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Challenges in decision-making support processes regarding living kidney donation: A qualitative study

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Abstract

Background: Previous studies on decision-making of living kidney donors have indicated issues regarding donors' autonomy is inherent in decision-making to donate their kidney. Establishing effective decision-making support that guarantees autonomy of living kidney donor candidates is important.

Objectives: The aim of this study was to identify the difficulties in the decision-making support when clinical transplant coordinators advocating for the autonomy of donor candidates of living donor kidney transplantation and to identify the methods to deal with these difficulties.

Design: A qualitative descriptive study.

Participants: Ten clinical transplant coordinators supporting living kidney donors.

Approach: Semi-structured interviews were conducted using an interview guide. The modified grounded theory approach was utilised to analyse.

Results: Three categories related to difficulties were as follows: issues inherent to the interaction between coordinators, donor candidates and their families; issues regarding the environment and institutional background in which coordinators operate; and emotional labour undertaken by coordinators in the decision-making support process. Additionally, five categories related to methods were as follows: assessing the autonomy of donor candidates based on the coordinators nursing experience; interventions for the donor candidates and their family members based on the coordinators nursing experience; smooth coordination with medical staff; clarifying and asserting their views as coordinators; and readiness to protect the donor candidates.

Conclusion: The involvement of highly experienced coordinators with excellent and assertive communication skills as well as the ability to reflect on their own practices is essential. Moreover, we may need to fundamentally review the transplant community, where power domination is inherent.

KEYWORDS

chronic kidney disease, nursing, quality improvement, transplantation

INTRODUCTION

This paper investigates what difficulties clinical transplant coordinators (CTCs) face and how they deal with these difficulties in their decision-making support process for living kidney donor candidates (hereinafter referred to as donor candidates). We believe that the results of this study will help to improve the environment surrounding the decision-making support process to advocate the autonomy of donor candidates.

LITERATURE REVIEW

Living donor kidney transplantation (LDKT) has demonstrated superior graft survival rates than deceased-donor kidney transplantation (Yagisawa et al., 2019). The safety of living donor has been ensured through the development of global consensus based on systematic reviews of relevant studies that stipulate living organ donation is contraindicated in living donor with a reduced ability to make rational decisions made with sufficient information and in persons with severe organ disease, mental illness or drug abuse (Krista et al., 2017). In contrast, methods and approaches used to support living donors in decision-making differ due to the cultural differences between countries (Abacan, 2021; Holly, 2017; Rodrigue et al., 2007; Vittone & Crowell, 2021).

Previous studies on decision-making indicated that donor candidates are not provided with sufficient information and that the intervention by healthcare professionals is insufficient (Agerskov et al., 2018; Ruck et al., 2018; Sandal et al., 2019). Furthermore, other studies reported concerns about insufficient autonomy of donor candidates when the recipient and donor candidates are members of the same family (Filler et al., 2021; Halverson et al., 2018; Lee, 2018; Schick-Makaroff et al., 2021).

In Japan, the background of LDKT has two distinct characteristics when compared with that in other countries. The first is related to the percentage of kidney transplantation from living donors compared with that of transplantation from brain-dead organ donors (Johansen et al., 2022). The ratio of LDKT to the numbers of all kidney transplantation performed in Europe 2022 was 18%. On the contrary, in Japan, LDKT account for 88% of all kidney transplantation (European Directorate for the Quality of Medicines & HealthCare, 2023). The second is related to the selection criteria for donor candidates. The Japan Society for Transplantation (2018) which has created the principle of living donor organ transplantation expects that organ donation from a nonfamily donor may involve a possibility of receiving any valuable consideration (money or property) in exchange for the donation. Therefore, the basic rule in Japan is that organ donations can only be made by family members such as patient's parents, children, grandparents, great-grandparents, uncles, aunts, siblings, spouse and spouse's parents, grandparents, and siblings (The University of Tokyo Hospital, 2023). Owing to these circumstances, the family members of patients who require LDKT are naturally forced to decide whether to donate a kidney (Shuda, 2011). Therefore, the Japan Society for Transplantation (2018) introduced a certification system for CTCs to encourage safe and fair implementation of their services. The minimum requirement for certification of CTCs in Japan is at least 5 years of experiences as a general nurse. Among the four principles of medical ethics, regarding living organ transplantation, the autonomy of a donor candidate who injures a healthy body and donates organs should be respected as a top priority (Krista et al., 2017). Then, the question arose as follows: "In the Japanese LDKT community, is the autonomy of donor candidates, who are also members of the family, ensured in safe and fair implementation?" Thus, the aim of this study was to identify the difficulties in the decision-making support process when CTCs advocating for the autonomy of donor candidates and to explore the methods to deal with these difficulties.

METHODS

Study design

A qualitative descriptive method based on semi-structured interviews was undertaken.

Settings

CTCs involved in donor candidates' decision-making working at seven university-affiliated hospitals and two public hospitals in major cities throughout Japan were included. The role of Japanese CTCs are following: (1) assessing psychological and social issues faced by recipients, donor candidates, and their families and providing support during organ donation decision-making; (2) coordinating various issues in the treatment process and promoting communication within a medical team; (3) providing continuous education and support to recipients and their families before, during, and after the procedure; (4) conducting long-term medical follow-up of recipients and donors (Hagiwara, 2008). Regarding the standard process used to select donor candidates in Japan, nephrologists diagnose the need of LDKT first and explain to recipients' families that it is necessary to select donor candidates. Then, recipients' families discuss and select donor candidates from among themselves. Subsequently, they visit a transplant centre where they meet transplant surgeons and CTCs. Finally, assessment whether the donor candidates meet physical, psychological, and social criteria are conducted.

Sampling and recruitment

Potential participants were selected from 103 CTCs with ≥5 years of experience in LDKT as a CTC. Of these CTCs, 17 CTCs were randomly selected. The researcher mailed descriptions of the study to the transplant facilities to which the 17 CTCs were affiliated, asking for their approval. The researcher conducted a briefing session along

with written documents explaining the objective of and the methods used in this study to the 12 CTCs and their facility heads who provided the consent to participate. In total, the researcher received written consent forms from 10 CTCs confirming their willingness.

Data collection

The following interview questions were formulated based on literature reviews. "In your work supporting the autonomous decision-making by donor candidates, in what situations did you experience difficulties and why?" and "How do you deal with these difficulties?"

Semi-structured interviews were conducted with the 10 CTCs using an interview guide between May and August 2019. The interviews were conducted face-to-face, one-on-one between the researcher and the CTC. The interviews for the 10 CTCs were also conducted by same researcher to ensure consistency. Open-ended questions allowed for more prompts. The interviews were recorded with CTC's consent and later transcribed verbatim.

Ethical considerations

This study was approved by the Clinical Research Institutional Review Board of the author's university (approval no. 18072). Written consent was obtained from CTCs. In addition, we explained that participation in the study was voluntary, and that participants had a right to withdraw at any time without any prejudice. The data regarding CTCs were coded and anonymised according to the order in which the interviews were conducted. The data was stored on a password-protected USB storage device, which was placed in a locked cabinet.

Data analysis

Data analysis was performed using the modified grounded theory approach (M-GTA) derived from the qualitative research method known as the original grounded theory approach. Whereas GTA emphasises intercepting data to eliminate arbitrariness of the analyst and then generating theory, M-GTA emphasises understanding the context of data based on analyst's awareness of issues (Kinoshita, 2003, 2009, 2020). Therefore, M-GTA is suitable for use when study participants deal with interactive and process-oriented phenomena. In this study, the analytic themes were "What are the difficulties faced by the CTCs in the decision-making support process for LDKT donor candidates" and "How do CTCs deal with these difficulties to advocate for the autonomy of donor candidates?".

The analytical procedure was carried out as follows. First, we used analysis worksheets which were divided into four parts (concept name, concept definition, specific examples, and theoretical memos) based on the M-GTA analysis method (Kinoshita, 2009, 2020). We used one analysis worksheet to generate one concept. Second, we selected all parts from the transcripts of the interview related to the analytic themes and recorded them in the specific example column. Third, we used comparative analysis to examine other similar/contrary specific examples. Fourth, the meanings of the specific examples were reread to deepen their understanding and the concept definitions were described. Fifth, the concept definitions were repeatedly reviewed and concept names were created as a short statement. Sixth, analogous and contradictory data were stored in the theoretical memos. Seventh, the theoretical memos and specific examples were reviewed, and the concept names and concept definitions were corrected accordingly. Eighth, the multiple extracted concept names were carefully examined and a diagram was created demonstrating the relationships between the concepts. Ninth, the concepts demonstrating a strong relationship with each other on the diagram were divided into subcategories. Tenth, the subcategories were compared and classified and categories were created based on the level of abstraction. Eleventh, the researchers repeatedly examined each other's data collection and analysis. When no new data could be obtained, it was determined that data saturation had been achieved. Twelfth, the interrelationships between the categories were analysed and a schematised diagram was created. Finally, a storyline was created based on the schematised diagram that was created based on the results obtained from the abovementioned analysis process.

Rigor and transparency

To ensure consistency in the data analysis, the first author and second author analysed the interview data using the same analysis worksheets, which were created based on the M-GTA analysis method (Kinoshita, 2020). The mentor who was well-versed in qualitative studies constantly supervised the researchers during the analysis of the specific examples and the creation of concepts and definitions. In addition, the analysis results were verified under the supervision of the CTC and the nurse specialising in transplantation. The Consolidated Criteria for Reporting Qualitative Research (COREQ) has been used (Tong et al., 2007).

RESULTS

Overview of the participants

The 10 CTCs were women aged 30–59 years. Of the participants, eight were full-time CTCs, and two were nurses who also served as CTCs. The participants had 23.5 ± 7.1 and 11.8 ± 5.9 years of clinical experience as nurses and CTCs, respectively. The duration of the interviews with each participant was 89 ± 17 min.

Generated categories and subcategories

Overall, 60 concepts were extracted from 872 specific examples; 18 subcategories were generated from these concepts, and eight

categories were generated from these subcategories. Finally, these 8 categories were divided into three categories related to the difficulties faced by CTCs and five categories related to the methods used by them to deal with the difficulties.

Storyline

This storyline describes the schematised diagram (Figure 1) that was created to organise the three categories related to the difficulties faced by the CTCs and the five categories related to the methods used by them to deal with these difficulties into a coherent structure summarising the CTCs' decision-making support process to advocate for the autonomy of donor candidates. During the decision-making support process, CTCs faced '*Issues regarding the interaction between CTCs, donor candidates, and their families*'. To deal with these issues, the CTCs were carefully '***Assessing the autonomy of donor candidates based on the CTCs nursing experience***', and they repeatedly engaged in '*Interventions for the donor candidates and their family members based on the CTCs nursing experience*'. However, during the interventions for the donor candidates and their family members, from the perspective of the need for LDKT and bioethics, CTCs experienced '*Emotional labour undertaken by CTCs in the decision-making support process*'. To deal with this emotional labour, the CTCs controlled their own emotions and reconfirmed their '*Readiness to protect the donor candidates*'. Furthermore, CTCs were committed to '*Smooth coordination with the medical staff*' for the CTCs' practical interventions conducted to deal with the issues inherent in the interaction between CTCs, donor candidates, and their families. Despite the CTCs' efforts to maintain smooth coordination, they struggled with '*Issues regarding the environment and institutional background in which CTCs operate*'. Regarding these disadvantaged environmental and institutional issues, the CTCs have been actively '*Clarifying and asserting their views as CTCs*' to establish their position in the circumstances and provide better decision-making support (Figure 1).

The difficulties faced by CTCs in the decision-making support process are shown in Table 1.

Issues regarding the interaction between CTCs, donor candidates and their families

[Complex familial relations surrounding the donor candidate]

The issues faced by CTCs in assessing the relationship between donor candidate, recipient, and their family include:

> *There was a proposal from an elderly man who wanted to donate an organ to a young woman. They were a couple whose age difference was similar to that of a parent and child, who said they were married under the common law. However, I could not confirm that they lived together. The elderly man's relatives said they were unaware of his plan to donate an organ. I felt that there*

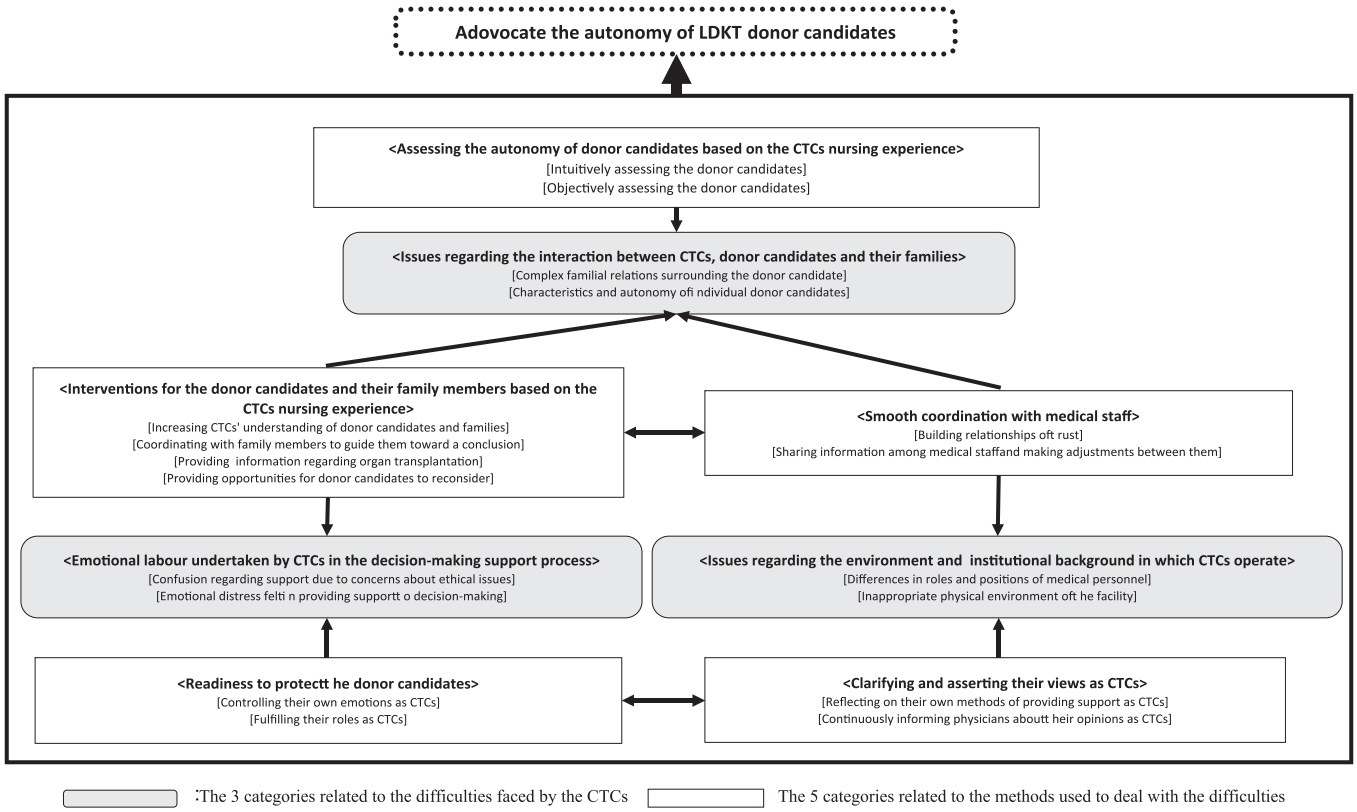

FIGURE 1 Difficulties and methods in clinical transplant coordinators (CTCs) decision-making support process for living donor kidney transplantation (LDKT) donor candidates.

TABLE 1 The difficulties faced by CTCs in the decision-making support process.

Category	Subcategories and concepts
<Issues regarding the interaction between CTCs, donor candidates and their families>	[Complex familial relations surrounding the donor candidate] • Difficulty in coordinating between siblings living in different households and their family members • Difficulty in supporting a family with dilemmas regarding kidney donation • Difficulty in mediating between common-low couples and their kinship • Difficulty in addressing the enthusiasm gap between the donor candidate and recipient • Difficulty in supporting a family in which the donor candidate appears to be pressured • Difficulty in intervening in a family with many donor candidates [Characteristics and autonomy of individual donor candidates] • Difficulty in assessing donor candidates' comprehension impacting on autonomy • Difficulty in promoting an understanding of the kidney donation's risks to donor candidates underestimating such risks • Difficulty in building a mutual understanding with foreign donor candidates
<Issues regarding the environment and institutional background in which CTCs operate>	[Differences in roles and positions of medical personnel] • Difficulty in collaborating with transplant surgeon disregarding CTCs' opinion • Difficulty in collaborating with psychiatrists lacking knowledge of transplantation • Difficulty in collaborating with nurses lacking interest in transplantation • Difficulty related to the uncertainty of CTCs' position and role • Difficulty with the dual role of CTC and nurse [Inappropriate physical environment of the facility] • Difficulty in functioning in the clinical environment with time and location restrictions • Difficulty in the practical education of junior CTCs to ensure the quality of support • Difficulty in finding support methods in the environment with confidentiality obligations
<Emotional labour undertaken by CTCs in the decision-making support process>	[Confusion regarding support due to concerns about ethical issues] • Difficulty of intervening while maintaining a neutral position as a CTC • Difficulty of intervening while having the dilemma regarding the legality of living organ transplantation • Difficulty of intervening while being confronted with a dilemma between donor advocacy and ethical issues • Difficulty in evaluating the suitability of a donor candidate based on an individual CTCs' ethics [Emotional distress felt in providing support to decision-making] • CTCs' emotional distress when offering support while feeling uncertainty or limitation in support methods • CTCs' emotional distress when listening to the complicated feelings of donor candidates • CTCs' emotional distress in building relationships with dysfunctional families in complex circumstances

was some kind of self-sacrifice or interest involved, and that the donation was not just a gift. (CTC9)

The older brother wished to donate a kidney to his younger brother. However, the older brother's (donor candidate's) wife was absolutely against it because she was worried about the health damage caused by a kidney donation. The older brother was unable to communicate this situation to his younger brother, and the discussion of kidney donation did not proceed. (CTC1)

[Characteristics and autonomy of individual donor candidates]

One CTC stated that difficulties in assessing the donor candidate's comprehension and the impact on the donor's autonomy in the donation.

An older brother wanted to donate a kidney to his younger sister, and their mother took them both to the hospital. I felt somewhat uncomfortable with this. When I spoke to the brother, I felt that he did not understand what a kidney donation meant at all. However, the mother expressed a strong desire for him to donate the kidney and said he understood and had no problem. (CTC10)

Issues regarding the environment and institutional background in which CTCs operate*

[Differences in roles and positions of medical personnel]

One CTC related her experience where the transplant surgeon did not consider her opinion regarding the evaluation of the donor candidate's suitability.

One cannot simply say, just do a transplantation. I think that the transplantation should not be done if there are major postoperative risks (psychosocial risks) for the donor. However, even if I express this concern to the transplant surgeon, he just says there are no physical problems with the transplantation, and the surgery proceeds as planned. (CTC6)

[Inappropriate physical environment of the facility]

CTCs experienced insufficient circumstances in their work environment.

Honestly, there is not enough time to devote solely to supporting donor candidate decisions. (CTC6)

It is difficult to teach younger CTCs the support methods that I have systematised to educate them to perform the same tasks, and there is not enough time to do so anyway. (CTC3)

Emotional labour undertaken by CTCs in the decision-making support process

[Confusion regarding support due to concerns about ethical issues]

One CTC stated that she faced with various ethical issues while providing decision-making support to donor candidates and felt perplexed by the decision-making support process.

I am always hesitant to support high (medical) risk donor candidates' decision to donate their organs because my true feelings are that such donor candidates should not donate organs. (CTC3)

[Emotional distress felt in providing support to decision-making]

CTCs talked about feeling various kinds of emotional distress while providing decision-making support to donor candidates.

I was almost losing myself in the psychological negativity of families struggling in complex circumstances surrounding organ donation. Patients and family members sometimes appear in my dreams while sleeping. (CTC10)

When I ask donor candidates about their complicated feelings on organ donation, it is difficult to control my emotions as a CTC to avoid losing my composure and getting deeply emotionally involved. (CTC7)

The methods used to deal with the difficulties faced by CTCs in the decision-making support process are shown in Table 2.

Assessing the autonomy of donor candidates based on the CTCs nursing experience

[Intuitively assessing the donor candidates]

On first meeting the donor candidate, the recipient, and their family members, the CTCs considered their own intuitive impression of the donor candidate and assessed the candidate's suitability after repeated interactions.

In cases in which donor candidate does not say much and the family member takes control of the conversation during a meeting with the CTC, I felt that the family member has forced the donor candidate into the meeting for kidney donation. (CTC9)

[Objectively assessing the donor candidates]

CTCs provided explanations of both, the merits and demerits of organ transplantation and further evaluated the donor candidate's preparedness to donate a kidney based on this more relevant information.

I explain that after the transplantation, even if the recipient takes care of the graft, there are some cases wherein graft failure occurs after 2–3 years. I assess their willingness to undergo transplantation through asking whether the donor candidate and the patient would regret in a case where the graft does not last for long. (CTC3)

Interventions for the donor candidates and their family members based on the CTCs nursing experience

[Increasing CTCs' understanding of donor candidates and families]

CTCs gained a deeper understanding of the recipient's lack of freedom, suffering, and feelings toward transplantation by imagining the recipient's (patient with kidney failure) and their family members' daily life and thoughts regarding their emotional pain and transplantation.

For a long time, approximately 10 years, a patient with kidney failure used oral medication and diet management. The patient was forced to live a life of limitations. I

TABLE 2 The methods used to deal with the difficulties faced by CTCs in the decision-making support process.

Category	Subcategories and concepts
<Assessing the autonomy of donor candidates based on the CTCs nursing experience>	[Intuitively assessing the donor candidates] • Assess the autonomy of donor candidates based on CTCs' intuitions • Evaluate based on the assessment criteria for donor candidates derived from CTCs' experiences • Confirm the intentions of donor candidates directly and assess their reactions • Select the appropriate conversation content for donor candidates based on CTCs' experiences • Assess the autonomy of donor candidates based on the donor candidates' attitude [Objectively assessing the donor candidates] • Assess the suitability of donor candidates using information-gathering tools • Assess donor candidates' readiness regarding kidney donation
<Interventions for the donor candidates and their family members based on the CTCs nursing experience>	[Increasing CTCs' understanding of donor candidates and families] • Imagine the inconveniences of daily life for patients with renal failure and their families • Continue to approach donor candidates experiencing uncomfortable reactions • Identify problems regarding kidney donation based on interactions with donor candidates • Understand the suffering of patients and their families from multiple perspectives [Coordinating with family members to guide them toward a conclusion] • Provide the opportunities for family discussions • Deepen CTCs' understanding for family relationships • Summarise the family's intentions for kidney donation • Support the individual donor candidate based on the their family's intentions for kidney donation [Providing information regarding organ transplantation] • Promote the donor candidates' understanding of the risks regarding organ transplantation • Explain the possibility of change in regard to donor candidates' intention for kidney donation • Promote the recipients' understanding of the importance of kidney donation from donor candidates [Providing opportunities for donor candidates to reconsider] • Solicit the donor candidates' specific thoughts about kidney donation • Identify the family relationships impact on donor candidates regarding kidney donation • Advocate the autonomy of donor candidates and identify ethical issues • Provide the opportunities donor candidates to reconsider their intentions for kidney donation
<Smooth coordination with medical staff>	[Building relationships of trust] • Establish a trusting relationship and enhance collaboration with transplant surgeon • Establish a trusting relationship and enhance collaboration with psychiatrist • Establish a trusting relationship and enhance collaboration with medical staff [Sharing information among medical staff and making adjustments between them] • Provide and share the information on donor candidates and their families • Coordinate discussion opportunities with the medical staff
<Clarifying and asserting their views as CTCs>	[Reflecting on their own methods of providing support as CTCs] • Understand the medical staff's views on the autonomy of donor candidates • Review CTCs' views on the autonomy of donor candidates and their support methods [Continuously informing physicians about their opinions as CTCs]

(Continues)

TABLE 2 (Continued)

Category	Subcategories and concepts
	• Clarify CTCs' views on the autonomy of donor candidates
	• Assertively communicate CTCs' views on the autonomy of donor candidates with the physicians
<Readiness to protect the donor candidates>	[Controlling their own emotions as CTCs]
	• Explore the compromises on assessment regarding autonomy of donor candidates
	• Assign meaning to CTC's own role
	[Fulfilling their role as CTCs]
	• Reaffirm its role as an advocator for donor candidates
	• Respect the donor candidates' intention to donate their kidney
	• Provide the support that puts the donor candidates' decision first

think I need to understand the background of this kind of mental anguish. (CTC2)

[Coordinating with family members to guide them toward a conclusion]

After gaining a deeper understanding of family members, including the donor candidate, the CTCs provided an opportunity for family members to have discussions.

I provide opportunities for family members involved in the process to select an individual to accompany the donor candidate to the hospital. This enables me to guide them in such a way that they are encouraged to exchange views. There are cases in which family members shared their thoughts about organ donation in an honest manner. (CTC6)

[Providing information regarding organ transplantation]

As the CTCs formed relationships with the donor candidates, they provided the donor candidates with information about risks in accordance with each donor candidate's level of understanding and ability to understand.

I explain that when a person is subjected to a great deal of physical stress as a result of surgery, the person may not be able to return to the lifestyle that they had before surgery. I then say that you can proceed with the operation if you want to donate a kidney despite the risk. (CTC7)

[Providing opportunities for donor candidates to reconsider]

CTCs discovered ways to offer support tailored to individual candidates, and encouraged donor candidates to reconsider kidney donation when necessary.

Immediately after the donor candidate's approval, the donor candidate eligibility test begins, but there are cases in which I tell them that they do not have to undergo the test on the same day and they can take some time to think about it. (CTC6)

Smooth coordination with medical staff

[Building relationships of trust]

To maintain smooth collaboration and advocate for the autonomy for donor candidates, CTCs tried to understand the different roles and perceptions of transplant surgeons and other medical staff and to establish trusting relationships with them.

I have faith in doctors and strive to actively consult with them to grasp their point of view. I recognise that doctors and nurses have distinct perspectives on patients. (CTC2)

[Sharing information among medical staff and making adjustments between them]

The CTCs planned conferences to share information obtained from the donor candidates and family members with other members of the medical staff and reviewed donor candidates' decision-making.

When I suspect that an ethical issue may exist, I hold a conference with surgeons and psychiatrists to discuss the relevant information. (CTC3)

Clarifying and asserting their views as CTCs

[Reflecting on their own methods of providing support as CTCs]

While they exchanged opinions with transplant surgeons, psychiatrists, clinical psychologists, and nurses, CTCs identified whether the CTCs' own assessments of the donor candidates contained any bias.

The perspective from which the transplant surgeon and psychiatrist view the patient differs from that of the CTC as a nurse. This was a learning experience for me. I make objective assessments when I consider perspectives other than my own. (CTC10)

[Continuously informing physicians about their opinions as CTCs]

CTCs clarified their own opinions on the assessment of donor candidate autonomy, and assertively conveyed their honest opinions to transplant surgeons who had different views from CTCs.

> *I tell transplant surgeons what is really on my mind over and over again, even if it has a negative impact on our relationship. (CTC4)*

Readiness to protect the donor candidates

[Controlling their own emotions as CTCs]

While considering ethical issues and the thoughts and ideas of donor candidates and family members, CTCs continually questioned what an autonomous decision by those individuals would be and simultaneously looked for points in their evaluation of decisions that could be compromised.

> *There are occasions when the donor candidate's autonomy does not make sense to me. So, before proceeding to the next phase, I try to force myself to reconcile my thoughts and prioritise my feelings towards the donor candidate. (CTC5)*

[Fulfilling their role as CTCs]

Even if the CTC had only minor doubts about a donor candidate's decision, they respected the donor candidate's process and thoughts about whether he/she should donate a kidney, and the CTC provided support that prioritised this decision.

> *Ultimately, I respect the various thoughts of the donor candidate and family members. I continue to engage with the donor candidates until they arrive at a decision that satisfies them. (CTC2)*

DISCUSSION

This study aimed to identify the difficulties in the decision-making support process when CTCs advocating for the autonomy of donor candidates and to explore the methods to deal with these difficulties.

Issues regarding the interaction between CTCs, donor candidates and their families

CTCs in this study felt the difficulties to discern how the autonomy of donor candidate has been affected by the complex intra-family relationships. A previous study of post-donation donors showed that they were concerned about deterioration of family relationships due to refusal of donation and that they felt pressure from family members (Ismail et al., 2014). Therefore, to exclude family pressure or coercion on the donor candidate, CTCs need to actively and continuously intervene with the complex relationships in the family. Moreover, prior research revealed that including thorough consideration of individual input from family members is important for decision-making process. (Goldschmidt et al., 2015; Irving et al., 2014). In contrast, prior studies described that family members' various opinions, such as a strong desire for organ donation, can have a strong coercion on a donor candidate's decision-making process (Ismail et al., 2014; Shaw, 2015). Therefore, CTCs should recognise the blurry line between family influence and coercion. Additionally, carefully considering various factors inherent in a donor candidate's perception of family influence and autonomy is important (Nizam et al., 2022).

Furthermore, although there are the ethical guidelines to support decision-making (The Japan Society for Transplantation, 2018), CTCs in this study were practically characterised by the overwhelming use of their own intuitive judgements based on their various experiences as nursing professionals in assessing the autonomy of donor candidates. Nizam et al. (2022) described the difficulty in determining a donor candidate's autonomy, which should consider the balance between the depth and strength of feeling for organ donation as well as the level of understanding in regard to the risks of organ donation. Fry and Johnstone (2008) indicated that there is no recipe for ethical judgement in nursing practice, and that nurses act according to cognitive abilities, moral intuitions, personal values and life experiences. To improve accuracy and objectivity of the evaluation for autonomy, it may be necessary to establish and disseminate an evaluation criteria for autonomy based on the multifaceted elements of intuitive judgements used by individual CTCs in their practice.

Issues regarding the environment and institutional background in which CTCs operate

In Japan, the evaluation of donor candidates primarily involves transplant surgeons, CTCs and nurses (Nishimura et al., 2021). First, for recipient and donor candidate who visit a transplant centre, the transplant surgeon performs the following: (1) Explanation of the advantages and disadvantages of LDKT; (2) Initial confirmation of the donor candidate's willingness to donate; (3) Initial evaluation and acceptance of the donor candidate; (4) Explanation to the donor candidate that an adequate cooling-off period is provided. Next, the recipient and donor candidate schedule a consultation date with CTC. During the initial face-to-face consultation with the donor candidate, CTC confirms the donor candidate's willingness for donation and assesses the reasons for donation. CTC also asks the relationship with the recipient. Moreover, during the initial face-to-face consultation with the recipient, CTC confirms the recipient's knowledge of LDKT, post-transplant diet and lifestyle management, as well as the relationship with the donor candidate. CTC provides transplant education to recipient and donor candidate. CTC supports the decision-making until the operation of kidney transplantation is performed. The reason for CTCs supporting both recipient and donor candidate as a dual role is due to a basic rule in Japan. The basic rule assures organ donations can only be made by family members. Since

LDKT is a medical treatment that requires support of family members, we believe that comprehensive assistance including family members is necessary (Hagiwara, 2008).

Furthermore, it is recommended that psychiatrists and clinical psychologists intervene to protect donor candidates' autonomy and prevent ethical issues (Nishimura et al., 2021). However, this study clarified that simply adding evaluators to the transplant community would not prevent ethical issues. Transplant surgeons evaluate primarily based on the patient's treatment-first perspective, while psychiatrists simply diagnose presence or absence of psychiatric disorders in donor candidates. Therefore, by whom a responsibility for decision-making donor candidates besides to is ambiguous. This ambiguity may hinder prevention of ethical issues. Moreover, this study found that some inhibiting factors including transplant surgeons who have ultimate authority on making final decision as a leader in transplant community. An unequal power balance exists between the transplant surgeons and CTCs. Stevens et al. (2021) stated that although leadership is necessary in multidisciplinary team medicine, an unequal power balance could lead to various errors. In the absence of common axis of evaluation for donor candidates' decision-making, various problems may arise. Therefore, it is important that providing the time to learn the option of LDKT and reconsider will strengthen the donors' own autonomy and also it will be effective to establish an objective indicator of donor understanding and make it common understanding. (Grossi et al., 2023).

Emotional labour undertaken by CTCs in the decision-making support process

In this study, CTCs were hesitant to provide decision-making support because they were sceptical of coercion and pressure from family members on donor candidates. CTCs also expressed a negative view of their own self-worth and ethics in the transplant community. There are two possible causes for the issues related to emotional aspects of the CTCs. One is that the ethical structure in transplant medicine differs from that of conventional medicine. Previous studies stated that in advanced medical care, such as organ transplant medicine, ethical issues related to the decision-making of donor candidates have the topmost priority to be resolved (Arie, 2008; Goldschmidt et al., 2015). Healthcare professionals have developed ethical values based on the four principles of medical ethics; respect for autonomy, non-maleficence, beneficence, and justice (Varkey, 2020). However, in living organ transplant community there is a contradiction in the concepts of beneficence and non-maleficence, where donor candidate donates the organ to save recipient's life, the ethical conflicts and hesitation experienced by CTCs are inevitable. Therefore, it is essential to develop educational programmes that allow medical professionals in the transplant community to continually update their values and ethics regarding advanced medical care and human life (Australian Government Organ and Tissue Authority, 2022; Fortin & Bourget, 2020; Mucsi et al., 2018; Rudow, 2009; Tarabeih & Bokek-Cohen, 2020). Second, intrinsic issues inherent in the role of CTCs may be the cause. CTCs faced various conflicts because they were very close and sympathetic to donor candidate, recipient, and their families to maintain a neutral position. Bokek-Cohen and Tarabeih (2021) pointed the difficulty of dual role of CTCs as an advocator for donor candidates and as a supporter of recipients and their families. On the other hand, Hagiwara (2008) described the dual role of CTCs as useful in the long-term support, from the donor decision to the post-transplant period. Hence, CTCs may need to improve the ability to constantly have objective view of their own role and support so that they can maximise the advantages of their neutral position in providing comprehensive support to donor candidates and their families, including recipient.

STRENGTH AND LIMITATIONS

First, by randomly selecting CTCs included in this study, we were able to eliminate the selection bias and obtain a wider spectrum of characteristics regarding the difficulties faced by CTCs and their coping methods. Thus, a comprehensive view of decision-making support provided by CTCs was obtained. However, there were some differences in the characteristics of the working environments and facilities and regional differences among CTCs that may have been reflected in the differences in the factors affecting the difficulties and the methods used to deal with them. Second, this study focused on CTCs with 5 or more years of experiences. Because difficulties and their coping strategies are subject to introspective judgements influenced by an individual's daily experiences and personality, the generalisability of our findings is limited CTCs who are experienced in decision-making support. As a strength of this study, to avoid heterogeneity of the subjects in terms of experience, as many difficulties caused by inexperience as possible is excluded.

IMPLICATION FOR CLINICAL PRACTICE

Our recommendation is that the transplant community where power domination is inherent should be resolved and CTCs need to constantly update their knowledge and skills based on the latest research results.

CONCLUSIONS

This study identified three difficulties faced by CTCs and five methods to deal with these difficulties in providing decision-making support to donor candidates. We found that donor candidates and their families face various complex issues and that the involvement of CTCs with excellent communication skills in the decision-making process is essential, and their ability for self-reflection and to contemplate their own practice is critical to this process.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]: Yuri Wada: Principal Project Leader, conceived study, participated in design and coordination, analysed the data, undertook interviews, read and approved the final manuscript. Takayoshi Ueno: Analysed the data, helped to draft manuscript and approved the final manuscript. Koji Umeshita: Conceived study, analysed the data and helped to draft manuscript. Kuniko Hagiwara: Undertook interviews, analysed the data and helped to draft manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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