Parents' experiences of donation to their child before kidney transplantation

A qualitative study

Agerskov, Hanne; Thiesson, Helle; Specht, Kirsten; Pedersen, Birthe D

Published in:
Journal of Clinical Nursing

DOI:
10.1111/jocn.14734

Publication date:
2019

Document version
Accepted manuscript

Citation for published version (APA):

Terms of use
This work is brought to you by the University of Southern Denmark through the SDU Research Portal. Unless otherwise specified it has been shared according to the terms for self-archiving. If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying this open access version.

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim. Please direct all enquiries to puresupport@bib.sdu.dk
Parents’ experiences of donation to their child before kidney transplantation: A qualitative study

Corresponding author
Hanne Agerskov, Research Nurse, PhD, Assistant Professor, Department of Nephrology Odense University Hospital and Department of Clinical Institute, University of Southern Denmark. Kløvervænget 6, 11. 5000 Odense C, Denmark.
Hanne.agerskov@rsyd.dk

Authors
Hanne Agerskov, Research Nurse, Assistant Professor, PhD. Department of Nephrology Odense University Hospital and Department of Clinical Institute, University of Southern Denmark

Helle Thiesson, Consultant, Associate Professor, PhD. Department of Nephrology, Odense University Hospital and Department of Clinical Institute, University of Southern Denmark

Kirsten Specht Assistant Professor, PhD MPH RN CRNA. Department of Orthopaedic Surgery, Zealand University Hospital, Køge, and Department of Regional Health Research, Faculty of Health Science, University of Southern Denmark

Birthe D. Pedersen, Associate Professor, PhD, MScN, SA, BA (philosophy), RN. Department of Clinical Institute, University of Southern Denmark

Acknowledgement: The authors wish to thank the families for participation.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jocn.14734
This article is protected by copyright. All rights reserved.
Conflict of interest: None to declare

Funding: The Region of Southern Denmark research foundation, Danish National Kidney Foundation

Title
Parents’ experiences of donation to their child before kidney transplantation: A qualitative study

Abstract
Aim and objectives
To explore Parents’ experiences of donation to their child before kidney transplantation.

Background
Transplantation is the treatment of choice for pediatric patients with end-stage renal disease. Living donor kidney transplantation has shown a higher long-term transplant survival compared to deceased donor transplantation and entails a more controllable process, with shorter waiting time. Besides complex care and treatment of their child, parents must reflect on the prospects of being a donor for their child. However, little is known about the parent donor and parent caregiver perspective.

Design
A qualitative exploratory study taking a phenomenological-hermeneutic approach.

Method
The study was conducted in a Danish university hospital. Interviews were conducted with the parents of seven children, aged between 5-15 years, with end-stage renal disease in the period before kidney transplantation. Data were analysed with inspiration from Ricoeur’s theory of interpretation on three levels: naïve reading, structural analysis and critical interpretation and discussion.

This article is protected by copyright. All rights reserved.
Results

The decision about donation was experienced as a matter of course and commitment. There were preferences for a kidney from a living donor, including the hope of being accepted as a donor. Being refused as a donor revealed feelings of powerlessness. However, transformation was performed into having a new role providing care and comfort to the child during the transplant process. Asking family and friends about donation could feel like crossing a line.

Conclusion

The prospect of donating to one’s child had an impact on the well-being of the entire family. Parents were in a vulnerable situation and in need of support, regarding both living and deceased donation. Waiting time included hopeful thoughts and reflections on a new caregiver role for the child during transplantation.

Relevance to clinical practice

Health professionals’ attention, engagement and dialogue are essential in order to gain extensive and varied knowledge about the individual parent’s experiences and the well-being of the entire family to provide care and support before, during and after the donation and transplantation process.

What does this paper contribute to the wider global clinical community?

- The findings of this study provide new and unique knowledge of the parental perspective on donation before a kidney transplantation of their child.

- The paper demonstrates how strong emotional bond to the child and the family resulted in vulnerability and hopeful thoughts during the donor recruitment process.

- The study illustrates how nurses and other healthcare professionals’ should be aware that attention, engagement and dialogue are essential in order to provide care and support before, during and after the donation and transplantation process of a child.

Keywords: Kidney Transplantation, kidney donation, parent, family, experiences, interviews, qualitative.

This article is protected by copyright. All rights reserved.
Introduction

The study reported in this article explores both fathers’ and mothers’ experiences of donation during the period before their child’s kidney transplantation. The study is a part of a broader study to investigate how children with end stage renal disease (ESRD) and their close family members experience everyday life, and to study parental caregiving.

Children with ESRD have a life-threatening disease, and a high risk of psychological burden and social stress for themselves and their families. Not surprisingly, parents are in a vulnerable situation and concerned for their sick child, concerns that include the medical prognosis and developmental issues such as reliance on statural growth which requires careful considerations in their treatment and care (Shapiro and Sarwal, 2010). Furthermore, children on hemodialysis have poor self-esteem and experiences of losing their identity, body integrity, control and, independence (Tjalden et al., 2012). Therefore, when possible, kidney transplantation is the preferred treatment option in renal replacement therapy, importantly also due to decreased morbidity and mortality (Terasaki et al., 1995; Wolfe et al., 1999).

During the period 1994-2014, a total of 171 pediatric kidney transplantations were performed in Denmark, from 86 deceased and 85 living donors. In the majority of living donor cases, the donor was one of the child’s parents; however, other relationships between recipient and donor were also represented (Scandiatransplant, 2016).

Background

Pediatric kidney transplantation is today a well-established procedure, with excellent long-term outcomes regarding quality of life and transplant and patient survival, (Kim and Marks, 2014; Wittenhagen et al., 2014).

Renal transplantation improves clinical outcome significantly (Manificat et al., 2003; Smith and McDonnald, 2000) and, in recent decades, transplant survival in pediatric transplantation has improved as a result of development in immunosuppression and evolving expertise in surgical techniques and procedures, improved donor selection and advanced immunological methods (Shapiro and Sarwal, 2010; Kim and Marks, 2014;
After successful transplantation, children can return to more normalized everyday life activities and the need for clinical hospital visits is reduced. However, post-transplantation, intensive monitoring will continue for the period of the kidney transplant survival. If the child remains well, monitoring and outpatient consultations will become more infrequent.

Living donor kidney transplantation has shown a higher long-term graft survival compared to deceased donor transplantation (Dale-Shall et al., 2009; Shapiro and Sarwal, 2010). It entails a more controllable process, with shorter waiting time, and allows for the operative intervention to be planned for the optimal point in time.

The duration of time on the transplant waiting list is unknown, and prolongation can include the risk of progression in ESRD, the development of co-morbidities, poor growth and quality of life and early death. Given this, a high proportion of living donor transplantations to pediatric patients are performed in the Western world. In Denmark, as in the rest of the Western world (Shapiro and Sarwal, 2010), relatives – particularly parents – are the most common source of living donors; however, other close family members, such as grandparents and parents’ siblings, also sometimes donate (Danish Society of Nephrology, 2016).

Being a living kidney donor to adult recipients involves considerations and dilemmas concerning one’s own health and the recipient’s health, everyday life and future prospects (Lennerling et al., 2003; Tong et al., 2012; Agerskov et al., 2014; Agerskov et al., 2015; Agerskov et al., 2018). Studies that investigated parent liver donation found that parents considered that they had no option when it came to the question and decision regarding donation to their own child. Their role as a parent made it impossible to refuse donation (Forsberg et al., 2004; Zeiler et al., 2010). However, it was shown that undergoing donation was perceived as an overwhelming experience, in terms of being transformed from a healthy individual to a surgical patient (Forsberg et al., 2004; Agerskov et al., 2016; Agerskov et al., 2018).

The care and treatment of children with ESRD are complex issues that call for a close collaboration with parents, who have to adopt a healthcare provider’s role in addition to their usual parent role and responsibilities. A study found that medical interventions meant
that parents had to adapt to a redefined role such as being dependent on staff members which could experiences of having conflicts with the health professionals (Tong et al., 2008). Additionally, the quality of care they provide is a determinant of their child’s health outcome. For instance, parents need to be responsible for peritoneal dialysis, tube feeding and the administration of medication. Because parents play such a key role in the care of children with ESRD, we argue for the importance of emphasizing both parents’ perspectives of donation. In this study we therefore sought to gain insight into how both parents experience decision making, and donation approval or rejection, and, furthermore, the significance of these factors in the period before transplantation of a child. This is with a view to supporting and improving care and treatment for the whole family. Thus, the aim was to explore Parents’ experiences of donation to their child before kidney transplantation.

Methods
This was an explorative study with a qualitative design. Since the focus of the study was individual parents’ experiences and considerations regarding donation and their child’s future need of transplant due to ESRD, a qualitative approach was chosen (Kvale and Brinkmann, 2014). The study was conducted within a phenomenological-hermeneutic approach, based on Ricoeur’s theory of narrative and interpretation (Ricoeur, 1976; Pedersen, 1999/2005). The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al. 2007) was used during the study (See supplementary file 1).

Setting and participants
The participants were recruited from Odense University Hospital. This is one of two Danish centers for pediatric kidney transplantation, covering a population of 3.1 Mio. Children with ESRD are treated by both pediatric and nephrology specialists. Before they can be accepted for transplantation, a careful evaluation takes place and they should be fully immunized according to childhood schedules and pediatric immunization guidelines. The timing of the transplantation is based on kidney function and the well-being of the child. To the patient and the family, this unknown waiting time from acceptance for transplantation until the transplant is performed is often very stressful. During this time, screening,
recruitment and evaluation of donor(s) also take place. A prolonged waiting time that can vary from month to years may involve the need for extra blood tests and clinical examinations to ensure the donor’s continuing suitability for donation.

Inclusion criteria: Danish/Nordic/English-speaking parents of children under the age of 18 with ESRD who had been accepted for transplantation.

Inclusion was done purposively; all children attending the outpatient clinic and the first parent listed in the child’s medical record were screened from a local list, and chosen according to specific criteria in relation to the children’s age and acceptance for transplantation, and invited to participate in the study. Subsequently, written information about the study was posted to the parent. The invitation brought into focus that we were interested in finding out about both parents’ everyday life experiences and perspectives on donation in an interview.

In total, eight families were invited to participate during the period May 2016 to November 2016. One family declined participation giving the reason that they did not have the energy to participate. In this part of the study, seven fathers and seven mothers accepted participation, signed informed consent forms and were included in the study. In six families the child’s kidney disease was inborn and in one family the child’s disease occurred after medical treatment. One child received dialysis treatment. The children represented an age range from 5-15 years. Table 1 gives an illustration of parent age, residential setting, working time and number of children in the family. Part time*: Parents were fully or partly economically reimbursed from their work.

Data collection

Data were collected through individual, open in-depth interviews (Kvale and Brinkman, 2014). The interviews followed a narrative form. To facilitate the interview, an interview guide with open-ended questions such as; ‘Please, tell me about your experiences during the period of finding a donor’. The guide was used to lead the interviewees into relating about their experiences and perspectives of daily life and donation to their child. The open approach allowed the parents to express experiences that were important to them;

This article is protected by copyright. All rights reserved.
However, as a researcher, the interviewer made an effort to cover topics such as intrapersonal issues, intra-familial issues and issues around daily life with a child with ESRD.

The interviews were performed individually, to give the participants space to talk about things that they might not address in a family or social setting. Furthermore, the interviews took place in the participants’ homes, to make the situation pleasant for the participants. The interviews were recorded and transcribed verbatim by the interviewer, who is the first author. The researcher had a professional background as a clinical research nurse and was trained in conducting interviews. The participants did not know the interviewer prior to the interviews. The interviews lasted between 22-65 minutes. Data transcriptions were not returned to the participants. Narration allows for a process of reflection in the narrator, and this provides new perspectives into their lives, and makes validation among the parents inappropriate (Ricoeur 1976).

Data analysis

Data analysis and interpretation were conducted by a recognized method inspired by Paul Ricoeur’s interpretation theory (Ricoeur, 1976; Pedersen, 1999/2005), on three levels: naïve reading, structural analysis and critical interpretation and discussion.

During the analysis, the interview transcripts were considered as one text. In the naïve reading, the text was read several times with an open-minded approach, to get an initial impression and an overall understanding of what the text was about. According to Ricoeur, at this initial level, an understanding is achieved by looking and listening for how the text affects you. Impressions are written down and an initial identification of semantic content is identified (Ricoeur, 1976; Pedersen, 1999/2005).

In the structural analysis, a primary interpretation was performed in a validation and adjustment of the naïve reading, by identifying quotations in the text (‘what is said’) that illuminated the meaning. By questioning the units of meaning (‘what the text speaks about’), a further interpretation was made, which led to the emergence of key themes, subthemes and patterns. At this level, the text was viewed as objectively as possible, and
the intention was to objectify the units of meaning from the text as a whole (Ricoeur, 1976; Pedersen, 1999/2005).

Figure 1 illustrates an example of the structural analysis as a dialectical movement between the parts and the whole of the text (Pedersen, 1999/2005).

In the critical interpretation and discussion, the themes were further interpreted and discussed in relation to other research results (Pedersen, 1999/2005). At this final level of the interpretation, the findings were incorporated into possible appropriate interpretations, including a discussion of the study’s implications for practice and its importance in relation to national and international research. Thus, in the critical interpretation process and discussion, there was a dialectic between explanation and understanding, with a view to revealing new knowledge and understanding of the parent donor and parent caregiver perspective.

**Ethical considerations**

Exploring experiences and perspectives of being a kidney donor and parent caregiver to a child with ESRD involves ethical considerations. In this regard, reflections in the research team and supervision and collaboration with an experienced psychologist in a pediatric department were done.

The participants were informed, both orally and in writing, about the study, in accordance with applicable ethical rules (Declaration of Helsinki, 2013). Furthermore, on the basis of information about the purpose of the study, they were informed that participation was voluntary and that they could withdraw from the study at any time without any adverse consequences. Furthermore, they were informed that interview recordings and transcribed transcripts would be processed and stored confidentially. The project was not notifiable to the National Committee on Health Research Ethics. The study was approved by the Danish Data Protection Agency (ID-Number 16/12249).
Results

In this section the naïve reading and the structural analysis will be presented.

Naïve reading

The naïve reading revealed that the parents considered donation to be a natural thing. There seemed to be feelings of vulnerability regarding willingness to donate among certain people in the family’s circle. The ‘circle’ refers to close family, friends, relatives, acquaintances, social networks, colleagues, and other people who are regularly around the family. The naïve reading revealed that there were thoughts about the prospects of the child receiving a kidney from a living donor, and how it was significant to the entire family. However, anxiety occurred when the only option was to be referred to the transplant waiting list.

Structural analysis

The structural analysis will be presented as a primary interpretation by identifying quotations from ‘what is said’ followed by a further interpretation of ‘what the text speaks about’. Themes derived from this level of interpretation is presented as headings in the section.

Through the structural analysis, three themes emerged:

- Commitment and hope
- Powerlessness and vulnerability
- Waiting time for better or worse

Quotations marked (F) refer to father and those marked (M) refer to mother.

Commitment and hope

The offer of a kidney for one’s child was experienced as a matter of course, and the decision was taken without prior consideration. However, there could be reservations regarding surgery: “There is nothing that would stop me from donating to my child, even if I had to have dialysis for the rest of my life or use a wheelchair” (F1) ...“I have never been strong...
about such things (hospitals and operations), but when it comes to my daughter, well, they just have to have what they can use” (F5).

The decision to donate was made unconditionally and as a moral commitment, based on the child’s need. The unique emotional bond that the parent had with his/her child was reflected in a deep sense of commitment and readiness to sacrifice one’s own health. Reservations about undergoing surgery were put aside, in the hope of helping the child. The prospect of waiting for a suitable donor was filled with unknowns such as waiting time, progression of the child’s kidney disease and start of dialysis treatment: “The need for start dialysis is a situation we must avoid” (F5). Furthermore, in response to the hypothetical question of donating to a friend or colleague, the response was: “I’d probably do it, but I’d think over it in a different way” (F6). The quotation illustrates that donation to one’s own child was considered as a matter of course. By comparison, although willingness was expressed, the thought of donating to a person in one’s wider circle included reflections on the possibility to withdraw. Living kidney donor transplantation of the child was a factor in the parents’ thoughts and wishes, and it included feelings of commitment and hope.

**Powerlessness and vulnerability**

Potential donors were not limited to the child’s parents. It was a positive surprise when a person in the family’s circle spontaneously volunteered to be a donor: We are friends with a couple, and the man said: “I would like to give him my kidney” ... and that was a huge thing (F2). Parents also thought about how it would be to get a kidney from a deceased donor: “It’s a relief that he doesn’t have to get one [a kidney] from someone who was smashed up in a traffic accident. It should last a bit longer when it’s taken from a living donor” (F1).

There was a lot at stake in finding a donor, and considerations about receiving a kidney from a deceased donor included powerlessness and thoughts about dramatic traffic accidents, that the kidney transplant might not last long, and vulnerability in the sense of physical and emotional harm. Hence, it was a relief to know that there was a living donor in the close family:”Purely from the perspective of one’s conscience, it is easier (that a donor is found from within close family), so you don’t have to wonder about the other person sort of sacrificing a part of their body to us” (F6). While there was a sense of joy about and
gratitude for the willingness of others to donate, it was a relief when a donor was found among close family members. Carrying the responsibility for the risk undertaken by a donor in the family's circle could present a dilemma and was associated with powerlessness and vulnerability.

To find out who could be a kidney donor revealed thoughts about how to approach family and friends: “We raised it at a get-together we had one day. It was not as if they formed a queue to offer their help!” (F2) It could be difficult to formulate the question about donation, and it could be received in different ways. Asking family and friends about donation could feel like crossing a line, and there were feelings of vulnerability and disappointment if those who were asked declined. The following quotation illustrates how reluctance or aversion could be experienced as dishonesty wrapped up: “I could accept a ‘no’. I would rather have a ‘no’ than some stupid response like that they have to save them for their own children” (F3). Reasons given could be experienced as selfish, or as a lack of sympathy for the parents’ difficult situation. Although rejection could lead to feelings of vulnerability and powerlessness, openness and honesty meant a lot to the parents and could make a refusal easier to live with.

**Waiting time for better or worse**

Parents had confidence in the clinicians’ assessment of their child’s need for transplantation, and their estimation of the right time to start donor evaluation. Throughout the donor evaluation, the parents were taken up by thoughts about their own suitability as donors: “The question was whether I actually had two kidneys” (F1). Another said: “It was like an exam, because it was to find out whether or not we were actually able to help” (F5). There was a lot at stake in being accepted or rejected, and one had no influence on the evaluation outcome. In the waiting period, there were opposing feelings of nervousness or powerlessness and the hope of being able to help their child.

Being accepted as a donor led to feelings of joy and relief. However, if the transplant was postponed, there could be a need to be re-evaluated: “It gave me a sense of calm in the moment when I was approved. In that moment when I found out that she was going to have a new kidney, I could get going and help” (F5). Another said: “It’s the third time that I’ve
been evaluated, and the wait has been psychologically difficult. Not a day goes by that I don’t wonder about whether or not I can still (donate)” (F2). Once a donor had been accepted, the clarification led to certainty, together with a significant sense of calm and physical and mental readiness. However, an extended or uncertain waiting time could result in the feeling of certainty being replaced by uncertainty and nervousness about whether one would continue to be considered a suitable donor.

The time during evaluation was associated with positive expectations; however, when donation turned out to be impossible, one was left with feelings of disappointment and denial: “I was frustrated and disappointed, because it was simply ‘a given’ (to donate) and now we have to wait for a (kidney from a deceased person)” (M3). Conversely, rejection could also mean a new recognition, including another role for the parent, as a mother or a father in the transplant process. One mother expressed: “I had a feeling that I couldn’t help my own daughter, but now I have accepted that of course I can, because I’m needed in another way, to give comfort and hold her hand” (M5). Being rejected as a donor resulted in feelings of vulnerability, frustrations and powerlessness. This was particularly the case in situations with an unknown waiting time for a kidney from a deceased donor, where it might become necessary to start dialysis treatment. However, the sense of powerlessness as a rejected donor could be transformed into a new and significant recognition of being close to the child, giving care and support, both before and after transplantation.

The period before donation was also a time for considerations about the process and how life after the child’s transplant would transpire: “I want just to be happy that he can be transplanted, that’s not something I’m afraid of ... and I can just see my kidney there inside my son, who will hopefully be much better for it” (F1). The prospect of – and time waiting for – a transplantation was experienced as being ‘for better or worse’. However, it could be a joyful time with hopeful thoughts about an outcome that would enhance the child’s well-being and help the whole family to have a better everyday life and new opportunities.
Discussion

This study showed that parents experienced the decision about donation as a matter of course and a commitment, with a view to helping their child in a difficult illness situation. There were preferences for a kidney from a living donor, which would give certainty that the renal transplant functioning, would be better and last longer than a kidney from a deceased donor. Asking relatives and friends about their willingness to donate could be like crossing a line and associated with vulnerability. There were hopeful thoughts of being accepted as a parent donor and preferences that a donor could be found among the close family. Being rejected as a parent donor led to feelings of frustration and powerlessness. However, rejected parents transformed their feelings when they came to a recognition about their role as a parent providing care and comfort to the child during the transplant process. The parents reflected on the future with positive prospects for the transplant process, the improved health of their child and new opportunities for the entire family.

The findings of the study will be critical interpreted and discussed in relation to research results and system theory, as described by Bertalanffy (1968). According to our study, systemic thinking refers to such systems as that in our study: where the child and the family constitute one system, which is seen in reference to the society, which represents another system. All systems must be seen as open social systems based on movement and reciprocity. When discussing the findings of this study with the system theory it becomes evident that there is scope to develop specialised knowledge and understanding of how parents experience kidney donation to their child.

On the basis of the findings, the child with ESRD is central and represents a system together with the parents and siblings. In relation to systemic thinking, the study showed how the unique and emotional relation of the parents with their child rendered the decision about donation a matter of course, without any feelings of internal or external pressure. In view of Bertalanffy’s systemic thinking (Bertalanffy, 1968), the strong bonds between child and its parents mean that illness in one family member has an impact on the rest of the family. In our study, concern for the sick child included a commitment to donate, even though there could be reservations regarding surgery. Studies found that the parental feelings of love and concern represented the overriding motivation to donate and, similar to our findings, the donation of a kidney was simply a result of the nature of being a parent. Furthermore,
parents accepted that harm might come to them, and even the prospect of losing their own life, to achieve a positive progression in their child’s well-being (Burnell et al., 2015; Zeiler et al., 2010). Similarly, we found that parents reflected on ending up sick or disabled for the benefit of their child. From the perspective of systemic thinking, the parents/family adapted to the changes in the child’s health by donating a kidney in order to ‘preserve’ the system – i.e. the existence of the family.

All parents knew about the voluntary nature of donation. Taormina et al. (2017) found in a single center study barriers to live kidney donation in a pediatric population, reported in the recipients’ hospital journals: Caregiver barriers, health, financial, and religious/cultural concern. However, the findings may be limited regarding initial reflections and considerations among potential donors. Other studies show how donation to an adult included reflections in relation to one’s own life, family situation and the recipient (Agerskov et al., 2014, 2018; Burnell et al., 2015; Zeiler et al., 2010; Lennerling et al., 2003; Watermann et al., 2004; Sanner, 2005; Tong et al., 2012). Furthermore, considerations of dilemmas and reservations can occur during the decision-making process (Agerskov et al., 2014, 2018). In Denmark, the donors’ economic costs associated with evaluation, donation and recovery, including loss of income from employment, are fully reimbursed. However, lack of reimbursement of the donors’ expenses still presents a challenge in some countries (Lennerling et al. 2013, Dew et al. 2014). The findings in our study showed an unambiguous decision to donate to one’s child. This was in comparison to a hypothetical situation of donating to an adult friend – which, unlike in the case of one’s own child, involved reflections on the possibility of withdrawing from donation.

The period of donor evaluation was a time of hopeful thoughts regarding approval as a donor. Being accepted as a donor revealed feelings of relief and gave peace of mind. The parents knew that they now could prepare and be ready to help when the time came for transplantation. The findings are confirmed in several studies: Lennerling et al., 2003; Agerskov et al., 2015; Sanner, 2005; Marizaris et al., 2012. Being rejected as a donor involved feelings of frustration, powerlessness, vulnerability and insecurity. A previous study found similar reactions (Agerskov et al., 2015). Our findings reflect how a lot was at stake in being accepted or rejected for donation; however, the initial reactions could be transformed into recognition of one’s new role as a parent providing care and comfort to their child.
during the transplant process. We found that, a clinical reason should be given by the health professionals in cases where the parents could not donate. This was confirmed by Zeiler et al. (2010). Furthermore, Zeiler et al. revealed how parents felt a sense of shame on considering the possibility of not donating to their child. However, in the case in Zeiler’s study, both parents were accepted as donors (Zeiler et al., 2010). In Western culture, it can be considered morally controversial to discuss openly one’s doubts about donation to one’s child. Crouch and Elliot (1999) discuss how parents can be pressured into donating by other family members or by health care teams including perspectives such as the parents’ “internal coercion” or guilt (Crouch and Elliot, 1999). It is, therefore, a cause for ethical or moral concern that the strong bond between parent and child could define or limit the room for reflection about declining or withdrawing from donation. In our study, none of the parents described themselves as unwilling or in a dilemma regarding donation. Spital and Taylor (2007) discuss the ways people make choices. Choices are based in a context of close personal relationships, which characterize kidney donation, especially to a child. Before donation, informed consent must be obtained; however, informed consent is based on autonomy and deemphasizes personal relationships (Spital and Taylor, 2007). We found that parents would do anything to help their child and that potential risks were regarded as less important to them than the well-being and benefits to their sick child. It is important that potential parent donors listen to all the information given by health professionals about the possibility to withdraw from donation, and about risks and benefits of being a kidney donor. However, it should also be taken into consideration that, despite the health professionals’ best efforts, parent understanding regarding donation remains complex and incomplete from living kidney donor consideration to an adult (Sanner, 2005; Tong et al., 2012; Agerskov et al., 2014).

We found that living donor transplantation was the parents’ first choice when reflecting on organ source options. Thoughts of receiving a kidney from a deceased donor were connected to dramatic traffic accidents, and furthermore, included uncertainty about the quality of the renal transplant and an unknown duration of being wait-listed for transplantation. The unknown waiting time involved concerns about the progression of the kidney disease and the possible need to start dialysis treatment. Our findings are confirmed by Lennerling et al. (2003, 2004) and Burnell et al. (2015).
During recent decades, developments in immunology have led to new treatment options and, as a result, new and extended possibilities in donor-recipient match. In our study, the parents revealed how it could be barrier-breaking and connected with a sense of vulnerability to ask or initiate dialogue with relatives and friends about their willingness to be a donor. We found no publications that have addressed this topic from a parent perspective. Martin (2013) found that kidney recipients were willing to discuss donor possibilities with their family and friends. However, most were reluctant to go on to ask others directly to consider live donation (Martin, 2013). The findings of the current study reflect strong parental emotional feelings when faced with the suffering of a child with ESRD, and the maintenance of hope of health progression through living donor kidney transplantation in the near future.

According to systems theory, the healthcare system represents the society and argues for living donation as the best option for the child. However, it is also more economical for the healthcare system. The systemic way of thinking could emphasize, in one sense, parents took on a double role as donor and receiver, by being both a potential and willing donor and, figuratively, on behalf of the child, being a recipient – given that they ask the family’s circle about donation. We found how willingness to donate among those in the circle resulted in joy and, in contrast, how unwillingness led to frustrations, vulnerability and powerlessness. From the perspective of systems thinking, the findings focus on openness, interaction and reciprocity. The family is part of a larger system of social relations, and therefore can be seen as a system of interaction that is constantly moving. The family members interact with each other and the environment according to their perceptions of the situation. It is a part of the parents’ role to be responsible for their child’s well-being. This is, however, challenged when faced with an irreversible illness. In relation to the system theory, we found how the unique and close emotional relationship to the child resulted in vulnerability and hope of being able to find a donor to ensure the health of the child. The findings showed the impact on the parent when people in their circle responded with either willingness or aversion to donating. Such dilemmas and the risks to the health of people in the family’s circle resulted in a preference among parents to find the donor among close family members. Systems thinking recognize the importance of diverse and multiple
perspectives in understanding parents, and the study revealed how donation to a child had an impact on the well-being of the entire family.

**Strengths and limitations of the study**

The main strength of the study is the open, in-depth interviews of both fathers and mothers, as potential donors and caregivers, considering the donation perspective in the time before transplantation of their child – thus, not being affected by the outcome of the donation/transplantation. Other studies investigated the parent donor perspective (Forsberg et al., 2004; Burnell et al., 2015). However, data was obtained after (successful) transplantation/donation – a circumstance that might have influence on the retrospective perspective. It might be a limitation that only ethnic Danes and couples participated. Perspectives from parents with other ethnicities and solo mothers or solo fathers might have enriched the data material and provided results in a more nuanced way. Moreover, in Denmark, (parent) donors’ economic costs associated with evaluation, donation and recovery, including loss of income from employment, are fully reimbursed. Furthermore, depending on the severity of the child’s ESRD, parents can be fully or partly reimbursed from their place of work.

The study explored experiences regarding donation from a parent perspective. It is a strength that the results were discussed in relation to systemic thinking involving the entire family and explaining the finding in a broader context, however only parents participated. Interviewing children about donation including dilemmas might, however be ethical controversial.

**Conclusion**

The knowledge acquired in this study is unique, in that it reveals the parental perspective on donation before a kidney transplantation of their child not affected about the outcome of transplantation. This has not previously been elucidated and adds to the literature. The study clearly identifies that the decision to donate was experienced as a matter of course and an obligation. The strong emotional bond to the child and the family resulted in
vulnerability and hopeful thoughts during the donor evaluation process. Accepted donors felt a sense of relief. Being refused revealed feelings of frustration and powerlessness; however, there was transformation into a new caregiver role. Asking about willingness to donate within the family’s circle brought feelings like crossing a line and vulnerability, and there were preferences for finding the donor in-house. During the waiting time, there were reflections on positive future prospects; however, fear of onset of dialysis treatment was prominent in cases of being referred to the transplant waiting list.

Relevance to clinical practice

In clinical practice, health professionals’ attention, engagement and dialogue are essential in order to gain extensive and varied knowledge about the individual parent’s experiences and the well-being of the entire family. The study draws attention to the need for health professionals to be open and sensitive to parents´ descriptions of their unique experiences. Therefore, nursing care could be organized to optimally involve parents´ narratives and address possible concerns and/or emotional dilemmas in order to provide optimal care and support before, during and after the donation and transplantation process.

References


Scandiatransplant (2016); The Nordic Pediatric Renal Transplant Group.


Tong, A., Sainsbury P., Craig J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for


Table 1: Presentation of parents’ ages, numbers of children, residential setting and working time.

<table>
<thead>
<tr>
<th>Family number</th>
<th>Age/year</th>
<th>Number of children</th>
<th>Residential setting</th>
<th>Working time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mother</td>
<td>31</td>
<td>1</td>
<td>Suburb</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>33</td>
<td></td>
<td>Part time</td>
</tr>
<tr>
<td>2</td>
<td>Mother</td>
<td>48</td>
<td>2</td>
<td>Suburb</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>44</td>
<td></td>
<td>Full time</td>
</tr>
<tr>
<td>3</td>
<td>Mother</td>
<td>48</td>
<td>2</td>
<td>Rural</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>51</td>
<td></td>
<td>Leave*</td>
</tr>
<tr>
<td>4</td>
<td>Mother</td>
<td>43</td>
<td>2</td>
<td>Suburb</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>47</td>
<td></td>
<td>Full time</td>
</tr>
<tr>
<td>5</td>
<td>Mother</td>
<td>41</td>
<td>2</td>
<td>Suburb</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>45</td>
<td></td>
<td>Full time</td>
</tr>
<tr>
<td>6</td>
<td>Mother</td>
<td>37</td>
<td>3</td>
<td>Suburb</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>36</td>
<td></td>
<td>Full time</td>
</tr>
<tr>
<td>7</td>
<td>Mother</td>
<td>37</td>
<td>3</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>35</td>
<td></td>
<td>Full time</td>
</tr>
</tbody>
</table>

Figure 1: Illustration of structural analysis

<table>
<thead>
<tr>
<th>Units of Meaning</th>
<th>Units of Significance</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is said</td>
<td>What the text speaks about</td>
<td>Emergence of key themes</td>
</tr>
<tr>
<td>&quot;I was happy that I would be a donor, but then I was diagnosed with diabetes, and was completely shut out. I was so down in the dumps&quot;</td>
<td>Being rejected as a kidney donor and being faced with a diabetes diagnosis revealed feelings and reactions of disappointment, frustrations and powerlessness</td>
<td>Waiting time for better or worse</td>
</tr>
</tbody>
</table>

This article is protected by copyright. All rights reserved.