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RESEARCH ARTICLE

Paediatric Organ and Tissue Donation: Developing a Comprehensive Protocol for Effective Donation Procedures in the Netherlands

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ABSTRACT

The waiting list for children needing organ and tissue transplantation increases yearly; some die while waiting for a suitable transplant. Most of them need small organs or tissues from paediatric donors. Paediatric donation is a unique and extremely sensitive process that requires specific knowledge and competencies. Because paediatric donation is relatively rare and complex, gaining knowledge and experience in this field is difficult.

This article describes essential facts about donation and transplantation concerning children in the Netherlands and summarises studies reporting on the various factors influencing paediatric donation.

The methodology used combines various research methods, including literature review, online survey, face-to-face interviews, and retrospective study, to evaluate the organ and tissue donation protocols for the paediatric population in Dutch Paediatric Intensive Care Units and Neonatal Intensive Care Units. The studies provide insights into the current process and limitations of paediatric donation and offer recommendations for the development of a paediatric donation protocol.

Recurrent themes that emphasise the importance of a robust paediatric donation process were identified and later used to form the groundwork for a paediatric donation protocol.

Healthcare professionals lack knowledge and experience with donation procedures. Work experience at the Paediatric Intensive Care Unit or Neonatal Intensive Care Unit is not related to the gained experience in the organ or tissue donation procedure. Paediatric Intensive Care nurses had significantly less experience than Paediatric Intensivists.

The survey respondents confirmed needing more guidance on the paediatric donation process. They further agreed there was a need for an easily accessible and clear guidelines document for paediatrics known as "the children's protocol" to cover all types of paediatric donation procedures (Donation after Brain Death, Donation after Circulatory Death and tissue donation). Neonatal Intensive Care Unit donation potential is limited.

A new donation protocol for paediatrics was designed using the results of all the above studies. The comprehensive protocol for paediatric organ donation in the Netherlands aims to assist healthcare professionals in identifying potential donors and referring them to an Organ Procurement Organization in a timely manner. Additionally, the protocol will support healthcare professionals in conducting sensitive yet necessary discussions with the family regarding the possibility of organ and tissue donation. Finally, while using the protocol, healthcare professionals provide the appropriate state-of-the-art support to the parents during a challenging and emotional time.

Introduction

Transplantation medicine continues to develop as surgical techniques improve and advance, resulting in more successful transplantation. It also applies to the paediatric population, including very small children and neonates. In industrialised countries, solid organ transplants become routine procedures to save and improve the lives of children with life-threatening conditions. At the same time, paediatric tissue transplantation plays a vital role in improving the quality of life for children who need a heart valve or cornea transplant. These transplants may not be considered life-saving procedures but are crucial for improving the child's overall well-being^{1,2}.

However, paediatric organ and tissue transplantation still faces several challenges and limitations. One of the biggest obstacles in paediatric organ and tissue transplantation is the scarcity of available donor organs and tissues. This shortage often leads to extended waiting time or, in some cases, deaths while awaiting a transplant¹.

On average, about 200 children under 16 are on Eurotransplant's active waiting list². Most children are waiting for a kidney, followed by a liver, heart, and lung transplantation (Table 1)². Many of the children on the waiting list required an organ or tissue from paediatric donors, as a size-matched donated organ or tissue is required to ensure successful outcomes. This is even more critical in neonates and small children. Therefore, the utilisation of paediatric donors has become essential for these groups. Despite efforts to increase the number of paediatric donors, the shortage of donated tissues and organs remains a significant challenge in paediatric transplantation. This can be attributed to various factors, including a lack of knowledge and absence of clear guidelines regarding the possibilities of paediatric organ and tissue donation for healthcare professionals at the Paediatric Intensive Care Unit (PICU) or Neonatal Intensive Care Unit (NICU)^{3,4}. Implementing a donation protocol specific to the paediatric population can benefit healthcare professionals immensely.

Table 1. Organ and tissue donation options classified by age categories and donation type.

Age	Organ
Newborn up to 3 months (gestational age > 37 weeks and weight > 3 kg):	DBD: heart, lungs
Baby aged 3 months to 1 year:	DBD: heart, liver, lungs DCD: liver
Child aged 1 year to 5 years:	DBD: kidneys, heart, liver, lungs, small intestine DCD: kidneys, liver, lungs
Child older than 5 years:	DBD: kidneys, heart, liver, lungs, pancreas (whole pancreas and islets, weight > 20 kg), small intestine DCD: kidneys, heart, liver, lungs, pancreas (whole pancreas and islets, weight > 20 kg), heart (weight > 50 kg)
Age	Tissue
Newborn (weight > 3000 g) up to 2 years:	heart valves
Child aged 2 years to 16 years:	heart valves, cornea
Child older than 16 years:	heart valves, cornea, bone, cartilage and tendon tissue, femoral arteries

The potential paediatric donor can be identified among children admitted to a PICU or, in rare cases, newborns admitted to a NICU. In the Netherlands, like in other countries, there are specific restrictions regarding weight, age, and type of donation procedure. Depending on these factors, children can become heart and/or liver donors from the age of just three months. Tissue donation also carries age limitations: while heart valve donation is permitted from the time of birth, cornea donation is only possible from the age of two. See Table 1 for a list of all the organ and tissue donation options in the Netherlands.

Because paediatric donation is relatively rare and comes with unique processes, gaining knowledge

and experience in this field is not easy. Many differentiating factors must be considered, covering medical, legal, and ethical domains, which can be offputtingly challenging for healthcare professionals. Previous studies confirm that the major obstacles to paediatric donation are the lack of knowledge and experience, which in turn fails to recognise potential donors; a reluctance to discuss the sensitive issue of a dying and donation with their families; or to report the donor to the Organ Procurement Organizations (OPO)³⁻⁹. Some studies suggest that compassionate, well-informed, competent professionals play a critical role in overcoming these obstacles^{4,10,11}. Figure 1 presents the course of the paediatric donation process in the Netherlands.

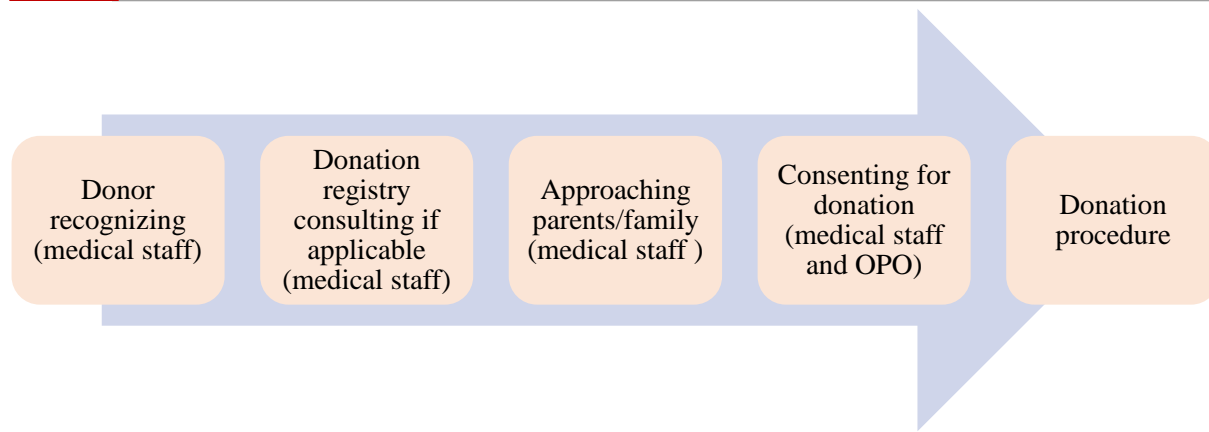


Figure 1. Pediatric donation process

Methods

The methodology used in this report involves a combination of different research methods, including a literature overview, an online survey, face-to-face interviews, and a retrospective study.

The literature overview was conducted to evaluate the international literature and practice for specific organ and tissue donation protocols for the paediatric population. The online survey and face-to-face interviews among healthcare professionals from PICUs and NICUs aimed to evaluate the current paediatric donation process in Dutch PICUs and NICUs and establish recommendations regarding the paediatric donation process. Because of a lack of data, a retrospective study was carried out to assess the potential for neonatal donation in Dutch NICUs.

These research methods were chosen because they offered a comprehensive approach to understanding the challenges and limitations faced in paediatric donation as a whole.

Together these studies provide important insights into the rationale behind the gained knowledge and outline the development of a paediatric donation protocol.

Healthcare professionals Perspective

One of the main barriers to organ donation is the failure to recognise a potential donor. A study of Dutch PICUs reported that approximately 11% of the children who died were potential organ donors, and 19% were potential tissue donors¹². Further, around 84% of potential organ donors and only 48% of tissue donors were recognised by medical staff¹². The same study showed that older children were identified as potential organ and tissue donors more often than younger children¹². A recent study featuring two large Dutch NICUs

reported that approximately 2% of neonates were potential organ donors, and 12% were potential tissue donors. Of these, only one potential tissue donor was reported to OPO¹³.

Both studies show potential for organ and tissue donation at PICUs and NICUs. However, medical teams still fail to recognise the percentage of potential donors and are not discussing this possibility with parents and making referrals to OPO^{13,14}. These findings highlight a lack of knowledge and experience in a study of Dutch PICUs and NICUs¹⁴. Participants in this study stated that paediatric organ and tissue donation was an important and delicate topic within PICUs and that their experience with the donation procedure was limited¹⁴. The study also showed that years of experience in the field did not correspond with the amount of experience gained in the organ or tissue donation procedure and that PICU nurses had significantly less experience than PICU intensivists¹⁴.

The rarity of paediatric donation can explain these findings. Currently, in the Netherlands, between 5 and 8 paediatric organ donations are effectuated yearly¹⁵. Considering there are 7 PICUs in the Netherlands, this means that, on average, each PICU performs one donation at best. One of the PICU doctor's comments: "Actuality, there are very few paediatric donors in the Netherlands and many PICU intensivists. We have limited opportunities to deal with donation procedures here". Another intensivist, with more than 12 years of experience working at a PICU, stated: "Last year, I did my first paediatric DCD (Donation after Circulatory Death) procedure. I have experience with several DBD (Donation after Brain Death) procedures in this hospital and during a fellowship abroad...we do not do it very often here".

None of the NICU respondents had previous experience in neonatal donation, as the same study of Dutch PICUs and NICUs showed¹⁴. One of the neonatologists spoke on this topic: *“Actually, I do not have any practical experience with a donation, at least not at NICU. At PICU, when I was in training, once, I stood on the sidelines when a donation was discussed.”*

Some respondents have mentioned that some parents have raised questions regarding organ or tissue donation in neonates. Even though this experience was limited, the staff reacted to it: *“I think parents don’t just ask that, they are very consciously considering, apparently it is very important for them... so suddenly you have to know more about organ and tissue donation so you can explain it to parents.”*

Legal and Ethical Domains

Since the Organ Donation Act 1998 was passed in the Netherlands, medics are obliged to consult the Dutch donation registry for suitable donors. The act was modified in 2020 to stipulate that everyone from the age of 18 is obliged to record in the Dutch Donor Register whether they do or do not wish to donate organs and tissue in the event of their death. If an individual does not confirm their choice, the ‘no objections to organ donation’ option will be marked as the default in the register¹⁶.

The Dutch Donor Act also applies to children with several age-related conditions. The legislation allows children aged 12 and over to register their donation choices. Parents or legal guardians can overrule a child’s consent but not their choice to abstain from becoming a donor. However, a parent’s or legal guardian’s right to overrule their child’s consent is removed once the child turns 16.

This law requires medical staff to consult the Donor Register for every potential donor patient aged 12 years and older. However, this only happens inconsistently, according to studies on the subject, with results revealing that PICU staff only recognised 34-56% of potential eligible child donors^{12,14}. As one of the respondents has agreed: *“The register can be consulted for children as well, for children from the age of 12, that is something that is not always clear to everyone...”*. The studies could not pinpoint a particular reason for this lack of compliance. Is it due to deficiencies in knowledge and experience due to an absence of adequate legal guidance or a combination of both?

The law changes again for children younger than 12, as the decision about donation lies solely with the parents or legal guardians. Consequently, many

potential donors cared for at PICUs cannot officially register a choice regarding organ and tissue donation. Therefore, it is crucial for parents or legal guardians to know their child’s wishes, feelings, beliefs, and values when making a donor decision, but this is often a difficult conversation to have.

A law clearly distinguishes from what age children can register their choice regarding donation and who has to make the decision. Even or just then, it can still be difficult for parents or legal guardians and create moral dilemmas. For example, what should be done if a 12-year-old child has registered the choice for donation but parents are against it? The law says it is OK to ignore the child’s consent, but it is not easy to go against their child’s expressed will. One respondent commented: *“Many parents want to decide in the child’s mind, and some parents just can’t; they just cannot get over that threshold and cannot give that consent, but that is OK....”*

What if a child under 12 already has an opinion about the donation? Can a child under 12 think and discuss organ and tissue donation? Is it fair to ask their opinion on this topic? The capacity of children to make choices regarding donation is not rigidly age-dependent. However, as younger children may have a clear opinion on the subject, some older children might still struggle with the issue¹⁷. One of the PICU intensivists reflects on this topic: *“Then parents have to decide for and about their child. The last few times, parents said, ‘Yes, we talked about organ donation, and he said he wanted to,’ or ‘she said she wanted to,’ so that also gives parents some support, then apparently the decision-making becomes easier”*.

Knowledge about Healthcare Providers’ Needs

We conducted a literature overview to seek answers to the following questions: What support does a healthcare professional need to gain confidence and experience in dealing with complex paediatric donation procedures? Are there any protocols or clinical guidelines specifically designed for the paediatric population? Our analysis of existing literature has revealed a distinct lack of guidelines or protocols for the paediatric donation process¹⁸. We found that publications concerning the paediatric donation process or protocols are scarce, with most focusing on 1 or 2 aspects. However, the literature has recurrent themes that emphasise the importance of a robust paediatric donation process¹⁸. Firstly, the manner and timing when approaching parents to discuss the possibility of organ and tissue donation are crucial^{3,5-9,18-22}.

The study by Darlington et al. (2019) supports these findings and shows the great value of discussing the possibility of donation with the child's parents or guardians²³. Secondly, the literature emphasised the importance of medical staff education regarding organ and tissue donation and the declaration of brain death in children of various ages^{3,7-9,18,19,21,24}. Collaboration with OPO and exceptional attention to palliative care of potential organ and tissue donors are essential aspects of the paediatric donation process^{3,5,8,9,18,19,21}.

All these aspects form the groundwork for a paediatric donation protocol, which would make the professionals more comfortable and confident when handling the complex and sensitive donation process.

The former Dutch National Donation Protocol was too Generic.

Previously, Dutch PICU and NICU professionals followed the Dutch national donation protocol - a key document for all organ and tissue donation types, including legal and practical information¹⁶. However, this generic document did not cover aspects particularly important to potential paediatric donors, including details related to age and weight ranges, approaching grieving parents, and complexities surrounding guardianship. As evaluated in a survey, compliance with the generic Dutch donation protocol in PICUs and NICUs in the Netherlands was low; only 36% of PICU healthcare professionals referred to the protocol as a guide during the donation process¹⁴. Medical staff have made some critical remarks regarding this national protocol and have noticed some areas that require improvement for this protocol to be more suitable for use at PICU: *"Too much focused on adult donors, therefore less useful for children"; "it is quite much reading when it should be compact... I think an explanation should be given along with something short, structured, and easy to use"*.

As previously mentioned, none of the NICU respondents had experience with donation in neonates. Only 2% of respondents were familiar with the generic Dutch donation protocol, with 13% somewhat familiar¹⁴. NICU respondents have explained the situation: *"Of course, the protocol is not very well known, as there is never really a reason to look at it because donation never actually happens in our department"*.

Recommendations and Need for Paediatric Donation Protocol

Most respondents in PICU and NICU generally agreed that an established paediatric donation

protocol would form an essential part of palliative care and that effective communication (including providing information for parents), knowledge of processes and procedures, and effective collaboration with OPO would be essential¹⁴. One respondent stated, *"Clarity, honesty, and open communication are required. It must be clear to parents what the options are and what they can expect, especially the possibilities for donation should be discussed. It is necessary to talk about organ donation at the right time"*.

Thus, most survey respondents confirmed needing more guidance on the paediatric donation process. There is a need for an easily accessible and clear guidelines document for paediatric donation procedure, described as *"the children's protocol"*¹⁴. A protocol to outline all types of paediatric donation procedures (DBD, DCD, and tissue), providing clear suitability criteria for paediatric donation according to age and weight, explaining collaboration opportunities with OPO, and clarifying the responsibilities for involved disciplines. As one of the respondents emphasised: *"It has to be practical, focused on children when you do not get that feeling of missing or forgetting something, because you do it so little, so it will be useful if the information will be kept summarised."* Another participant stated: *"It is important that all legal information is linked with legal acts. This is especially important for junior professionals to read the legal information about what is allowed and what is not."* Moreover, respondents recommended involving other relevant parties, such as chaplains or social workers, to optimise the care processes of potential donors and their families. They suggested the protocol includes *"support for the parents and family," "aftercare," and "ensuring that parents can say farewell to their child."*

Despite the NICU participant having no experience using the National Donation protocol, they have expressed their recommendations for the future paediatric donation protocol. Those recommendations were in line with PICU respondents: *"That it is a situation that you do not experience often ... It must be short and summarise different aspects of the procedure and the practical course of events."*

New Donation Protocol for Paediatrics

We created the Child as Donor protocol using the comments and recommendations from our studies and research summarised above, including the conclusions from the literature review.^{13,14,18}. The following recommendations for a paediatric donation protocol have been taken into consideration: criteria for identifying potential

donors, communication with families, referral process, consent process, donor management and post-donation care. Out of these, we formulated a clear and pragmatic protocol which guides healthcare professionals through all the various and specific aspects of paediatric organ and tissue donation. The protocol provides guidelines on the legal, medical-technical, and logistical aspects of the donation process. This protocol emphasises the importance of the timely recognition and reporting of a potential donor to OPO. It gives practical advice on approaching and providing support to the parents or legal guardians and family of a child donor. The protocol is designed to be used by all healthcare professionals in Dutch PICUs and NICUs and other relevant professionals such as chaplains and social workers. The relevant legal acts¹⁶ were also consulted, and an existing generic donation protocol was taken into consideration²⁵. The main overarching goal of designing this protocol is to ensure that healthcare professionals provide the best care possible and offer the appropriate support, of state-of-the-art support to the child's entire family (including siblings) during the complex decision-making process regarding donation and the donation process.

To start the donation process, healthcare professionals should check a child's suitability for organ and tissue donation, not only via a general contraindication list but also by making a decision considering the age and weight of the potential donor. Then, the significance of the Donor Register is underlined when the child is 12 years or older. The protocol offers a fresh approach to discussing organ or tissue donation with a child's family. Guidelines emphasise the importance of time and breathing space given to parents to decide on their child's behalf and the importance of *offering* the choice of their child becoming a donor rather than *asking*. The latter can add pressure to the parents' already difficult decisions and make medical professionals uncomfortable. After making a decision, the protocol also covers the following steps of the donation process: collaboration with OPO, palliative care for the potential organ/tissue donor, and aftercare for the family. Different types of donations (DBD, DCD, and tissue donation) are discussed in separate chapters and include some practical advice for nurses.

The Child as Donor protocol has been designed in ongoing and close collaboration with Dutch NICU and PICU professionals and Dutch Transplantation Foundation (NTS) professionals. The Dutch paediatric donation protocol is now legally recognised in the Netherlands. It is of equal legal status to its generic counterpart, meaning that

every hospital is obliged to consult the Child as Donor protocol when dealing with a paediatric patient. The NTS is tasked with maintaining and safeguarding the protocol that was published on the NTS website in March, which can be found under the [Protocols section](#). Clinical leads in each PICU coordinate the Child as Donor protocol implementation in their respective departments. However, we are aware that this protocol is a new concept. We recommend further research on the suitability of this protocol in practice and welcome any adjustments that would optimise the effectiveness of the protocol all around.

This comprehensive Dutch paediatric donation protocol will help professionals recognise potential donors in a timely manner and refer them to OPO. Additionally, the protocol will support healthcare professionals in conducting sensitive yet necessary discussions with the family regarding the possibility of organ and tissue donation. In turn, this will support parents in making careful donation decisions during difficult and emotional times. In addition, this protocol is also expected to make professionals feel more competent and comfortable with the paediatric donation process and provide the appropriate state-of-the-art support to the parents during a challenging and emotional time. It will contribute to the quality of palliative care for paediatric donors and possibly increase the paediatric donor pool.

Conclusion

Paediatric organ and tissue donation is a complex process that demands specific knowledge and competencies. The scarcity of donated tissues and organs can be attributed to various factors, including a lack of knowledge and the absence of clear guidelines regarding the possibilities of paediatric organ and tissue donation for healthcare professionals at the PICU or the NICU. However, implementing a donation protocol specific to the paediatric population can immensely benefit healthcare professionals. In the Netherlands, we have developed a comprehensive protocol for paediatric organ donation based on the outcomes of these studies. This protocol provides healthcare professionals with clear and easily accessible guidelines for all paediatric donation procedures, including DBD, DCD, and tissue donation. The protocol is designed to assist healthcare professionals in efficiently identifying potential donors and referring them to an OPO. The protocol will also support healthcare professionals in conducting sensitive yet necessary discussions with the family, offering them the possibility of organ and tissue donation. Moreover, when healthcare professionals are competent and

comfortable with the paediatric donation process, they can offer appropriate support to parents during a challenging and emotional time. This protocol is expected to contribute to the quality of palliative care for paediatric donors and their families and possibly increase the paediatric donor pool.

Conflicts of Interest Statement

The authors have no conflicts of interest to declare.

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