lead to refusal and it can be very hard for the relatives to make a decision, there should at least be more promotion about donor registration.

As lack of information and support is an important reason for refusing organ donation [14,15,18] it seems motivated to focus on the approach and how the relatives are treated in this situation. Several studies also show that care, a sensitive approach, positive attitude and good communication from the healthcare professionals were key factors for the relatives to give consent to organ donation [17,18,22,23]. Some relatives who have been part of decision making state that to increase the organ donations there should be more information offered to the public [13]. This shows that there are different factors that affect the relatives in the decision making and the relatives' right to veto itself does not have to be a barrier against organ donation. The responsibility lies with the healthcare system to make sure that the relatives have all the information and support they need to make a safe decision.

Sharif and Moorlock discuss an alternative to remove the relatives' right to veto because of the distress for relatives and healthcare professionals if the wish of the deceased does not agree with the relatives' opinions. Their suggestion would apply in cases where either the deceased clearly has stated a positive mind on organ donation and the relatives are themselves opposed to donation or in cases where the deceased have a positive mind but the relatives think that during the specific circumstances he/she would not have wanted to donate. The authors discuss a way of influencing the relatives to make the right decision and in the direction of what the deceased would have wanted. One behavioural intervention strategy is based on nudge theory.<sup>5</sup> The authors argue that a carefully designed nudge can influence the relatives to make a decision they would have made in a less stressful situation and decrease the risk of regret in a later stage. They also discuss the importance of not being manipulative in the nudge, to not

<sup>5</sup> Nudging is a kind of behavioural science intervention and the idea is that small means could have great impact on people's behaviour. (Thaler & Sunstein (2008), *Nudge: Improving decisions about health, wealth, and happiness*, New Haven: Yale University Press)

restrict the options, always make it possible for the relatives to go against the nudge and that the nudge should always agree with the potential donor's wish [39].

Black and Forsberg discuss the use of motivational interviewing (MI) in conversations with next-of-kin about organ donation. <sup>6</sup> They argue that MI can help next-of-kin in their ambivalence and to influence their decision. The authors also discuss manipulation and that MI might not be manipulative if it encourages behaviour change consistent with an individual's core values and beliefs and the wishes of the deceased. The risk of unethical manipulation is low in countries where the general wish to donate is high, but implementation of MI would of course be challenging. However, since it seems to increase the consent rate, maybe MI can be used carefully to help next-of-kin to make a decision on organ donation [40].

It may be seen as unethical to try to influence the relatives in their decision making, but on the other hand, it is not considered unethical to try to increase the number of organ donors, since that can save other people's lives, or to fulfil the wishes of an organ donor. It might not be necessary to implement a specific strategy for conversations about organ donation, as nudge or MI, but since the approach from healthcare professionals has an impact on the relatives' decision good communication seems like a quite easy way to increase the consent rate, make the relatives satisfied with their decision and respect individuals' autonomy.

As earlier mentioned, there is a presumed consent to organ donation in Sweden. Several other countries in Europe also has presumed consent. Rosenblum et al. performed a study to investigate the authority of the next-of-kin in different nations depending on explicit or presumed consent to organ donation. In 21 of the 25 nations with presumed consent the next-of-kin is allowed to object and prevent organ donation. In all 29 nations with explicit consent the next-of-kin's consent is required whether the wish of the deceased is known or not [41]. Other studies also show that even if there is a presumed consent the relatives can, in practice, overrule the wishes of the potential donor [28] or at least, they are involved in the decision [22]. Healthcare professionals seem to think that, in some cases, the relatives' answer does not reflect the true opinion of the deceased [22].

As presented above there are several strong arguments against the relatives' right to veto and also that it might be a problem that the relatives can overrule the presumed consent. Spain has the highest rate of

<sup>6</sup> Motivational interviewing is a client-centred conversation style with focus on the individual's motivation and commitment to change. (Miller & Rollnick (2012), *Motivational Interviewing: Helping people change*, 3<sup>rd</sup> edn, New York, NY: Guilford Press)

deceased organ donors in the world (48.3 per million population, compared to 19.1 in Sweden) [7]. There is a presumed consent to organ donation, but the relatives are always consulted and their wish respected [42]. They do not have a donor register, nor a register to opt-out, but the wish on donation should be told to the relatives. Maybe it is the work of the transplant coordinators, regular courses for all professionals involved in organ donation and the close work with media that give the high consent rate in Spain [43]. According to the Spanish model, neither removing the relatives' right to veto nor strengthening the impact of a donor register would be necessary to increase the number of organ donors, but it strengthens the idea of improvements in the process and the role of healthcare professionals. It would be interesting to get a closer look at what Spain does to reach that high consent rate on organ donation.

It should be mentioned that the difference between bringing up the question about organ donation after the breaking point or after time of death is not considered in this paper. The reasons are that the change that healthcare professionals can start searching in the register after the breaking point is made quite recently in Sweden and the delimitations of time and space in this master thesis. It could be interesting in further research to investigate both the consent rate and how relatives feel depending on when the question about organ donation is asked.

## 5. Conclusions

The factors identified in this study that influence relatives in their decision concerning organ donation are “incompetence to decide”, “disagreement among relatives”, “lack of information and support”, “comprehension of brain death” and “protection of the body”. There are arguments both in favour of and against relatives' right to veto, but the principle of right to autonomy, the difficulty for relatives to make a decision in that situation and the fact that organ donation saves lives argue strongly against it. However, removing the veto would not be without complications and there would still be dilemmas for the relatives and the healthcare professionals, as the difficulties in going against the relatives and to differ between the relatives' opinion and the actual wish of the deceased.

Since an unknown wish of the deceased can lead to difficulties for the relatives and refusal of organ donation there should be more promotion about donor registration. It is also important that the healthcare professionals have the right approach in the conversation about organ donation considering that lack of information and support is a reason for refusal. The relatives should have support in the process to make the right decision for their loved one.

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## References

1. Riksdagsförvaltningen. Lag (1987:269) om kriterier för bestämmande av människans död Svensk författningssamling 1987:1987:269 t.o.m. SFS 2005:132 [Internet]. Riksdagsförvaltningen; [citerad 2019 sep 9]. Available from: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1987269-om-kriterier-for-bestammande-av\\_sfs-1987-269](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1987269-om-kriterier-for-bestammande-av_sfs-1987-269)
2. Socialstyrelsen. Organ- och vävnadsdonation i Sverige 2018 [Internet]. Socialstyrelsen; 2019 [citerad 2019 sep 9]. 2019-6-24. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-6-24.pdf>
3. MOD - Mer Organdonation. DCD-projektet [Internet]. MOD; Okänt datum [citerad 2019 okt 15]. Available from: <https://merorgandonation.se/dcd-projektet/>
4. Socialstyrelsen. Organ- och vävnadsdonation [Internet]. Socialstyrelsen; [citerad 2019 sep 9]. Available from: <https://www.socialstyrelsen.se/stod-i-arbetet/organ-och-vavnadsdonation/>
5. Riksdagsförvaltningen. Lag (1995:831) om transplantation m.m. Svensk författningssamling 1995:1995:831 t.o.m. SFS 2017:42 [Internet]. Riksdagsförvaltningen; [citerad 2019 okt 11]. Available from: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm\\_sfs-1995-831](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1995831-om-transplantation-mm_sfs-1995-831)
6. Milton A. Organdonation. En livsviktig verksamhet (SOU 2015:84). Stockholm: Statens Offentliga Utredningar; 2015.
7. Domínguez-Gil B. Newsletter Transplant 2019 [Internet]. CD-P-TO and ONT; 2019 [citerad 2019 nov 21]. Available from: <http://www.transplant-observatory.org/download/newsletter-transplant-2019/>
8. Scandiatransplant. Transplantation and waiting list figures 2018 [Internet]. Scandiatransplant; 2019 [citerad 2019 okt 28]. Available from: [http://www.scandiatransplant.org/data/sctp\\_figures\\_2018\\_4Q.pdf](http://www.scandiatransplant.org/data/sctp_figures_2018_4Q.pdf)
9. Riksdagsförvaltningen. Förordning (2018:307) om donationsregister hos Socialstyrelsen Svensk författningssamling 2018:2018:307 - Riksdagen [Internet]. Riksdagsförvaltningen; [citerad 2019 sep 9]. Available from: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/forordning-2018307-om-donationsregister-hos\\_sfs-2018-307](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/forordning-2018307-om-donationsregister-hos_sfs-2018-307)
10. Trysell K. Första donationerna efter cirkulationsstopp genomförda. Läkartidningen [Internet] 2018 [citerad 2019 sep 10]; Available from: <https://www.lakartidningen.se/Aktuellt/Nyheter/2018/04/Forsta-donationerna-efter-cirkulationsstopp-genomforda/>
11. Vävnadsrådet. Frågor & svar [Internet]. Vävnadsrådet; Okänt datum [citerad 2019 sep 10]. Available from: <http://vavnad.se/dcd-projektet/fragor-svar/>
12. Heckscher S. Organbevarande behandling för donation (SOU 2019:26). Stockholm: Statens Offentliga Utredningar; 2019.
13. Morais M, da Silva RCMA, Duca WJ, Rol JL, de Felicio HCC, Arroyo- PC, m.fl. Families who previously refused organ donation would agree to donate in a new situation: a cross-sectional study. *Transplant Proc* 2012; 44:2268–71.
14. de Groot J, van Hoek M, Hoedemaekers C, Hoitsma A, Smeets W, Vernooij-Dassen M, m.fl. Decision making on organ donation: the dilemmas of relatives of potential brain dead donors. *BMC Med Ethics* 2015; 16:64.
15. de Groot J, van Hoek M, Hoedemaekers C, Hoitsma A, Schilderman H, Smeets W, m.fl. Request for organ donation without donor registration: a qualitative study of the perspectives of bereaved relatives. *BMC Med Ethics* 2016; 17:38.
16. Bramstedt KA. Family refusals of registered consents: the disruption of organ donation by double-standard surrogate decision-making. *Intern Med J* 2013; 43:120–3.
17. Hulme W, Allen J, Manara AR, Murphy PG, Gardiner D, Poppitt E. Factors influencing the family consent rate for organ donation in the UK. *Anaesthesia* 2016; 71:1053–63.

18. Can F, Hovardaoglu S. Organ Donation: A Comparison of Donating and Nondonating Families in Turkey. *Transplant Proc* 2017; 49:1969–74.
19. Ghorbani F, Khoddami-Vishteh HR, Ghobadi O, Shafaghi S, Louyeh AR, Najafzadeh K. Causes of family refusal for organ donation. *Transplant Proc* 2011; 43:405–6.
20. Mojtabae M, Ghorbani F, Mohsenzadeh M, Beigee FS. Update on Causes of Family Refusal for Organ Donation and the Related Factors: Reporting the Changes Over 6 Years. *Transplant Proc* 2018; 50:10–3.
21. Anker AE, Feeley TH. Why families decline donation: the perspective of organ procurement coordinators. *Prog Transplant Aliso Viejo Calif* 2010; 20:239–46.
22. Michaut C, Baumann A, Gregoire H, Laviale C, Audibert G, Ducrocq X. An assessment of advance relatives approach for brain death organ donation. *Nurs Ethics* 2019; 26:553–63.
23. Sque M, Walker W, Long-Sutehall T, Morgan M, Randhawa G, Rodney A. Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making. *J Crit Care* 2018; 45:82–9.
24. Berntzen H, Bjørk IT. Experiences of donor families after consenting to organ donation: a qualitative study. *Intensive Crit Care Nurs* 2014; 30:266–74.
25. Gyllström Krekula L, Forinder U, Tibell A. What do people agree to when stating willingness to donate? On the medical interventions enabling organ donation after death. *PloS One* 2018; 13:e0202544.
26. Sque M, Galasinski D. "Keeping her whole": bereaved families' account of declining a request for organ donation. *Camb Q Healthc Ethics CQ Int J Healthc Ethics Comm* 2013; 22:55–63.
27. Vincent A, Logan L. Consent for organ donation. *Br J Anaesth* 2012; 108 Suppl 1:i80–87.
28. Shaw D, Georgieva D, Haase B, Gardiner D, Lewis P, Jansen N, m.fl. Family Over Rules? An Ethical Analysis of Allowing Families to Overrule Donation Intentions. *Transplantation* 2017; 101:482–7.
29. Transplantationscentrum - Sahlgrenska Universitetssjukhuset. Flödesschema donationsprocessen [Internet]. Västra Götalandsregionen; 2018 [citerad 2019 okt 10]. Available from: <https://alfresco.vgregion.se/alfresco/service/vgr/storage/node/content/workspace/SpacesStore/06a3b001-c058-407c-b6b7-cbcf73e5c418/Kap%204%20Fl%C3%B6desschema%20donationsprocessen.pdf?a=false&guest=true>
30. Transplantationscentrum - Sahlgrenska Universitetssjukhuset. Donatorkaraktärisering [Internet]. Västra Götalandsregionen; 2018 [citerad 2019 okt 30]. Available from: <https://alfresco.vgregion.se/alfresco/service/vgr/storage/node/content/workspace/SpacesStore/438825dd-17ce-41d8-afbd-18641e35d4f0/Kap%206%20Bilaga%20Donatorkarakt%C3%A4risering.pdf?a=false&guest=true>
31. Söderlind Rutberg K. Transplantation och transparens. *Läkartidningen* [Internet] 2019 [citerad 2019 nov 20]; Available from: <http://lakartidningen.se/Opinion/Debatt/2019/11/Transplantation-och-transparens/>
32. Johnston Y. Donation decisions after death: The case for a family veto. *Ethics Med Public Health* 2017; 3:486–92.
33. Statens Medicinsk-Etiska Råd. Informerat samtycke [Internet]. Stockholm: SMER; [citerad 2019 okt 10]. Available from: <http://www.smer.se/etik/informerat-samtycke/>
34. Barlov K. Anhörigveto försvårar organdonation. *Läkartidningen* [Internet] 2017 [citerad 2019 okt 9]; Available from: <http://lakartidningen.se/Opinion/Debatt/2017/11/Anhorigveto-forsvarar-organdonation/>
35. Blidberg M. Fler organ skulle kunna doneras [Internet]. Göteborg: Sveriges Radio; 2019 [citerad 2019 nov 20]. Available from: <https://sverigesradio.se/sida/artikel.aspx?programid=104&artikel=7337667>
36. Leal de Moraes E, de Barros E Silva LB, Pilan L a. SL, de Lima E a. A, de Santana AC,

da Paixão NCS, m.fl. My Loved One Was Not an Organ Donor: Ethical Dilemmas for Family Members of Deceased Potential Donors When Making the Decision on Donation. *Transplant Proc* 2019; 51:1540–4.

37. Livsviktigt. Statistik [Internet]. Livsviktigt; 2019 [citerad 2019 dec 3]. Available from: <https://www.livsviktigt.se/omdonation/statistik/Sidor/default.aspx>

38. Berg L. Krav på aktivt nej till donation föreslås [Internet]. *Dagens Medicin*; 2019 [citerad 2019 dec 3]. Available from: <https://www.dagensmedicin.se/artiklar/2019/10/28/krav-pa-aktivt-nej-till-donation-foreslas/>

39. Sharif A, Moorlock G. Influencing relatives to respect donor autonomy: Should we nudge families to consent to organ donation? *Bioethics* 2018; 32:155–63.

40. Black I, Forsberg L. Would it be ethical to use motivational interviewing to increase family consent to deceased solid organ donation? *J Med Ethics* 2014; 40:63–8.

41. Rosenblum AM, Horvat LD, Siminoff LA, Prakash V, Beitel J, Garg AX. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012; 27:2533–46.

42. Organización Nacional de Transplantes. Donación [Internet]. ONT; Okänt datum [citerad 2019 nov 21]. Available from: <http://www.ont.es/informacion/Paginas/Donaci%c3%b3n.aspx>

43. Fabre J, Murphy P, Matesanz R. Presumed consent: a distraction in the quest for increasing rates of organ donation. *BMJ* 2010; 341:c4973.

## Appendix 1 – Populärvetenskaplig sammanfattning

Förra året dog 38 patienter i väntan på organtransplantation i Sverige. Samtidigt använde närstående sitt veto och sa nej i 37 fall där organdonation hade varit möjlig. Att organdonation kan rädda livet på flera andra personer är ett av argumenten mot närståendeveto. Ett annat argument är autonomiprincipen, individens rätt att själv bestämma vad som ska hända med kroppen. Vi har sedan 1996 ett förmodat samtycke till donation vilket innebär att om man inte sagt nej så är det ja, men samtidigt har närstående veto om den avlidne inte uttryckt sin vilja. I denna studie har vetenskapliga artiklar, debattartiklar, författningstexter, rapporter m.m. valts ut för att undersöka vilka faktorer som påverkar närstående vid beslut om organdonation och vilka argument som finns för och emot närståendeveto. Studier baserade på intervjuer med närstående eller personal som varit involverade vid beslut om organdonation tyder på att närstående kan känna att de inte kan fatta ett sådant beslut i en så svår situation, att de inte fått tillräcklig information och stöd för att fatta beslutet och en svårighet att förstå att personen verkligen är död när hjärtat slår och huden är varm. Är det då rimligt att de ska behöva fatta ett beslut om organdonation? Det finns ett förslag om att närståendeveto ska tas bort vilket denna studie talar för. Även att registrera sig i donationsregistret och hur personal bemöter närstående med frågan om organdonation är viktiga faktorer för ett ökat samtycke och för att uppfylla den avlidnes önskan.

## Appendix 2 – Cover letter

Dear Editor of the BMC Medical Ethics,

Please, consider publication of the enclosed manuscript entitled “The Role of Relatives in Decision Making on Organ Donation – an Ethical Analysis”.

This manuscript may be of interest to the readers for the following reasons:

- It is a contribution to the debate about the role of relatives in decision making on organ donation.
- It is a synthesis of many different texts, perspectives and opinions. It includes different countries, cultures, religions and both debate and scientific articles.
- There are arguments both in favour of and against relatives’ right to veto which is interesting since there is a proposal about removing the veto in Sweden.
- Five themes based on what influences relatives in their decision have been identified: incompetence to decide, disagreement among relatives, lack of information and support, comprehension of brain death and protection of the body.
- There are suggestions on how to increase the consent rate concerning organ donation.

There are no potential competing interests known. All authors have approved the publication. The manuscript has not been published and is not considered being published elsewhere.

Yours sincerely,

Lovisa Svensson MB  
School of Medical Sciences  
Örebro University  
Örebro  
Sweden

## Appendix 3 – Etisk reflektion

Det är flera svåra etiska frågor som tas upp i detta arbete, men eftersom analysen i sig är baserad på tidigare publicerade studier, artiklar och andra texter föreligger inga specifika etiska överväganden. Det är inga känsliga personuppgifter som behandlats. Ett etiskt dilemma skulle kunna vara att studien blir subjektiv och partisk eftersom artiklar och argument väljs ut baserat på relevans av författaren och därmed skulle kunna ge en förvrängd bild. Det är av stor vikt att inse denna begränsning och att sträva efter opartiskhet så långt som möjligt.

Den primära planen var att detta arbete skulle baseras på intervjuer med antingen anhöriga eller personal med erfarenhet av beslutsfattande kring organdonation vilket skulle ha inneburit en etiskt känsligare studie. Det hade behövts en noga genomtänkt metod för hur kontakt skulle ske, tillfrågan om deltagande, skriftlig forskningspersonsinformation, formulär med informerat samtycke, pseudonymisering, hantering av kodnyckel samt att på andra sätt säkra att forskningspersonernas åsikter och tankar inte skulle kunna spåras tillbaka till dem och användas emot dem. Om enskilda patientfall hade tagits upp hade det varit viktigt att begränsa uppgifterna kring dem för att försvåra identifiering. Samtycke från anhöriga hade behövts. För den typen av studie hade en etikprövning också varit nödvändig.