

科技部補助專題研究計畫成果報告 期末報告

親屬間活體器官捐贈決策的性別權力與家庭政治

計畫類別：個別型計畫
計畫編號：MOST 107-2629-H-182-002-
執行期間：107年08月01日至109年01月31日
執行單位：長庚大學醫學系

計畫主持人：林雅萍
共同主持人：黃智婉、朱俊霖、江仰仁、李威震、王敘涵
計畫參與人員：碩士級-專任助理：陳容

本研究具有政策應用參考價值：否 是，建議提供機關
(勾選「是」者，請列舉建議可提供施政參考之業務主管機關)
本研究具影響公共利益之重大發現：否 是

中華民國 109 年 04 月 27 日

中文摘要：台灣目前的性別與醫療或是女性健康照護研究已有相當豐碩的成果，但對於器官捐贈移植所涉及的性別議題仍缺乏深度討論。親屬間活體器官捐贈移植所涉及的倫理議題相當複雜，其決策過程交織著醫療、生命、文化、身體概念、性別與家庭角色的期待，以及家庭互動關係等因素，非常值得深入探究。

活體器官捐贈移植手術，不同於一般的醫療行為，其目的並非促進捐贈者的健康，而是對其施以侵入性手術，摘取(部分)器官延續受贈者生命或改善生活品質，捐贈者可能因此面臨手術過程及術後發生併發症，導致傷害、失能或甚至死亡的風險，因此醫學倫理上對於活體器官捐贈決定的自主性有格外審慎的考量。親屬間活體器官捐贈移植所涉及的倫理議題則更加複雜，因為捐贈者與受贈者之間通常存在緊密連結，雙方的動機與決策協商過程往往交織著社會文化價值，家庭組成、互動模式、勞務分工、性別角色的規範與期待，以及對於生命與身體的看法等錯綜複雜的因素。許多研究已經指出器官捐贈是一個性別化的經驗與決定，而且親屬間之活體器官捐贈移植決策深受家庭關係與社會性別意識形態的影響，某些情況甚至牽涉到原生家庭與姻親家庭的利害衝突。本研究採取文獻分析、參與觀察與深度訪談，自2019年2月至今，邀請林口長庚醫院參與親屬間活體肝臟捐贈移植決策之重要關係人，包含受贈者、捐贈者、潛在捐贈者、主要照顧者等，共14個家庭，38位受訪者，進行半結構式深度訪談，希望更細緻與脈絡化地深入探究親屬間活體器官捐贈移植的決策過程與經驗，挖掘其中深埋的複雜關係與權力過程，理解與闡明相關各造在整個器捐決策過程中的互動、情感與意義建構，以及鑲嵌於性別與家庭關係中的自主性，更有意識地看見性別階序、家庭勞務分工與性別角色等因素相互牽連而成的面向。最後，本計畫希望能將理論研究成果回饋應用於臨床政策的實踐，提出具有參考價值的具體案例，幫助移植醫療團隊更敏感於性別文化與權力配置對於易受傷害與弱勢群體所造成的壓迫，發展更為完善的器捐移植評估指引與照護建議。本報告將針對研究計劃期間的研究工作與相關論文發表提出簡要說明。

中文關鍵詞：器官捐贈，器官移植，活體器官捐贈，醫療決策，醫療倫理，自主，性別，家庭

英文摘要：While women/ gender, medicine and healthcare studies in Taiwan have had fruitful research achievements, gender issues in organ donation and transplantation have not been well explored. This project investigates the decision-making process of the living-related organ donation within the socio-cultural context of Taiwan, focusing on gender hierarchy, division of labor and gender roles in families, and power in families. We conducted semi-structured interviews with 38 participants from 14 families that included donors, recipients, caregivers, and family members involved at Chang Gung Memorial Hospital during February - December 2019. Interviews were audio-recorded, transcribed, and translated from Mandarin to English and

analyzed utilizing grounded theory and thematic analysis. This project also attempts to offer suggestions of ethical guidelines for the evaluation of living organ donation and support living organ donor candidates. In this report I shall present an overview of my research work performed and papers published during the project period.

英文關鍵詞： organ donation, organ transplantation, living organ donation, medical decision-making, medical ethics, autonomy, gender, family

科技部補助專題研究計畫成果報告

(期中進度報告/期末報告)

親屬間活體器官捐贈決策的性別權力與家庭政治

計畫類別：個別型計畫 整合型計畫

計畫編號：MOST 107-2629-H-182 -002 -

執行期間：2018 年 8 月 1 日至 2020 年 1 月 31 日

執行機構及系所：長庚大學醫學系

計畫主持人：林雅萍

共同主持人：李威震、江仰仁、王敘涵、黃智婉、朱俊霖

計畫參與人員：陳容(碩士級專任研究助理)

本計畫除繳交成果報告外，另含下列出國報告，共 ____ 份：

執行國際合作與移地研究心得報告

出席國際學術會議心得報告

出國參訪及考察心得報告

本研究具有政策應用參考價值：否 是，建議提供機關_____

(勾選「是」者，請列舉建議可提供施政參考之業務主管機關)

本研究具影響公共利益之重大發現：否 是

中 華 民 國 109 年 4 月 27 日

目錄

一、中文摘要.....	3
二、英文摘要.....	4
三、報告內容.....	5
(一) 本研究計畫迄今研究成果簡述.....	5
(二) 本研究計畫迄今研究結果與討論.....	6
【論文一】.....	7
【論文二】.....	20
四、科技部補助專題研究計畫成果自評表.....	39
五、科技部補助專題研究計畫成果彙整表.....	41

行政院國家科學委員會補助專題研究計畫成果報告

親屬間活體器官捐贈決策的性別權力與家庭政治

一、中文摘要

台灣目前的性別與醫療或是女性健康照護研究已有相當豐碩的成果，但對於器官捐贈移植所涉及的性別議題仍缺乏深度討論。親屬間活體器官捐贈移植所涉及的倫理議題相當複雜，其決策過程交織著醫療、生命、文化、身體概念、性別與家庭角色的期待，以及家庭互動關係等因素，非常值得深入探究。

活體器官捐贈移植手術，不同於一般的醫療行為，其目的並非促進捐贈者的健康，而是對其施以侵入性手術，摘取(部分)器官延續受贈者生命或改善生活品質，捐贈者可能因此面臨手術過程及術後發生併發症，導致傷害、失能或甚至死亡的風險，因此醫學倫理上對於活體器官捐贈決定的自主性有格外審慎的考量。親屬間活體器官捐贈移植所涉及的倫理議題則更加複雜，因為捐贈者與受贈者之間通常存在緊密連結，雙方的動機與決策協商過程往往交織著社會文化價值，家庭組成、互動模式、勞務分工、性別角色的規範與期待，以及對於生命與身體的看法等錯綜複雜的因素。許多研究已經指出器官捐贈是一個性別化的經驗與決定，而且親屬間之活體器官捐贈移植決策深受家庭關係與社會性別意識形態的影響，某些情況甚至牽涉到原生家庭與姻親家庭的利害衝突。本研究採取文獻分析、參與觀察與深度訪談，自 2019 年 2 月至今，邀請林口長庚醫院參與親屬間活體肝臟與腎臟捐贈移植決策之重要關係人，包含受贈者、捐贈者、潛在捐贈者、主要照顧者等，共 14 個家庭，38 位受訪者，進行半結構式深度訪談，希望更細緻與脈絡化地深入探究親屬間活體器官捐贈移植的決策過程與經驗，挖掘其中深埋的複雜關係與權力過程，理解與闡明相關各造在整個器捐決策過程中的互動、情感與意義建構，以及鑲嵌於性別與家庭關係中的自主性，更有意識地看見性別階序、家庭勞務分工與性別角色等因素相互牽連而成的面向。最後，本計畫希望能將理論研究成果回饋應用於臨床政策的實踐，提出具有參考價值的具體案例，幫助移植醫療團隊更敏感於性別文化與權力配置對於易受傷害與弱勢群體所造成的壓迫，發展更為完善的器捐移植評估指引與照護建議

本報告將針對研究計劃期間的研究工作與相關論文發表提出簡要說明。

關鍵字：器官捐贈，器官移植，活體器官捐贈，醫療決策，醫療倫理，自主，性別，家庭

二、英文摘要

While women/ gender, medicine and healthcare studies in Taiwan have had fruitful research achievements, gender issues in organ donation and transplantation have not been well explored. This project investigates the decision-making process of the living-related organ donation within the socio-cultural context of Taiwan, focusing on gender hierarchy, division of labor and gender roles in families, and power in families. We conducted semi-structured interviews with 38 participants from 14 families that included donors, recipients, caregivers, and family members involved at Chang Gung Memorial Hospital during February–December 2019. Interviews were audio-recorded, transcribed, and translated from Mandarin to English and analyzed utilizing grounded theory and thematic analysis. This project also attempts to offer suggestions of ethical guidelines for the evaluation of living organ donation and support living organ donor candidates. In this report I shall present an overview of my research work performed and papers published during the project period.

Keywords : organ donation, organ transplantation, living organ donation, medical decision-making, medical ethics, autonomy, gender, family

三、報告內容

(一) 本研究計畫迄今研究成果簡述

本研究計畫主題是基於筆者在醫學院系的教學與學術研究，以及醫院的臨床倫理審查服務經驗累積之上所逐漸發展而成。2014年至2016年之研究計畫以死亡、自主與家庭參與醫療決策為研究主題，在研究進行中逐步開展出對「女性主義」與「關係自主」(relational autonomy)的理論建構與實際應用之探究(2016-2018)，並延續至本計畫繼續深入，是筆者第一次走出純粹哲學理論，進行跨領域的質性訪談經驗研究。

原計畫書所擬定的研究範圍和預期進度，大致上皆順利完成，包含訪談林口長庚醫院進行親屬間活體肝臟與腎臟捐贈移植之家庭、將研究成果發表至國內外學術研討會議(三篇)、並且接受計畫審查委員建議，投稿研究論文至國際高水準之學術期刊(一篇)、正在撰寫中論文(兩篇)，同時也將本計畫部分研究成果融入教學、演講與討論會，豐富傳統醫學倫理學與性別研究的理論架構。

【投稿期刊論文】

1. (in re-submission). Ya-Ping Lin*, Jung Chen, Wei-Chen Lee, Yang-Jen Chiang, Chih-Wan Huang. Understanding Family Dynamics in Adult-to-Adult Living Donor Liver Transplantation Decision-Making in Taiwan: Motivation, Communication, and Ambivalence. *American Journal of Transplantation*. Impact factor: 7.163; 2/25 (Transplantation).

【投稿學術研討會論文】

1. 親屬間活體器官捐贈決策的自主、家庭與性別：初步觀察，2019年台灣科技與社會研究學會年會。高雄駁二特區，20-21, April, 2019.
2. “Logic of Care”: Understanding the Family Dynamics in Living Donor Liver Transplantation Decision-Making in Taiwan, The International Association of Bioethics’ 2020 World Congress of Bioethics, 6/19-6/21, University of Pennsylvania
3. Family, Gender Politics, and Invisible Care in Living Donor Liver Transplantation in Taiwan, International Conference of Gendering Transformations: Feminist Knowledge Production and Trans/national Activist Engagement, 7th Sino-Nordic Women and Gender Studies Conference.

【與本研究計畫主題相關的演講活動】

1. 教育部國民及學前教育署高級中等學校人文及社會科學基礎人才培育計畫：108 年度高中人社班專題討論暨教學研習營隊「研究實作」課程(2019. 7. 3)：「醫院裡的哲學思考：以親屬間活體器官捐贈決策的性別權力與家庭政治研究為例」
2. 陽明大學公共衛生研究所 Faculty Seminar (2019.11.04)：「親屬間活體器官捐贈決策的自主、家庭與性別」

(二) 本研究計畫迄今研究結果與討論

由於本計畫已撰寫為研究論文，以下檢附投稿期刊英文論文一篇，與投稿研討會中文論文初稿一篇，作為本研究迄今的結果與討論。

**UNDERSTANDING FAMILY DYNAMICS IN LIVING DONOR LIVER
TRANSPLANTATION DECISION-MAKING IN TAIWAN: MOTIVATION,
COMMUNICATION, AND AMBIVALENCE**

1. INTRODUCTION

Since the 1990s, living organ transplantation has gradually become a standard medical option for patients with severe liver diseases due to shortage of deceased donations [1-4]. In Asia, living organ transplantation has increased dramatically [5] given the relatively low number of deceased donors compared to those in Western countries. In Taiwan, 7,707 people are waiting for kidney donation and 1,058 people are waiting for liver donation, while there were only 279 deceased donations in 2019 [6]. This indicates that the number of urgent organ transplantations required far exceeds the deceased organ donations received.

From a medical perspective, living organ donations provide recipients with better outcomes and lower postoperative mortality rates compared to deceased organ donations [7]. As a result, living organ transplantation has become a preferable option for those who suffer from kidney and liver failure. The number of living organ donations has increased over the past decade, from 266 liver and 90 kidney donations in 2009 to 492 liver and 166 kidney donations in 2018 [8].

Nonetheless, living organ transplantation raises controversial ethical issues regarding potential risk and harm to the donor [9,10]. Previous studies have focused on donors' motivations for donation [11,12]. Studies that addressed family-related issues in living donor liver transplantation (LDLT) decision-making processes highlight the situational, relational, and emotional-affective concept of autonomy in donors' thinking [12-16]. However, there is little qualitative research on the complex family dynamics and decision-making process in LDLT [17]. Previous studies on the familial decision-making process in LDLT distinguished "individual decision-making" from "family-level decision-making" as two separate and contradicting medical decision-making models [18]. Thus, this article emphasizes the need to explore relational factors in order to understand intra-familial decision-making in the context of LDLT.

To the authors' knowledge, this is the first in-depth qualitative study that investigates the rationale and motivation for donation as well as the decision-making process from the perspective of donor–recipient–caregiver relationship dynamics in the socio-cultural context of Taiwan. We focus on the complexities of intra-familial communication and

decision-making processes and investigate how donors, recipients, and caregivers co-construct the ethical significance of LDLT. In addition, we describe the vulnerability living donor candidates may experience during the communication and decision-making process.

2. METHODS

2.1 Research Design

This research aims to explore family dynamics in the decision-making process by conducting interviews with family units [12,18], encompassing not only the dual relation between the donor and recipient but also caregivers and other family members involved. Qualitative methods including participant observation and semi-structured interviews were utilized. Interview questions were categorized into three areas: “understanding of transplantation and medical treatments,” “the decision-making process of the transplantation,” and “family relations and self-understanding,” which were designed to encourage participants to express their experiences, feelings, and emotions during the interview process. Interview questions are in Table 1.

2.2 Participants

According to regulations in Taiwan, living liver donors must meet the following conditions: 1) be at least 20 years old, or 18 with their custodian’s consent, 2) within the fifth degree of kinship, and 3) volunteer to donate without coercion. The living organ transplantation procedure used in the medical center we observed requires potential donors to: 1) undergo primary examination by liver transplantation physicians, 2) undergo further medical examinations, including cross-matching tests, 3) attend consultations with the transplantation coordinator, 4) undergo psychosocial evaluation by a psychiatrist and social worker, 5) undergo risk evaluation by surgeons, and 6) be evaluated by an ethical evaluation committee.

Patients and their families, who had already passed these evaluations and were to undergo surgery within a month, were recruited as participants by liver transplant surgeons and transplant coordinators in Chang Gung Memorial Hospital. There were 36 participants from 13 families interviewed, including donors, recipients, caregivers, and family members who had been participating in LDLT (Table 2). Participants provided written consent before observations and interviews.

Participant observations were conducted at LDLT-related meetings with the family and transplant team before each surgery and at organ transplantation psychological assessments in order to observe family dynamics before conducting interviews. The researchers were invited to attend LDLT-related meetings with the medical team and introduced to the family by the transplantation coordinator before the meeting.

In-depth semi-structured interviews [19,20] were conducted by the researchers during February–December 2019, on the day before transplantation surgery, in hospital wards, common rooms, or meeting rooms. Each interview lasted 30 to 60 minutes and was audio-recorded.

2.3 Analysis

Interviews were transcribed verbatim and translated from Mandarin to English. Transcripts were coded and analyzed utilizing grounded theory and thematic analysis to identify motivations for LDLT and three intra-familial communication and decision-making patterns [21,22].

2.4 Ethical considerations

Chang Gung Medical Foundation Institutional Review Board approved the research (IRB No. 201801812A3).

3. RESULTS

Key findings on the three main themes, “Saving Life: Becoming a Donor,” “Logic of Care: Choosing the Donor,” and “Autonomy and Vulnerability: The Ambivalent Donors” are below, with illustrative quotes in Table 3. A thematic map illustrating selected themes in the data is shown in Figure 1.

3.1 Saving Life: Becoming a Donor

LDLT, serves as a “desperate remedy,” is more urgent than living donor kidney transplantation, which attempts to improve patient quality of life [20]. In Asian countries, family relationships influence donors’ motivation for liver donation [5,17]. Living liver donors are highly motivated to donate in order to save the lives of family members, though they might harbor concerns about the operation.

In our research, all 13 donors reported that they decided to donate without considering the risks of living donation. When facing the recipient’s life-threatening illness, the donation of a part of their liver was considered “natural and right.” Our study revealed that the priority of saving a life and patients’ trust in modern medical technology and the transplant team, together with the sense of “taken-for-grantedness” of family bonds and obligations, reinforced the naturalness of donation. Prompted by the motive of saving lives, family members co-constructed multiple layers of meaning and ethical significance for LDLT.

3.1.1 Helping family members

Recipients, donors, and family members were guided by two primary motives in the decision for LDLT: saving lives and helping family members. This echoes previous studies on

Asian LDLT and suggests that saving a loved one's life takes priority over other considerations [20]. From our interviews, both donor and other family members such as caregivers mentioned willingness to help the recipient regardless of risk because family ought to help one another.

3.1.2 Fulfilling family responsibilities

Willingness to donate and receive is also an attempt to meet social and family commitments. Participants with these motives were much more aware of and concerned about the emotional needs of the recipient and the fulfillment of societal norms or family obligations. Some even felt grateful for being able to donate, while others justified their liver transplant with family obligations (families 01, 06). These recipients highlighted their self-identity in the context of relationships and framed transplantation as a fulfillment of family roles and expectations, such as taking care of children (family 01) and having the recipient's company for longer (family 06).

3.1.3 Repaying the indebtedness to family

Previous empirical studies explained donor–recipient relations in LDLT as reciprocal gift-giving relations, based on Marcel Mauss's theory [15,23-31]. However, we found that the motivation for LDLT in Taiwan did not completely conform to Mauss's construct of voluntary gift exchange, but was based on the obligation of indebtedness toward family members.

In child-to-parent donations, donors often felt they “owed something to their parents” and considered the donation “natural and instinctive” and a reciprocal repayment for the body/life given by their parents. This sense of “indebtedness” binds the parent–child relationship and other family relations, including husband–wife (family 01) and even family-in-law (family 11). Donors felt they had an obligation to repay not only because of support and care received from the recipients in the past but simply for the closeness of being together as a family.

3.2 Logic of Care: Choosing the Donor

The intra-familial decision-making in LDLT is a complex, dynamic process influenced by factors referring to different actors and temporal moments. Considering the severity of liver failure and the priority of saving a life, the decision-making process lies not in the dilemma of “to donate or not” but in the deliberation of “who should donate.”

3.2.1 Multiple considerations in familial relations

Considerations in choosing a family donor include candidates' medical evaluations, age, financial considerations, marital status, and gendered factors. In choosing potential donors to undergo medical evaluations, members of the newer family, such as spouses and adult

children, were prioritized over those of the family-of-origin (families 01, 10, 11). Unmarried daughters tend to be considered as potential donors because they are deemed as staying within the family-of-origin, unlike daughters who have “married out into another family” (families 07, 12). Gendered factors such as leaving unmarried daughters with surgery scars (02-C, 05-D, 09-D) and the perception that females are physically weaker and afraid of pain in comparison to males (02-D, 06-D) were mentioned as reasons why males might be more appropriate donors.

Overall, the main consideration involved in choosing the donor is centered on the arrangement of post-operative care and financial costs within the household. Among medically suitable candidates, the person who is not the breadwinner in the family is more likely to donate (01-D, 07-D). Females, however, are more likely to be the primary caregiver in the household, expected to take up post-operative care of both donor and recipient. Thus, potential female donors were less likely to be chosen if there was another suitable candidate.

3.2.2 Three intra-familial communication and decision-making patterns in LDLT

Whereas previous studies often characterize the medical decision-making model in Chinese society as simply collectivist and family-centered [32], we constructed three patterns of communication and decision-making processes based on different family structures and relationships, family history and experiences, and personal characteristics (personality traits, emotions, religious beliefs, etc.).

3.2.2.1 Pattern I: All family members participate actively in the communication and decision-making process

In the first pattern, donors, recipients, caregivers, and other family members shared medical information and together came to the final decision on transplantation after having open, free, and frank discussions (families 01, 03, 04, 11, 13). The communication and decision-making process was smooth, active, and straightforward, based on intimate family relationships and past positive experience of having open discussions. In wife-to-husband and in-law-to-in-law donations, donors and recipients held nearly equal status in household and family decision-making (families 01, 11).

Families in this pattern reported that they had intimate relationships and connected with one another frequently in their daily lives. Their relatively smooth and openly-discussed medical decision-making rested on high-quality long-term family relationships and the atmosphere of equality they shared. They described the parent–child relationship as “friend-like” and “avoiding an authoritative parenting style.”

3.2.2.2 Pattern II: Donors participate actively and lead the decision-making process

When donors’ willingness to donate was stronger, they took a more active role in

communication and decision-making (families 06, 07, 08, 09, 12). Donors' commitment to donate depends on both affective and embodied familial links with recipients. Donors of this type underwent evaluation tests voluntarily once informed of recipients' severe medical condition. This pattern has two subtypes: II-1 and II-2, differing in recipients' attitudes toward transplantation and their involvement in the decision-making process.

3.2.2.2.1 II-1: Recipients participate passively in discussion and are persuaded by donors to accept the donation

Living-related liver recipients may experience stress and reluctance to accept the donation due to the close emotional donor–recipient relationship and concerns over risks to donors (families 06, 09). Recipients tended to have a reserved attitude toward transplantation and sometimes refused the suggestion of LDLT offered by the donor since they were not willing to see family suffer in exchange for their own health. Donors of this type have positive, affirmative personalities. Some of them helped other family members alleviate worries and cope with their own emotions by encouraging them to express their concerns (family 09).

A gendered difference in attitudes toward LDLT among recipients was found in this pattern: female recipients were more withdrawn than males. Most of these recipients were mothers of donors and expressed emotional resistance to transplantation because they felt it would hurt their children.

3.2.2.2.2 II-2: Recipients do not participate in discussion but accept the arrangement made by donors and the caregivers or other family members

The process in this pattern took place mainly between donor and caregiver (the mothers) (families 07, 08, 12). Strong donor–caregiver intimacy helped them support each other and “stay the course.” All recipients of this type were donors' father of the donor. Donor and caregiver excluded the recipient from the decision-making process out of care and compassion for the recipient and the wish not to disappoint him if the negotiation or cross-matching tests failed. Some recipients also did not take part in discussion due to poor health or temporary diminished mental capacity (family 07).

3.2.2.3 Pattern III: Donors participate passively in discussion while recipients or other family members lead the decision-making process

Some donors barely participated in discussion but agreed to donate at the demand of other, actively participating family members, including caregivers or senior members (families 02, 05, 10). They claimed that they were not coerced, but expressed their motivation as “saving the recipients' life.” However, donors of this type expressed fewer feelings and thoughts toward LDLT during the interviews and concluded that they “do not have other options” than becoming the donor. As juniors in the family, these donors seemed to speak less

and were obedient to senior family members. Some of them were almost forced to rearrange short-term life plans to meet a transplantation date decided on by the recipient or other senior family members (10-D).

3.3 Autonomy and Vulnerability: The Ambivalent Donors

Some donors may experience mixed feelings alongside the intention to donate, leading to psychological burden in donor–recipient–caregiver relationship dynamics and decision-making. This kind of negative mental status is described in the literature as ambivalence of living liver donors. The concept of “ambivalence” is used to describe simultaneous contradictory attitudes or feelings toward a person or action [33]. Ambivalent donors encounter their conflicting perceptions of LDLT while confronting the dilemma between saving the life of a family member and feeling anxiety and distress at donating under pressure [3,33,34].

3.3.1 Junior donor under pressure from family and the social norm of reciprocity and filial piety

Some studies mention that filial piety (*xiào*) is an important motivation for living organ donation in Confucianism-influenced families [17,35]. However, in our interviews, only two participants mentioned “filial piety,” and in a negative way, characterizing the situation in terms of an imbalance of family relationships and the moral duty of filial piety as a burden, present in the decision-making process (families 05, 12).

In the case of son-to-father donation, the donor met the informed consent requirements and expressed willingness to donate, but reported that he felt unable to refuse due to family and social pressure. When direct communication between donor and the recipient absent, the donor felt that he was not being respected during the process and was slightly oppressed by senior family members. He kept silent since his opinion was seldom taken into account. He was not the one to decide when to conduct the surgery, and felt he was almost forced to donate by his father and other family members. He felt like he did not have a say during evaluation and that the decision was automatically made once medical results indicated he was a suitable donor. He was afraid of social disapproval and being regarded as “disobeying filial piety” if he refused to donate. He said he would donate his liver to his father under any circumstances because “he is my father”; however, he struggled between the unpleasant feeling of poor treatment and the social norms of reciprocity and filial piety.

Donors who decide to donate mainly due to pressure of social norms such as filial piety are more likely to develop negative feelings and psychological burdens during the decision-making process. Medical teams, psychiatrists, and social workers participating in evaluation should be cognizant of this dynamic.

3.3.2 Unmarried female donor with overloaded caregiver burden and financial vulnerability

Donors who are the main family caregiver might suffer from extra pressure during LDLT. In the daughter-to-father donation, the donor had been the primary caregiver for her ill father for years (family 07). She was initially chosen as caregiver because of her low income compared to siblings. Since she had resigned from her job to take care of her father, it was considered straightforward that this unmarried and unemployed daughter was the best candidate for donation. She was placed in an awkward position when the initial decision who would donate was made before any discussion, based on the previous division of care work in the household.

Although her siblings offered financial support, the donor struggled with stress and anxiety while making her final decision. She described the pressure of being the long-term caregiver as unbearable and was worried about her ability to give post-operative care. She also felt uncertain about the risks of her surgery and the outcome of her father's transplantation. Lack of emotional support from family caused her to experience extra pressure, facing the dilemma of "saving the life of the beloved" and "feeling helpless in the situation of having no choice."

4. DISCUSSION

In many Asian societies, illness is considered a family matter, and medical decisions are often made as a family. Based on our in-depth qualitative study, for the first time, we present a detailed analysis of how multiple family members co-constructed the ethical significance of LDLT and how the dynamic of donor–recipient–caregiver relationships may shape communication, negotiation, and decision-making processes in Taiwan.

Existing qualitative studies on LDLT primarily focus on donor's motivation and psychological concerns [12,17,20,36] or the donor–recipient dyad [19,37]. To obtain a complete picture of intra-familial decision-making dynamics, we interviewed not only living liver donors and recipients but also caregivers and other family members who are usually not involved in transplant evaluation. Findings revealed that LDLT is not merely a personal choice of either donor or recipient but fundamentally a collaborative process of family-centered medical decision-making, intertwined with socio-economic conditions, cultural and social norms, gender roles, and the division of labor in the household. Furthermore, the ethical significance of intra-familial LDLT should be conceptualized and analyzed with a broader focus on family relations beyond the donor–recipient dyad.

We found that the decision-making process had started long before the donor candidates were first nominated and suggested to the health care professionals. The traditionally hierarchical and gendered division of labor and role expectations within the family shaped the caring relationship, which led to consideration of them being suitable candidates. Regardless

of the type of communication, negotiation, and decision-making (as illustrated in the Results section), the co-construction of the ethical significance of LDLT as a family matter reflects the complexity of decision-making processes in the context of an on-going, interdependent relational system.

This research elaborated on how family dynamics and the Confucian familial power relations shape decision-making patterns in LDLT. The interaction between donor, recipient, and caregiver in this study illustrated family communication in the patriarchal structure of traditional Chinese families. We argue that the decision-making process of LDLT reflects how family members understand and interpret familial obligations, values, and gendered role expectations in a patriarchal society.

In Confucian-influenced societies such as Taiwan, strong emphasis is placed on familial common good and mutual obligations for family members. In the context of intra-familial LDLT, the notion of reciprocity and indebtedness is a central theme underlying the entire process of motivation, deliberation, and decision-making. Our analysis showed that Mauss's gift-exchange framework has limited application in this context because the rationale of living-related organ donation is the obligation of repayment, which is based upon profound flesh-and-blood ties rather than a relationship of voluntary "giving, receiving, reciprocating."

However, this study does not suggest that Western and Eastern societies hold obviously dichotomized family decision-making patterns and avoids Western/Eastern cultural stereotypes [38] by illustrating how family structure, history, and dynamic interactions shape Taiwanese families. From our interview data, for instance, families with more intimate and equal relationships tend to dilute the density of the Confucian credo and embrace the discourse of reciprocal affection and love to justify their motivations for donation. In contrast, families with remote and tense relationships are more likely to cling to social norms and consider LDLT as a way to fulfil filial piety.

Among patriarchally structured families, the donor (usually the son) as well as the caregiver (usually the mother or daughter) were deemed to lack decision-making authority. The LDLT decision-making process of this type started with the recipient's strong wish to live and their dominant attitude toward other family members. However, due to power imbalance, the recipients did not communicate candidly with potential donors but instead asked caregivers to pass on the request. The father, being the person who is the most dominant and in control in patriarchal family structures, does not directly talk with children but simply asks them to obey. Family caregivers, who are invisible in the living donor evaluation process, often serve as mediators and coordinators in the decision-making process. Throughout the process, the caregiver, mostly the mother or wife, often undertakes exhaustive care effort and experiences burden and stress. They not only take care of the recipient and the donor before and after the surgery but also feel responsible for the wellbeing of the whole family, which requires a considerable amount of time, effort, and emotional devotion.

5. CONCLUSION AND CLINICAL IMPLICATIONS

This study revealed that LDLT in Taiwan is essentially a collaborative process of family-centered medical decision-making embedded within donor–recipient–caregiver relationships, intertwined with socio-economic conditions, cultural and social norms, gender roles, and the division of labor in the household. We offered a deeper and detailed description of three intra-familial communication and decision-making patterns and called special attention to the significant role of the caregiver during LDLT dynamics, which has been largely invisible in both medical practice and research.

Based on the analysis, our findings provide healthcare professionals with insight into the contextual and relational factors involved in family dynamics during the decision-making process of LDLT. The transplant team can provide sufficient support to donor candidates and caregivers by using our characterization of family decision-making patterns to identify the patterns they are in and the possible negative mental states that different individuals may experience under social and family pressure. We suggest that healthcare professionals should be aware of family caregivers' well-being and be more sensitive to the power imbalance between recipients and donors during the evaluation process and the voluntariness of donors. We do not imply that a mere detection of vulnerability or ambivalence would immediately disqualify potential donors, but that professionals should offer adequate aid to empower potential donors to reflect on their views and values as well as express their doubts and anxiety.

REFERENCES

1. Russo M, Brown RJ. Ethical issues in living donor liver transplantation. *Curr Gastroenterol Rep.* 2003;5(1):26-30.
2. Knibbe ME. *Not a matter of choice': ethical perspectives on decision making about living parental liver donation.* Groningen: Faculty of Medical Sciences, University of Groningen; 2009.
3. Lai Y-C, Lee W-C, Juang Y-Y, Yen L-L, Weng L-C, Chou HF. Effect of social support and donation-related concerns on ambivalence of living liver donor candidates. *Liver Transplantation.* 2014;20(11):1365-1371.
4. Fujita M, Slingsby BT, Akabayashi A. Three patterns of voluntary consent in the case of adult-to-adult living related liver transplantation in Japan. *Transplantation Proceedings.* 2004;36(5):1425-1428.
5. Chen C-L, Kabling CS, Concejero AM. Why does living donor liver transplantation flourish in Asia? *Nature Reviews Gastroenterology & Hepatology.* 2013;10(12):746-751.
6. Taiwan Organ Registry and Sharing Center. Real-time Statistics of Candidates on

- Organ Waiting List. https://www.torsc.org.tw/about/about_08.jsp. Accessed February 2020.
7. Lee S-G. Living-donor liver transplantation in adults. *British Medical Bulletin*. 2010;94(1):33-48.
 8. Taiwan Organ Registry and Sharing Center. Statistics of Living Liver and Kidney Donations 2009-2018. <https://www.torsc.org.tw/FileUploads/docatt/3c75c7b6-9615-8059-0c8c-dae8d562b6f0.pdf>. Accessed October 2019.
 9. Crouch RA, Elliott C. Moral agency and the family: the case of living related organ transplantation. *Camb Q Healthc Ethics*. 1999;8(3):275-287.
 10. Molinari M, Matz J, DeCoutere S, El-Tawil K, Abu-Wasel B, Keough V. Live liver donors' risk thresholds: risking a life to save a life. *HPB (Oxford)*. 2014;16(6):560-574.
 11. Biller-Andorno N, Agich GJ, Doepkens K, Schauenburg H. Who shall be Allowed to Give? Living Organ Donors and the Concept of Autonomy. *Theoretical Medicine and Bioethics*. 2001;22(4):351-368.
 12. Papachristou C, Walter M, Dietrich K, et al. Motivation for living-donor liver transplantation from the donor's perspective: an in-depth qualitative research study. *Transplantation*. 2004;78(10):1506-1514.
 13. Russell S, Jacob RG. Living-related organ donation: The donor's dilemma. *Patient Education and Counseling*. 1993;21(1):89-99.
 14. Abdeldayem H, Kashkoush S, Hegab BS, Aziz A, Shoreem H, Saleh S. Analysis of donor motivations in living donor liver transplantation. *Frontiers in surgery*. 2014;1:25-25.
 15. Scheper-Hughes N. The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants. *American Journal of Transplantation*. 2007;7(3):507-511.
 16. Lee SH, Jeong JS, Ha HS, et al. Decision-Related Factors and Attitudes Toward Donation in Living Related Liver Transplantation: Ten-Year Experience. *Transplantation Proceedings*. 2005;37(2):1081-1084.
 17. Ryu S, Yoon SC, Hong KE, Kim JM. Psychosocial Issues Related to Donor's Decision-Making in Living Donor Liver Transplantation. *Ann Transplant*. 2019;24:576-583.
 18. Uehara M, 3; Hayashi, Akiko²; Murai, Toshiya¹; Noma, Shun'ichi¹. Psychological Factors Influencing Donors' Decision-Making Pattern in Living-Donor Liver Transplantation. *Transplantation*. 2011;92(8):936-942.
 19. Simmons RG, Hickey K, Kjellstrand CM, Simmons RL. Family Tension in the Search for a Kidney Donor. *JAMA*. 1971;215(6):909-912.
 20. Fujita M, Akabayashi A, Slingsby BT, Kosugi S, Fujimoto Y, Tanaka K. A model of

- donors' decision-making in adult-to-adult living donor liver transplantation in Japan: Having no choice. *Liver Transplantation*. 2006;12(5):768-774.
21. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine; 1967.
 22. Strauss AL, Corbin JM. Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology*. 1990;13(1):3-20.
 23. Spital A, Jacobs CL. The beauty of the gift: the wonder of living organ donation. *Clinical Transplantation*. 2007;21(4):435-440.
 24. Shaw RM. Altruism, solidarity and affect in live kidney donation and breastmilk sharing. *Sociology of Health & Illness*. 2018;0(0).
 25. Schwering KL. *Gift dynamics and identity construction within the family*. 2015.
 26. Harrington J, Morgan M. Understanding kidney transplant patients' treatment choices: The interaction of emotion with medical and social influences on risk preferences. *Social Science & Medicine*. 2016;155:43-50.
 27. Gill P, Lowes L. Gift exchange and organ donation: Donor and recipient experiences of live related kidney transplantation. *International Journal of Nursing Studies*. 2008;45(11):1607-1617.
 28. Crowley-Matoka M, Hamdy SF. Gendering the Gift of Life: Family Politics and Kidney Donation in Egypt and Mexico. *Med Anthropology*. 2016;35(1):31-44.
 29. Boas H. Where do human organs come from? Trends of generalized and restricted altruism in organ donations. *Social Science & Medicine*. 2011;73(9):1378-1385.
 30. Bailey PK, Ben-Shlomo Y, de Salis I, Tomson C, Owen-Smith A. Better the donor you know? A qualitative study of renal patients' views on 'altruistic' live-donor kidney transplantation. *Social Science & Medicine*. 2016;150:104-111.
 31. Fox R, C., Swazey J, P. . *Spare Parts: Organ Replacement in American Society*. Vol Oxford Oxford University Press; 1992.
 32. Ozdemir S, Jafar TH, Choong LHL, Finkelstein EA. Family dynamics in a multi-ethnic Asian society: comparison of elderly CKD patients and their family caregivers experience with medical decision making for managing end stage kidney disease. *BMC Nephrology*. 2019;20(1):73.
 33. Simpson MA, Kendrick J, Verbese JE, et al. Ambivalence in living liver donors. *Liver Transpl*. 2011;17(10):1226-1233.
 34. Simmons RG, Marine SK, Simmons RL. *Gift of life : the effect of organ transplantation on individual, family, and societal dynamics*. New Brunswick, N.J.; Oxford: Transaction; 2002.
 35. Oliver M, Woywodt A, Ahmed A, Saif I. Organ donation, transplantation and religion. *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association*. 2010;26:437-444.

36. DiMartini A, Cruz Jr. RJ, Dew MA, et al. Motives and Decision Making of Potential Living Liver Donors: Comparisons Between Gender, Relationships and Ambivalence. *American Journal of Transplantation*. 2012;12(1):136-151.
37. Walter M, Papachristou C, Danzer G, Klapp B, Frommer J. Willingness to donate: An interview study before liver transplantation. *Journal of medical ethics*. 2005;30:544-550.
38. Alden DL, Friend J, Lee PY, et al. Who Decides: Me or We? Family Involvement in Medical Decision Making in Eastern and Western Countries. *Medical Decision Making*. 2017;38(1):14-25.

【論文二】

親屬間活體器官捐贈決策的自主、家庭與性別：初步觀察

一、導論

器官移植醫學的進步為器官衰竭病人帶來一線生機，維持其生命、緩解痛苦，並提升生活品質。然而台灣由於屍體(大愛)器官捐贈的風氣並不盛行，等候器官移植的人數與大愛器官捐贈的人數之間有相當大的落差。依據台灣財團法人器官移植捐贈登錄中心截至2019年4月15日的統計¹，108年度等候接受器官捐贈的病人為9649人，而大愛捐贈人數為82人。其中等候肝臟捐贈的病人有1109人，僅有34人接受移植；等候腎臟的病人有7451人，僅有70人接受移植。有鑒於此，親屬之間的活體器官捐贈移植漸漸成為等待大愛捐贈以外的另一項醫療選擇。然而，活體器官移植所引起的相關討論涉及錯綜複雜的倫理考量、社會文化脈絡，以及經濟與法律規範等多重面向的議題。有別於其他西方國家及部份亞洲國家²可以進行非親屬間之活體器官捐贈，根據台灣《人體器官移植條例》第八條，活體肝臟移植僅限定於配偶及五等親內血親或姻親之親屬捐贈、活體腎臟捐贈僅限於配偶或五等親內血親親屬捐贈，不具有血緣關係或法定親屬關係者不可捐贈。

雖然器官移植技術日益進步，但活體器官捐贈不同於一般的醫療行為，其目的並非促進捐贈者的健康，而是對其施以侵入性手術，摘取(部分)器官延續受贈者生命或改善生活品質，捐贈者可能因此面臨手術過程及術後發生併發症，導致傷害、失能或甚至死亡的風險，而有道德上的疑慮。因此，台灣《人體器官移植條例》規範，活體器官捐贈「應以無償方式為之」³，出於捐贈者的自主同意⁴，並且在進行器官捐贈與移植手術之前，必須經由移植團隊、社工師與精神科醫師共同進行一套完整的醫療、心理、家庭與

¹ 財團法人器官移植捐贈登錄中心(2019)，108年度等候/捐贈移植統計。資料檢索日期：2019年4月15日。<https://www.torsc.org.tw/>。

² 亞洲僅有印度和新加坡可以進行非親屬間活體器官捐贈。

Donate Life: What You Need To Know About Organ Donation in India (2016)。資料檢索日期：2018年12月3日。<https://www.thebetterindia.com/75687/organ-donation-india/>

National University Centre for Organ Transplantation (2018)。資料檢索日期：2018年12月3日。<https://www.nuh.com.sg/nucot/about-transplant/faq.html>。

³ 根據台灣人體器官移植條例第十二條，器官捐贈「應以無償方式為之」，不可涉及任何金錢上的交易，以防治器官買賣。

⁴ 根據台灣人體器官移植條例第八條，捐贈者應為二十歲以上，且有意思能力，於自由意志下出具書面同意。

社會的審慎評估程序，並透過醫院倫理委員會的嚴格審查，確保捐贈者與受贈者的心智能力健全，對於手術的過程、風險與術後照護有充分適當的知情與理解，而且在不受脅迫或不當壓力的情況下做出自願決定，使得捐贈者的權益能夠受到程序性的保障。

目前在醫學倫理的討論中，除了幫助器官受贈者延續生命的行善原則之外，此傷害行為的道德合理性基礎主要奠定在捐贈者的自主性(autonomy)或自願性(voluntariness)之上(N. Biller-Andorno, 2011; Spital & Taylor, 2007)。然而，到底何謂「自願」的器捐決定？親屬間器官移植的捐贈者與受贈者之間通常存在緊密連結，雖然隨之而來的情感與道德責任不必然可以視為個人自主性的阻礙，因為只要個人作為道德主體，有充分的理性思考能力，能批判地反思其信念與價值，仍能做出一個自主決定，但我們似乎也不能輕忽，來自於家庭與社會的情感與道德壓力的確會影響潛在捐贈者的判斷與決定。研究活體器官捐贈的瑞士醫療倫理學者 Nikola Biller-Andorno(2001)就認為：「將自願捐贈僅只理解為無脅迫(mere absence of coercion)，並不能夠把握所有非自願決定的情況，尤其是親屬之間的活體捐贈」。而在台灣社會中，當子女面對長輩病危或配偶有一方病重時，潛在捐贈者都可能承受來自家族及社會之壓力，其器捐決定甚至會被拿來作為「孝順與否」或「相愛與否」的證明，在某些家族關係極強的情況中，捐贈者可能甚至會覺得自己其實是沒有選擇餘地的(賴秀昫, 蔡甫昌, & 陳慶餘, 2005)。

我自 2013 年起開始參與北部某醫學中心的臨床倫理委員會，審查親屬間的活體器官(包含肝臟與腎臟)捐贈移植案例。倫委會收到的審查案件通常是已經通過移植團隊的醫療評估、社工師的社福評估，以及精神科醫師的精神評估之後，彙整所有相關資料，送交會議討論。在倫理審查的階段，主要關注的重點是根據「精神評估單」當中受贈者和捐贈者的「醫療決策過程」、「精神狀態」與「知情同意」項目，以及「社福評估單」當中對於「家庭狀況」與「社會心理」的評估結果，審視醫護團隊告知同意的程序是否完備，察看捐贈者是否心智健全、是否有足夠的理性認知與決定能力，且未受到明顯的脅迫與施壓，倘若這些條件皆已滿足，則通常認為該捐贈移植案件沒有倫理疑慮，予以通過。然而，我在審查過程中對於有些捐贈者本身是家庭中較為弱勢或是處於較不利權力位置，總是思慮再三：例如，沒有工作的家庭成員會自認為自己不具經濟生產力、「不用養家」⁵，故應該由自己來捐贈；或是未婚的女兒認為自己「還沒有嫁出去」⁶，依附在原生家庭中，跟其他已婚手足比起來較適合捐贈；亦有離婚的女兒因為「不用面對夫家壓力」⁷，所以在家人建議下決定捐贈一顆腎臟給父親。但如前所述，諸如此類的器捐個案在目前的醫療—社會—心理—倫理評估模式中，除非出現明顯脅迫情況，否則不見得會特別受到矚目與進一步討論。

的確，華人社會文化價值當中講求家族血緣連結、緊密的情感與利益關係及由此衍生而來的倫理責任，深深影響個人的道德判斷與重大決策。尤其在傳統長幼有序、重男輕女的父權觀念下，醫療決策過程涉及了家庭中的互動關係與權力結構、經濟需求、勞

⁵ 精神評估單中捐贈者自述。

⁶ 精神評估單中捐贈者自述。

⁷ 精神評估單中捐贈者自述。

務分工、以及性別角色的規範與期待等各種複雜因素，若是配偶之間或是家庭內已婚子女的器捐，則甚至又會牽涉到原生家庭與姻親家庭之間的關係。此外，根據我的初步觀察，台灣社會上普遍推崇器官捐贈的大愛奉獻，強調受贈者的重生希望，但對於捐贈者的手術傷害風險較少著墨，尤其輿論與媒體的推波助瀾，更將親人器官捐贈行為道德化甚至神聖化。例如許多新聞媒體的標題皆讚揚捐贈器官給父母是孝順的行為：「親子器官捐贈，孝子捐肝捐腎救爸媽」⁸、「孝心感動天，四孝子抽籤搶捐肝救父」⁹。此外，針對配偶之間的器捐，媒體特別選在七夕情人節以「夫妻同肝苦，捐肝妻多於夫」¹⁰、「夫捐妻佔 12%，妻捐夫達 88%」¹¹為標題發布新聞，表彰夫妻之間同肝共苦的相愛之情；值得注意的是，這些報導同時點出了配偶間器官捐贈的性別差距(gender disparity)與性別失衡(gender imbalance)狀況：「以中國醫藥大學附設醫院換肝病患 508 例分析，其中父母小孩 387 例，兄弟姐妹 41 例，夫妻 44 例，其他則為 36 例。在夫妻換肝的 44 例中，先生捐給太太者只有 4 例，其他 40 例皆是太太捐給先生」¹²，背後原因值得探究。

台灣目前的性別與健康或是婦女健康照護研究已有相當豐碩的成果，但議題比較多涉及生殖，例如生育自主、法律與醫療的生育自主權、生殖科技下的女性身體政治等；或是性別化的醫療，例如冠狀動脈心臟疾病、更年期、乳癌、子宮切除術等，對於器官捐贈移植所涉及之性別向度的深度討論則仍缺乏。我基於這幾年所累積的倫理審查經驗與研究關懷，努力向移植醫療團隊徵詢相關意見，注意到親屬器官捐贈移植的決策過程交織著醫療、生命、倫理、文化、社會價值，家庭關係與性別角色的期待與規範。捐贈者、受贈者，與重要關係人常糾結於矛盾與掙扎的心情，決策過程中錯綜著彼此要求、說服、協商與妥協等環節。本研究企圖更加細緻與深入地探究親屬之間活體器官捐贈移植的決策過程與經驗，挖掘其中深埋的複雜關係與權力過程，希望能夠更有意識地看見性別角色、家庭勞務分工與互動、身體概念與醫療科技等因素相互牽連而成的面向，一方面能夠更脈絡化、結構化地理解與闡明親屬器官捐贈移植的決策過程，另一方面則要揭露涉入在整個器捐過程中相關主體之真實與豐厚的經驗與感受。最終則希望能將理論研究成果回饋應用於臨床政策的實踐，提出具有參考價值的具體案例，幫助移植醫療團隊更敏感於性別文化與權力配置對於易受傷害與弱勢群體所造成的壓迫，並為親屬間活體器官捐贈移植評估與照護發展更為完善的標準及建議。

⁸ 健康醫療網-健康養生新聞資訊網路(2016)。

<http://www.healthnews.com.tw/news/article/26909/?act=>。檢索日期 2018 年 1 月 28 日。

⁹ 中央社即時新聞(2015)。 <http://www.cna.com.tw/news/firstnews/201504090043-1.aspx>。檢索日期 2018 年 1 月 28 日。

¹⁰ 中時電子報(2014)。 <http://www.chinatimes.com/realtimenews/20140802002088-260405>。檢索日期 2018 年 1 月 28 日。

¹¹ 蘋果日報(2017)。 <https://tw.appledaily.com/headline/daily/20170707/37707338/>。檢索日期 2019 年 4 月 15 日。

¹² 同註 11。

二、研究方法

本研究主要目的為更加細緻與深入了解台灣親屬間活體器官捐贈移植的決策過程與經驗，以及其中重要關係人的考量與感受。除了文獻分析之外，經驗研究以深度訪談為主、參與觀察為輔。

於 2019 年 1 月底通過人體試驗倫理委員會審查，自 2 月起開始於台灣北部某醫學中心進行研究。研究初期，研究者共同向腎臟科及肝臟科醫師、協調師請教器官移植的醫療程序；與兩位精神科醫師進行團隊會議，了解移植術前評估過程，初擬訪談大綱。隨後開始進行門診的參與觀察，藉此了解診間醫師與病人的互動、協調師向病家衛教的過程，以及醫療團隊在此過程中的分工協作。自 2 月中旬至今，已於腎臟移植科門診跟診 3 次、參與肝臟移植術前說明會 9 次、參與精神科評估門診 1 次。此外，研究者利用說明會後以及門診前空檔，與兩位腎臟及兩位肝臟移植協調師非正式會談共 10 次，從中瞭解移植審查的行政過程。

本研究採取兩階段方式招募肝臟移植受訪者。第一階段由移植協調師協助聯繫，邀請研究者共同參與術前說明會，讓病人、家屬與研究者有機會先初步認識，也讓研究者先了解病人的病情與醫療選項。術前說明會乃為移植團隊於肝臟移植手術前舉辦，藉此向病人及家屬說明病情近況、移植評估、手術過程、手術前後注意事項以及術後照顧。提供病人及家屬充分的醫療資訊告知與詢問機會，輔以衛教小冊子加以說明，另外亦協助彩色人生肝友協會進行宣導，提供病家多樣化的諮詢與支持管道。術前說明會結束後，隨即由協調師引介研究團隊，再由研究者詳細說明研究目的與方法、提出訪談邀請。第二階段則是另外約定日期的正式訪談。為了讓受訪者有充足時間考慮受訪意願、醞釀想分享的內容，訪談時間多數不在術前說明會當日，而是擇他日進行。大部分的訪談約在手術前一天傍晚，把握受贈者與捐贈者皆提前入院、檢查與等候隔日手術的空檔進行訪談。

訪談地點皆在醫院內，選擇兼具隱密性、方便錄音的半開放式空間，於病房交誼廳、病房內、或肝臟科移植會談室進行。受訪對象以家庭為單位，包含受贈者、捐贈者、潛在捐贈者、主要照顧者以及其他重要家人。訪談進行方式多數為受訪者單獨受訪，唯有少數以兩人共同受訪，以及其中一個家庭為共同受訪。所有訪談皆經過受訪者親自表示受訪意願，且簽署訪談同意書一式兩份。訪談時間約三十分鐘至一小時，全程以錄音筆錄音與筆記紀錄。

本研究的核心關懷聚焦於台灣親屬間器官捐贈移植決策中的家庭、性別與自主，因此研究設計的原初構想為：於術前說明會後，以目的性抽樣來篩選合適的家庭進行訪談。但考量到目前仍屬研究初期，欲了解移植過程與決策的整體樣貌，故在選擇受訪家庭的原則上，先不以目的性抽樣，而是邀請每一組參與術前說明會的家庭參與訪談。本研究採半結構式深度訪談。訪談大綱分為四大部分：移植醫療的選擇與理解、器官捐贈移植的協商過程、家庭結構與家庭成員互動，以及受訪者的自我認知，其中尤其側重於受訪者多加描述對器官捐贈移植協商與選擇的理解與感受（詳見附錄一：訪談大綱）。

從 2019 年 2 月迄今，已訪談 13 個肝臟移植家庭，31 位受訪者；1 個腎臟移植家庭，

2 位受訪者，全部共計 38 位受訪者。其中包含捐贈者、受贈者與主要照顧者（詳見附錄二：受訪者名單受訪者名單）。所有受訪者皆為北部某醫學中心肝臟移植之案例，以家庭為單位計算，其中妻子捐給丈夫一組，兒子捐給父親三組，兒子捐給母親一組，女兒捐給父親三組，女兒捐給母親兩組，姪子捐給舅舅一組，連襟捐贈一組，母親捐給女兒一組。腎臟則有一組手足之間的捐贈。

三、迄今研究發現與討論

如前所述，本文主要透過深入訪談參與親屬間活體器官捐贈移植決策過程之重要關係人，並輔以參與觀察移植外科門診、精神科評估門診，與手術說明會當中移植團隊醫師及協調師對於病情、醫療選項、手術過程與術後照護等事項的說明，並從旁觀察家庭成員之間的互動關係，嘗試梳理出台灣脈絡中的親屬間活體器官捐贈移植決策過程是如何牽連著家庭關係、性別角色、文化與社會價值規範，以及醫療科技與身體觀等各種因素的交織影響與型塑。同時，本文亦關注親屬活體器官捐贈移植的傳統醫學倫理議題，尤其是探討捐贈者的自主性是否會在過程中遭受來自於家庭權力關係與性別規範的不當壓力與傷害，希望透過本研究重新檢視並豐富自主的概念內涵與相關理論。

（一）親屬間活體器官捐贈移植的倫理意涵必須要在關係中理解

在我們的受訪者當中，幾乎所有的捐贈者或照顧者都是在以肝臟移植作為能夠「一勞永逸」治癒疾病的前提下，表示為了救家人，器捐是件「很自然的事情」。一位捐贈者在精神評估門診中很快說出自己捐肝是「天經地義」、「理所當然」。這種自然直覺所呈現出的理解框架讓我們思考，器捐決策為什麼如此直接立即地與家庭、血緣、角色等價值規範聯繫在一起？與其他醫療決策有何異同？兩個背景因素或許是：一，在台灣法律規範下，活體器官捐贈移植限定於五親等之內，捐贈者與受贈者本有緊密親緣關係。二，本研究迄今所訪談的家庭都是在確定捐贈、等待手術的階段，即使過去決策過程中曾有掙扎或衝突情緒，此刻也已經削弱。

不僅如此，我們的受訪者對於器官移植以及捐贈者人選的決定，並未出現相關文獻所指出的疑慮、抗拒、矛盾或衝突等情況，甚至連協商與說服的過程都沒有，為了拯救父母或配偶¹³，都是很快便做出決定。之所以如此，我們發現是因為器官捐贈移植的決策通常是延續著這個家庭過去的勞務分工與照護關係，現下的捐贈決定沒有經歷明顯的衝突與抵抗，可能是因為在更早之前就已經成為家內既定的照護模式，早就形構或限制了這個器官捐贈的決定，包括由誰捐贈、由誰照顧。於是，器官捐贈的決策常常是還沒有選擇就發生，在討論之前就決定了。

在家庭七的例子中，考量經濟來源的家庭分工與照顧安排，早在受贈者多年前開始生病且需要家人照護時便漸漸形成。身為女兒的捐贈者自述，因為自己的工作（服務業）薪資相較於弟弟的工作（水電）低，因此由她辭職照顧父親。最初三個子女皆進行評估，

¹³ 本研究目前尚未收到父母捐給子女的案例。有研究指出父母捐給子女、子女捐給父母，以及配偶間捐贈分別有不同的倫理意涵。此處暫且不深入討論。

大哥因為 B 肝不能捐，捐贈者與其胞弟的身體狀況符合捐贈資格，因家中經濟來源主要仰賴弟弟的收入，綜合考量下，捐贈者覺得由自己捐較合適。

「因為一開始就是，[...]因為他發作次數比較多，所以就辭掉工作，就很專心顧他，對，然後想說，就已經辭掉了，那就不用再另外一個多辭。然後如果要做應該就是，我就是還沒有找到工作之前，就[...]一直維持下去，然後有工作就工作、沒工作就去照顧[父親]這樣子。[...] 配對結果是，我跟弟弟可以，因為哥哥也 B 肝的關係，不然他應該也是可以。啊然後，評估之後是我跟弟弟都 OK，然後我們兩個都是可以捐的，然後因為考量到現實生活，工作的關係跟實際生活的那個開銷的問題，所以就是由我來開，然後弟弟要這個工作了，就以正常人下去，並不會說，[...]如果你捐肝，影響到你之後的工作。」
(家庭七／捐贈者／女兒捐給父親)

不過這也不表示捐贈者或照顧者在這個既定的分工與決策模式中毫無能動性，只能接受安排而已。某位女性捐贈者就利用這次機會向父親提出喘息要求，希望在術後聘僱外傭協助照顧，也希望父親能進入療養院接受專業照顧。

「是因為，上一次住院顧到很累。因為他發病的次數太多，可是，他並不曉得他自己在發病，可是我顧起來會覺得說，顧起來已經沒有喘息的.....我會覺得說，也許應該是由專人來幫忙，幫我們一下，我們還有喘息的機會。」(家庭七／捐贈者／女兒捐給父親)

而所謂的協商，也不只是討論由誰擔任捐贈者而已，而更多是在日常照護工作的安排上，甚至如果當捐贈者原本在家庭中就不是擔任照顧者角色，反而是在移植過程中最輕鬆的人，他需要貢獻的就只是肝臟的一部分而已。付出身體反而成為最簡單的一件事，綿密細瑣的長期照顧工作(care-work)才是最大的承擔。

器官移植不只是捐贈者與受贈者兩個人之間的事。捐贈者或受贈者個人的自我決定是關係性的：決定是在家族中各重要關係人之間的互動中共同做出來的，而自我亦是在倫理關係中定位。不只是捐贈者，連受贈者接受捐贈或拖延捐贈，都不是為了自己，而是為了家人，為了實現自己在家庭當中的角色。

「...當然會謝謝太太，到底這樣子...好還是不好，因為第一個我想到...現在是自己單身一個人，然後現在是兩個又加一個小朋友，然後我走了...以後小朋友...不要說誰來照顧，誰來.....經濟收入來源，所以最後就...就...，就...一家...會想很多啦，對啊，我走掉了這個家怎麼辦，最後就...不想那麼多了，那就...就是...為了老婆、為了小孩。」「不然我不養小孩誰來幫我養。」(家庭一／受贈者／妻子捐給丈夫)

捐贈者強調這是很自然而然的事，自己是媽媽生下來的，現在可以幫助媽媽，當然要做。

「當然不能說是拖累啊，因為我們的身體也是媽媽生給我們的嘛」(家庭六／捐贈者／女兒捐給母親)

「我跟你講喔，我們家庭是這樣，我說『妹妹對不起，媽媽不想』，她說『媽媽，你很笨，你生我們兩個開了兩次刀，啊你是你給我們的，我給你又怎樣？』」
(家庭六／受贈者／女兒捐給母親)

親屬活體器官捐贈捐移植決策不能僅以捐贈者與受贈者兩個人之間的二元對偶關係(dyadic relation)作為分析架構，而必須置放在更大的社會脈絡中理解。器官捐贈的決定不是某個捐或不捐的個人主張，而是一個關係人共同意義建構的過程。這個過程座落於整體文化的解釋之中，在社會文化規範的設定架構中發生。傳統的家庭與性別分工結構與角色倫理早就形構或限制了這個器官捐贈的決定。許多人會以幸運、感恩來定位器官移植這件事情：

「對啊，孩子說，你有機會「聽天命啊，啊也不知道確不確定啊。啊我就跟我兒子講，如果你可以，你比對配對可以的話，就是我的弟弟，就算很幸運，阿彌陀佛；如果不行，那我們就，盡人事啊，聽天命啊，對不對？」(家庭十／主要照顧者／連襟間捐贈)

「我感恩有機會，是不是這樣，我感恩有。我感恩有，那我有，我這個女兒有讓我有機會去換這個東西這樣子，就這樣。」(家庭六／受贈者／女兒捐給母親)

捐贈者與受贈者的情感(emotions)也與角色倫理有關。例如某位男性受贈者感到愧疚跟丟臉，因為自己生病，卻要太太捐給他。先生這種虧欠感不只是基於個人，而是來自於夫妻角色定位：

「講真的，就...不要說.....還真的是抬不起頭來，對太太就覺得很愧疚那樣子，那...還要她陪我挨這一刀.....還蠻大刀的。」(家庭一／受贈者／妻子捐給先生)

身為受贈者的媽媽，心疼自己的女兒要因為自己生病而跟著接受手術，因此想跟女兒說對不起，而不是謝謝。愧疚感來自於覺得生病是自己的事情，卻還要拖累到小孩。所以移植的事情一直拖延，不想讓小孩動刀。

「我自己也跟她講完了，不會啦，我也常跟她講說好幾次對不起，[女兒說：]『你不要跟我講對不起，為什麼要跟我講對不起？』不跟她講謝謝，講說，因為，她講說，她給我，我才有機會跟她陪她更久，不是這樣子嗎？『我當然是要媽媽陪我更久一點啊，對啊，啊有機會為什麼不給你？如果沒機會就沒有，有機會我幹嘛不給、不給媽媽？』對啊。她說，『你生我們兩個就挨一刀、挨兩刀，我幹嘛這樣挨一刀有什麼關係？就這樣而已啊』我不會跟她講『妹妹謝謝你』，不會。」(家庭六／受贈者／女兒捐給母親)

(二) 器官捐贈是一個性別化的醫療決定

若從器官捐贈移植的男女比例來看，眾多研究皆已指出活體器官捐贈中普遍的性別失衡(gender imbalance)或性別差距(gender disparity)狀況：女性捐贈人數多過於男性，而且女性多是捐贈者角色，男性多是受贈者。(Achille, Soos, and Fortin et al., 2007; Biller-Andorno, 2000; Fisher, Kropp, and Fleming, 2005; Giessing, Reuter, Deger et al., 2005; Isotani, Fujisawa, and Ichikawa et al., 2002; Khajehdehi, 1999; Kayler, Rasmussen, and Dykstra et al., 2003; Ojo and Port, 1993; Walton-Moss, Boulware, and Cooper et al., 2007; Zimmerman, Donnelly, and Miller et al., 2000)

而且，無論在接受屍體捐贈或是活體捐贈，相較於女性，男性較容易成為器官移植的受贈者 (Biller-Andorno, 2002)。1998 年美國統計資料顯示，有 60% 屍體捐贈、57% 活體捐贈的受贈者為男性。1999 年德國統計資料也呈現接受屍體捐贈的性別不均等現象，有 64% 受贈者是男性，卻僅有 36% 受贈者是女性 (Biller-Andorno, 2002)。造成此現象的醫學因素可能是因為男性相較於女性，較容易罹患腎臟疾病，因此而有較多的比例進入到等待器官捐贈的等候名單中。一項在加拿大多倫多某醫學中心的研究指出，配偶之間的活體腎臟捐贈，女性遠高於男性，且達五倍之多 (Zimmerman, Donnelly, Miller, Stewart, & Albert, 2000)。造成性別比例如此懸殊的原因包含：1. 男性因為高血壓和缺血性心臟病發病率較女性高，因此被排除在捐贈者之列。2. 妻子有可能因為先前的懷孕過程而導致對於丈夫的免疫過敏，因此不能接受來自先生的器官捐贈。3. 家庭主要收入來源與人力考量下，妻子較容易成為捐贈者，丈夫則否。4. 因為其他社會性及家庭因素，導致女性自覺「有其責任」成為捐贈者 (Zimmerman et al., 2000)。

許多社會學與生命倫理學者探究性別結構與意識形態如何對女性施展壓力，使其較易於成為器官捐贈者 (Shaw 2014; Zieler 2009; Biller-Adorno 2002)，並且指出性別不平等的普遍狀況傾向於讓男性受贈者得利，而使女性暴露於捐贈或販賣其腎臟的風險之中 (Simmons, Marine, and Simmons 1987; Cohen 1999; Moazam 2006; Scheper-Hughes 2007)。Crowley-Matoka and Hamdy(2016)在埃及與墨西哥進行的民族誌研究，論證活體腎臟捐贈是一個性別化的經驗(gendered experience)。在埃及與墨西哥的社會文化脈絡中，死後捐贈的觀念不彰，活體捐贈幾乎是末期腎病移植病人唯一的活路。該研究指出，性別意識形態是以「自我犧牲的母親」形象作為鼓勵活體器官捐贈的文化修辭，而母親

被設想為生命的源頭，其「生育的身體」連結起「賦予生命」與「贈予腎臟」兩種「生產」活動。不僅如此，不同的性別與家庭角色在腎臟捐贈與移植的決定中又各有不同的考量。母親被期待捐出器官，但需要腎臟移植的年輕女性卻在整體家庭經濟的算計下，「被拒絕」接受兄長的器官捐贈，因為父母認為兄長們日後也將要為自己的家庭負責任，因此現在要他們捐腎救妹是不公平的。至於女性配偶則是由於在家事的性別分工中扮演照顧者角色，很自然地要負起捐贈的責任，得以讓生病的丈夫恢復健康，回到職場工作承擔家計。這也顯示，對於器官捐贈的決定而言，確保家庭婚姻與生產的能力比起病患個人本身的健康與存活是更為顯著的考量(Crowley-Matoka & Hamdy, 2016)。

與上述文獻相同的是，本研究發現器官捐贈的確是一個性別化的決策過程，尤其女性捐贈者的自我認同往往並非銘刻在獨立的個人主義之下，而是鑲嵌在好太太的形象之下，順從於文化所賦予其的社會角色。

但是另一方面，當我們說親屬活體器官捐贈是一個性別化的醫療決定時，其意義不僅侷限於捐贈者與受贈者一對一的男女比例，而是在包含主要照顧者在內的整個照護過程中，都夾雜著性別分工的因素。在我們的受訪者中，有些女性雖然不是捐贈者，但卻花費更多的心力在安排所有的術前術後照顧工作，而且常常是要同時承擔捐贈者與受贈者兩個人的健康。

Kristin Zeiler (2009)將活體腎臟捐贈視為一種特別的照護工作(care-work)。倘若捐贈的行為是(完全或部分)以愛與對受贈者的關懷為動機，那麼女性捐贈者從醫療檢驗、捐贈、術後恢復，甚至在術後還要照顧受贈者的過程皆可視為一種勞務，而且可以與其他種類的照護工作相比擬，例如照顧年邁父母、照顧孩子、照顧生病的親人。在所有這些領域中，性別不均皆仍盛行。然而比較有趣的是，Zeiler 發現在活肝捐贈當中卻沒有相似的性別失衡，相反地，更多是男性捐給女性。

我認為導致 Zeiler 如此主張的理由是，她只看捐贈者與受贈者的男女比例，亦即是將性別角色分工的影響僅放在捐贈受贈兩者之間的二元關係來看，加上醫療因素的限制，使得性別向度在活肝移植中似乎並非那麼顯著。但若是以我在本段第一節所提出的關係架構來理解，親屬間的器捐決策其實是鑲嵌在更廣大的性別分工與家庭權力結構當中，而且必須將主要照顧者包含在內。在本研究當中，照顧者常常是太太與母親，她們的敘事呈顯出傳統性別分工的社會結構與角色倫理，非常耐人尋味。即使在我們的受訪家庭中，的確更多是由兒子來捐贈，但是女性依然在參與照護工作(care-work)上經驗到較大壓力，承擔更多責任。

從家庭關係中了解在移植手術過程中時間與心力的付出，會發現主要照顧者付出的心力與心中累積的壓力不容小覷。女性對於醫療訊息的掌握程度較佳，需要花費更多的心力在多工處理家務、聯繫、溝通和各種看似瑣碎但是關鍵的事情。包含安排就醫時間、安頓家中其他事務等等。在許多成年子女捐贈給父親的家庭中，身為捐贈者的母親同時也擔負捐贈者與受贈者兩人的主要照顧責任，雖然既不是病人也不是捐贈人，卻是在過程中最憂心且「操煩」的。

「對呀，我就一直跟我媽說辛苦了，她說是還好，她說是怕之後要更久、要

這樣子照顧更久，因為她照顧我爸一個多月了。／有請過幾天，我就跟我媽說很累，妳就請看護就好了，但請了幾天，又自己回來顧。」(家庭九／捐贈者／女兒捐給父親)

另一個家庭中的女兒，本身既是照護者，又是捐贈者，她所表現出的擔憂與情緒感受也複雜許多。

「是因為，上一次住院顧到很累。因為他發病的次數太多，可是，他並不曉得他自己在發病，可是我顧起來會覺得說，顧起來已經沒有喘息的地.....那個，地方，我會覺得說，也許應該是由專人來幫忙，幫我們一下，我們還有喘息的機會。不曉得這樣子，是不是這樣子，想.....」(07-1)

「那我唯一的好處是，我沒有家庭、我沒有負擔，所以我可以多照顧一點，可是，就是家人也會無形的去付出就對了。就不用想那麼多，就是家人。我覺得那就是家人。」(07-1)

器官捐贈看似個別的單一醫療決定，但其實是置放在相互關聯的更大脈絡下做出來的。往往延續過去既有的家務分工與照護模式。家庭、照護與醫療決策之間是更為綿密長久的纏繞關係。

除此之外，女性將自己的付出歸結於他人和整體性的協助，或是運氣使然。男性較傾向訴諸於自己的處理方式和能力。所有的女性照顧者與捐贈者在總結其感受時皆表示感恩自己能夠捐贈救人、或是感謝病人配合她好好完成自己的照顧責任。

「我感恩有機會，是不是這樣，我感恩有。我感恩有，那我有，我這個女兒有讓我有機會去換這個東西這樣子，就這樣。」(家庭六／受贈者／女兒捐給母親)

「我很幸運我的身體是健康，還可以捐給我爸爸。這是，就是惜福啊。」(家庭七／捐贈者／女兒捐給父親)

「足感心，很感恩，感恩的心來這樣跟兒子跟先生的配合，真的很感心，對呀！之後也希望他們二個好好的跟我配合，對呀！」(家庭八／主要照顧者／兒子捐給父親)

因此，本文認為在討論親屬活體器官捐贈移植的倫理與性別意涵時，不應該只考量捐贈者與受贈者二人，以及移植手術本身，而是要關照整個從生病、查找資料、諮詢醫師、決定移植、籌備款項、生活安排與手術前後的照護過程，以及尤其是在醫療－社會－心理－倫理評估程序與文件中隱身的照顧者。

(三) 親屬器官捐贈的隱喻：送禮或償還？

在 1970 年代，器官移植技術漸趨成熟之際，與之相關的研究也隨之出現，其中由醫療社會學家 Fox 與歷史學家 Swezey 所提出以「生命的禮物」譬喻器官移植的概念 (Fox & Swazey, 1974)，至今仍顯見於探究捐贈動機與捐贈與受贈關係的研究中 (Bailey, Ben-Shlomo, de Salis, Tomson, & Owen-Smith, 2016; Boas, 2011; Crowley-Matoka & Hamdy, 2016; Gill & Lowes, 2008; Harrington & Morgan, 2016; Scheper-Hughes, 2007; Schwering, 2014; Shaw, 2018; Spital & Jacobs, 2007)。禮物交換的過程既存在實質物品的流動(被捐贈與接受的器官)也具有象徵的意義，在器官移植的過程中，此意義即是「生命的贈禮」。透過「捐贈」與「接收」此份生命之禮的互動過程，捐贈者得以透過這份禮物給予受贈者重生的機會。以禮物交換的概念來檢視器官捐贈與移植，可以豐富對於家庭成員之間協商過程以及捐贈者對於自主的詮釋。

禮物交換是社會中關係性互動的具現形式(Mauss & Evans-Pritchard, 1967)，透過給予、接受與回報禮物的交換形式，體現出整社會中的道德秩序。Mauss (1967) 提出全面性報稱體系中所描述的「禮物交換」，係指尚未發展出法律制度的舊社會互動形式。他認為，透過微觀的禮物交換可窺見「整體社會現象」，並且連結社會其他制度、文化認知的運作方式。其概念的沿用，幫助研究者對於當代社會人際關係與互動更深層的理解，許多經驗研究將親屬之間的器官捐贈描繪為禮物餽贈與接收的相互關係。人們透過禮物交換所建立起的連帶關係建立於「贈禮」、「收禮」與「回禮」的循環，每個人都有其義務去執行。在這個循環中，送禮者與收禮者之間形成「欠債的關係」，必須透過收禮者予以回禮，才能解除兩造之間不平等的積欠關係。禮物交換的循環承載著社會連帶關係維持的意義和秩序，揭示人與人之間的關係既是物質性的，也同時傳遞其象徵意義。

過去將禮物隱喻為器官移植的研究有許多不同面向。包含陌生人之間的腎臟捐贈，禮物交換意味一種必須被償還的欠債關係，促使受贈者無論如何都必須回之以禮。相對於接受大愛腎臟捐贈而無意願接受非指定活體腎臟捐贈的人表示，不想因為腎臟移植而產生對於他人的負債感受。認為捐贈者與受贈者之間的互惠利益可促使末期腎臟疾病病人較有意願接受活體腎臟移植(Bailey et al., 2016)。以及探究在親屬關係中的活體腎臟移植，因為親子之間的關係是不對等的，年輕受贈者遇到別無選擇只能接受禮物的處境，因而可能造成心理上的負面影響，並可能產生無法償還這份貴重的生命的禮物的虧欠感(Schwering, 2014)。也有研究指出，親屬間(或認識的朋友)的活體腎臟捐贈並非全然無私、無條件的禮物贈與關係，而是基於社群團結價值、捐贈者與受贈者彼此間強烈的互為主體關聯(Shaw, 2018)。然而，較少有經驗研究著墨於親屬之間的肝臟移植關係，以及其中所涉及的家庭動態關係。

親屬之間的器官贈予和接受關係，可能是不求回報的付出(Kaufman, Russ, & Shim, 2006; Spital & Jacobs, 2007)，也可能帶有些許不甘願的犧牲情緒(Crowley-Matoka & Hamdy, 2016; Scheper-Hughes, 2007)。有些捐贈者覺得，親子關係意味著對於彼此有承諾性的義務存在(Kaufman et al., 2006)，因此，身為子女，捐肝給父母親就像是回報養育之恩，好比接收了別人的禮物，理所當然有回禮的必要。有些捐贈者覺得這是「沒有選擇的選擇」(Scheper-Hughes, 2007)，無論如何還是必須捐，與其說是「送禮」，或許也存

有「還債」的意味。據此，送禮與回禮在此一來一往的關係中反而帶有責任與犧牲的意涵。然而，到底是基於什麼樣的情境和感受「贈予」、「接受」親人的器官？而禮物交換的概念又如何移植過程中體現？

在台灣社會注重家庭連帶的脈絡中理解禮物交換的概念，便能夠詮釋上述那種「第一直覺就是要捐」的感受，其中包含自主的意願，同時也包含關係所衍生出的義務。意即，對於家人的付出與關懷被視為「理所當然」，不容易出現以「自我犧牲」的概念去理解自己捐贈器官給至親，反而以自然而然、應當如此的方式呈現。如捐贈者所述：「我當然會捐贈給爸爸」(05-1)；「我也是從媽媽身上出來的，現在割一塊給媽媽也是當然的」(04-2)；「我的身體也是媽媽給的，現在捐肝也是應該的。當初生我和哥哥都已經挨兩刀了，我現在開一刀又不會怎樣」(06-2)

如同禮物的贈予、接收與回禮，父母對於兒女的關愛可被譬喻為禮物，而子女自然覺得有其必要回禮給父母親。親屬間的器官捐贈透過身體化的「禮物交換」實踐來圓滿關係、情感連帶所產生的義務與責任。透過器官的「贈予」與「接受」，情感與義務作為人與人之間關係連結的重要概念，擴大了其所能夠延伸出來的能動。鑲嵌於家庭關係中的「禮物交換」介入了醫療場域中對於「救人一命」的實作，其中交織著對於家人的義務、以及自主決定含納著指向他人的關懷與互為主體自我認知。

四、小結

器官移植不是一個單純的醫療選項。往往不只是利益風險(benefit-risk)的線性評估，而是在一開始得知病情時就已經有了方向，之後只是在意義確認的過程中更加肯定，作出宣稱。器官捐贈的決定不只是捐贈者個人意願器官利用方式的意思表示，或對器官自主權的訴求，而是乘載著在家庭關係中界定與詮釋的倫理意涵。自我是在決策與照護過程與關係中獲取倫理定位。¹⁴

如前所述，對於家人身體健康的盼望，時常是捐贈者最優先的考量(A. Crouch & Elliott, 1999; Zeiler, 2009)。當捐贈者被問及「決定捐贈的第一個念頭是什麼？」，多數的回應是：「沒有想太多，當然要救」。台灣的家庭關係緊密，個人福祉的衡量中包含對於親人利益的考量。因此，在此重大醫療抉擇過程中，捐贈者對於親人恢復健康的期待，被擺放於較為關鍵的因素，而自己必須付出的代價與風險考量並不是捐贈者首要想到的。而移植技術的進步使得手術風險降低，亦大大減低了捐贈者對於手術的擔憂(Kaufman et al., 2006)。因此，「犧牲」的感受消融於家庭關係網絡中緊密的情感連帶中，以另一種方式呈現：更隱微而內化的，轉變為類似「合乎情理的義務」。

¹⁴器官捐贈同時也因為涉及身體的人際移轉，而開展出社會身體的意涵。本文著重於家庭與性別向度的分析，關於器官移植與身體的關係，待另文探討。

参考文献

- A. Crouch, R., & Elliott, C. (1999). *Moral Agency and the Family: The Case of Living Related Organ Transplantation* (Vol. 8).
- Bailey, P. K., Ben-Shlomo, Y., de Salis, I., Tomson, C., & Owen-Smith, A. (2016). Better the donor you know? A qualitative study of renal patients' views on 'altruistic' live-donor kidney transplantation. *Social Science & Medicine*, 150, 104-111. doi:<https://doi.org/10.1016/j.socscimed.2015.12.041>
- Biller-Andorno, N. (2011). Voluntariness in living-related organ donation. *Transplantation*, 92(6), 617-619. doi:10.1097/TP.0b013e3182279120
- Biller-Andorno, N., Agich, G. J., Doepkens, K., & Schauenburg, H. (2001). Who shall be Allowed to Give? Living Organ Donors and the Concept of Autonomy. *Theoretical Medicine and Bioethics*, 22(4), 351-368. doi:10.1023/a:1011842211016
- Boas, H. (2011). Where do human organs come from? Trends of generalized and restricted altruism in organ donations. *Social Science & Medicine*, 73(9), 1378-1385. doi:<https://doi.org/10.1016/j.socscimed.2011.07.028>
- Crowley-Matoka, M., & Hamdy, S. F. (2016). Gendering the Gift of Life: Family Politics and Kidney Donation in Egypt and Mexico. *Med Anthropology*, 35(1), 31-44. doi:10.1080/01459740.2015.1051181
- Fox, R. C., & Swazey, J. P. (1974). *The Courage to Fail Chicago*: University Of Chicago Press.
- Fujita, M., Akabayashi, A., Slingsby, B. T., Kosugi, S., Fujimoto, Y., & Tanaka, K. (2006). A model of donors' decision-making in adult-to-adult living donor liver transplantation in Japan: Having no choice. *Liver Transplantation*, 12(5), 768-774. doi:doi:10.1002/lt.20689
- Gill, P., & Lowes, L. (2008). Gift exchange and organ donation: Donor and recipient experiences of live related kidney transplantation. *International Journal of Nursing Studies*, 45(11), 1607-1617. doi:<https://doi.org/10.1016/j.ijnurstu.2008.03.004>
- Harrington, J., & Morgan, M. (2016). Understanding kidney transplant patients' treatment choices: The interaction of emotion with medical and social influences on risk preferences. *Social Science & Medicine*, 155, 43-50. doi:<https://doi.org/10.1016/j.socscimed.2016.02.027>
- Kaufman, S. R., Russ, A. J., & Shim, J. K. (2006). Aged bodies and kinship matters: The ethical field of kidney transplant. *American ethnologist*, 33(1), 81-99. doi:10.1525/ae.2006.33.1.81
- Mauss, M., & Evans-Pritchard, E. E. (1967). *The gift : forms and functions of exchange in*

- archaic societies. New York: Norton.
- Scheper-Hughes, N. (2007). The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants. *American Journal of Transplantation*, 7(3), 507-511. doi:doi:10.1111/j.1600-6143.2006.01679.x
- Schwering, K. L. (2014). Gift dynamics and identity construction within the family. In W. Weimar (Ed.), *Ethical, legal and psychosocial aspects of organ transplantation* (pp. 189-195): Pabst science.
- Shaw, R. M. (2018). Altruism, solidarity and affect in live kidney donation and breastmilk sharing. *Sociology of Health & Illness*, 0(0). doi:doi:10.1111/1467-9566.12805
- Spital, A., & Jacobs, C. L. (2007). The beauty of the gift: the wonder of living organ donation. *Clinical Transplantation*, 21(4), 435-440. doi:doi:10.1111/j.1399-0012.2007.00746.x
- Spital, A., & Taylor, J. S. (2007). Living Organ Donation: Always Ethically Complex. *Clinical Journal of the American Society of Nephrology*, 2(2), 203-204. doi:10.2215/cjn.04011206
- Zeiler, K. (2009). Just love in live organ donation. *Medicine, Health Care and Philosophy*, 12(3), 323-331. doi:10.1007/s11019-008-9151-1
- Zimmerman, D., Donnelly, S., Miller, J., Stewart, D., & Albert, S. E. (2000). Gender disparity in living renal transplant donation. *American Journal of Kidney Diseases*, 36(3), 534-540. doi:<https://doi.org/10.1053/ajkd.2000.9794>
- 賴秀昀, 蔡甫昌, & 陳慶餘. (2005). 器官移植倫理：活體肝臟捐贈與移植. *當代醫學*, 32(1), 57-61.

Part One: Understandings of Transplantation and Medical Treatments

1. Could you talk about your present illness and past history? [recipient]

Could you briefly talk about the patient's present illness and past history as you have been aware of?
[donor and caregiver]

2. Could you talk about how you take care of the patient? [caretaker]

3. As you could memorise, when was the first time you learned of living related organ transplantation?

4. How did you know about the procedure of living related liver donation and other related information, such as deceased organ donation and other options for medical treatments?

5. Why do you chose living liver transplantation as the treatment?

6. Could you describe the interactions with the transplantation medical team, including your doctor in charge, surgeons, transplantation coordinators and other medical staffs?

Part Two: The Decision-Making Process of the Transplantation

7. Who did you talk to about the forthcoming transplantation?

8. How did the negotiation and decision-making process go on within the family?

9. Have you ever been discussing the transplantation with any other person?

10. How were their reactions and response?

11. What were your family's opinions on organ transplantation?

12. How did you feel and react when you first been told that you might have to undergo a transplantation surgery?

13. Are you worried? What or who you worried about? What were you worried the most?

14. Have you ever felt conflicted about your decision on receiving the liver from your family/ donating the liver to your family?

15. How did you deal with your emotional changes and struggles during the decision-making process?

16. Do you consider that the transplantation surgery might cost great financial burden to you and family?

17. If yes, how are you and your family going to deal with that problem?

Part Three: Family Relations and Self-Understanding

18. Could you describe your relations and interactions with family members and your role in the family?

19. How would you describe yourself regarding your characteristics, personalities and attitude toward life?

20. Could you conclude the feelings of being a recipient/donor within one sentence?

21. What would you like to say to donor/ recipient/ caregiver/ your family?

Table 2. Demographic Data of Participants (n=38)

	Recipient* (n=11)				Donor (n=14)				Caregiver (n=13)			
	No.	Age	Gender	Disease	No.	Age	Gender	Donor-Recipient Relationship	No.	Age	Gender	Relationship
Family 01	01-R	42	Male	liver cirrhosis	01-D	41	Female	Wife to Husband	-	-	-	-
Family 02	02-R	54	Male	HCC**	02-D	22	Male	Son to Father	02-C1	47	Female	Recipient's Wife
									02-C2	48	Female	Recipient's Partner outside Marriage
Family 03	03-R	46	Female	liver cirrhosis	03-D	23	Male	Son to Mother	03-C1	54	Male	Recipient's Husband
									03-C2	26	Female	Recipient's Daughter
Family 04	04-R	57	Female	alcoholic cirrhosis	04-D	35	Female	Daughter to Mother	-	-	-	-
Family 05	-	-	-	-	05-D	21	Male	Son to Father	05-C	n/a	Female	Recipient's Wife
Family 06	06-R	58	Female	HBV, HCC	06-D	22	Female	Daughter to Mother	-	-	-	-
Family 07	-	-	-	HBV	07-D	41	Female	Daughter to Father	-	-	-	-
Family 08	08-R	58	Male	alcoholic cirrhosis	08-D	25	Male	Son to Father	08-C	56	Female	Recipient's Wife
Family 09	-	-	-	HBV, HCC	09-D	28	Female	Daughter to Father	-	-	-	-
Family 10	10-R	52	Male	alcoholic cirrhosis	10-D	24	Male	Nephew to Uncle	10-C1	n/a	Female	Recipient's Wife
									10-C2	n/a	Female	Donor's Mother
Family 11	11-R	50	Male	HBV, HCC	11-D	57	Male	In-law to In-law	11-C1	51	Female	Recipient's Wife
									11-C2	56	Female	Donor's Wife
Family 12	12-R	55	Male	alcoholic cirrhosis	12-D	30	Female	Daughter to Father	12-C	54	Female	Recipient's Wife
Family 13	13-R	18	Female	biliary atresia	13-D	43	Female	Mother to Daughter	13-C1	51	Male	Recipient's Father
									13-C2	19	Male	Recipient's Brother
Family 14	K01-R	42	Female	kidney failure	K01-D	45	Female	Sibling to sibling				

* Three of the recipients were not able to be interviewed due to the unwell condition or unconsciousness.

**Abbreviations: HCC, hepatocellular carcinoma; HCV, hepatitis C virus; LC, liver cirrhosis; HBV, hepatitis B virus

科技部補助專題研究計畫成果自評表

請就研究內容與原計畫相符程度、達成預期目標情況、研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性）、是否適合在學術期刊發表或申請專利、主要發現（簡要敘述成果是否具有政策應用參考價值及具影響公共利益之重大發現）或其他有關價值等，作一綜合評估。

1. 請就研究內容與原計畫相符程度、達成預期目標情況作一綜合評估

■ 達成目標

未達成目標（請說明，以 100 字為限）

實驗失敗

因故實驗中斷

其他原因

說明：

2. 研究成果在學術期刊發表或申請專利等情形(請於其他欄註明專利及技轉之證號、合約、申請及洽談等詳細資訊)

論文：■ 已發表 未發表之文稿 ■ 撰寫中 無

專利： 已獲得 申請中 無

技轉： 已技轉 洽談中

無

其他：(以 200 字為限)

3. 請依學術成就、技術創新、社會影響等方面，評估研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性，以 500 字為限）。

台灣目前的性別與健康或是女性健康照護研究已有相當豐碩的成果，但其議題比較多涉及生殖(生育自主、法律與醫療的自主權、生殖科技下的女性身體政治等)，與性別化的醫療(冠狀動脈心臟疾病、更年期、乳癌、子宮切除等)，對於器官捐贈移植議題的深度討論則仍缺乏。本研究深入探討親屬間活體器官捐贈移植的決策過程與經驗，挖掘其中深埋的複雜關係與權力過程，協助讀者更有意識地看見性別階序、家庭勞務分工與性別角色等因素相互牽連而成的面向，一方面能夠更脈絡化、結構化地理解與闡明親屬器官捐贈與移植的決策過程，另一方面則要揭露涉入在整個器捐移植過程中的相關主體之真實與豐厚的經驗與感受。本計畫同時能將理論研究成果回饋應用於臨床政策的實踐，提出具有參考價值的具體案例，幫助移植醫療團隊更敏感於性別文化與權力配置對於易受傷害與弱勢群體所造成的壓迫，並為活體器官捐贈移植評估與照護發展更為完善的標準及建議。

4. 主要發現

本研究具有政策應用參考價值： 否 是，建議提供機關_____

(勾選「是」者，請列舉建議可提供施政參考之業務主管機關)

本研究具影響公共利益之重大發現： 否 是

說明：(以 150 字為限)

科技部補助專題研究計畫成果彙整表

計畫主持人：林雅萍		計畫編號：MOST 107-2629-H-182-002-			
計畫名稱：親屬間活體器官捐贈決策的性別權力與家庭政治					
成果項目		量化	單位		
			質化 (說明：各成果項目請附佐證資料或細項說明，如期刊名稱、年份、卷期、起訖頁數、證號...等)		
國內	學術性論文	期刊論文			
		研討會論文	1	篇 林雅萍.(2019). 〈親屬間活體器官捐贈決策的自主、家庭與性別：初步觀察〉，2019年台灣科技與社會研究學會年會。高雄駁二特區，20-21, April, 2019.	
		專書		本 請附專書資訊。	
		專書論文		章 請附專書論文資訊。	
		技術報告		篇	
		其他		篇	
	智慧財產權及成果	專利	發明專利	申請中	請附佐證資料，如申請案號。
				已獲得	請附佐證資料，如獲證案號。
				新型/設計專利	
		商標權		件	
		營業秘密			
		積體電路電路布局權			
		著作權			
		品種權			
其他					
技術移轉	件數		件		
	收入		千元		

		收入		千元	1. 依「科技部科學技術研究發展成果歸屬及運用辦法」第2條規定，研發成果收入係指執行研究發展之單位因管理及運用研發成果所獲得之授權金、權利金、獎金、股權或其他權益。 2. 請註明合約金額。
參與計畫人力	本國籍	大專生		人次	
		碩士生			
		博士生			
		博士後研究員			
		專任助理	1		
	非本國籍	大專生			
		碩士生			
		博士生			
		博士後研究員			
		專任助理			
其他成果					
(無法以量化表達之成果如辦理學術活動、獲得獎項、重要國際合作、研究成果國際影響力及其他協助產業技術發展之具體效益事項等，請以文字敘述填列。)		部分計畫成果融入「教育部國民及學前教育署高級中等學校人文及社會科學基礎人才培育計畫：108 年度高中人社班專題討論暨教學研習營隊」研究實作課程教學內容。			

107年度專題研究計畫成果彙整表

計畫主持人：林雅萍		計畫編號：107-2629-H-182-002-			
計畫名稱：親屬間活體器官捐贈決策的性別權力與家庭政治					
成果項目		量化	單位	質化 (說明：各成果項目請附佐證資料或細項說明，如期刊名稱、年份、卷期、起訖頁數、證號...等)	
國內	學術性論文	期刊論文	0		
		研討會論文	2	篇	1. 〈親屬間活體器官捐贈決策的自主、家庭與性別：初步觀察〉，2019年台灣科技與社會研究學會年會。高雄駁二特區，20-21, April, 2019. 2. Family, Gender Politics, and Invisible Care in Living Donor Liver Transplantation in Taiwan, International Conference of Gendering Transformations: Feminist Knowledge Production and Trans/national Activist Engagement, 7th Sino-Nordic Women and Gender Studies Conference.
		專書	0	本	
		專書論文	0	章	
		技術報告	0	篇	
		其他	0	篇	
		國外	學術性論文	期刊論文	1
研討會論文	1				"Logic of Care": Understanding the Family Dynamics in Living Liver Donation and Transplantation Decision-Making in Taiwan, The International Association of Bioethics' 2020 World Congress of Bioethics, 6/19-6/21, University of Pennsylvania
專書	0			本	
專書論文	0			章	
技術報告	0			篇	

		其他	0	篇	
參與計畫人力	本國籍	大專生	0	人次	
		碩士生	0		
		博士生	0		
		博士級研究人員	0		
		專任人員	1		碩士級專任研究助理
	非本國籍	大專生	0		
		碩士生	0		
		博士生	0		
		博士級研究人員	0		
		專任人員	0		
其他成果 (無法以量化表達之成果如辦理學術活動、獲得獎項、重要國際合作、研究成果國際影響力及其他協助產業技術發展之具體效益事項等，請以文字敘述填列。)		部分計畫成果另發表於： 1. 教育部國民及學前教育署高級中等學校人文及社會科學基礎人才培育計畫：108年度高中人社班專題討論暨教學研習營隊「研究實作」課程(2019. 7. 3)：「醫院裡的哲學思考：以親屬間活體器官捐贈決策的性別權力與家庭政治研究為例」 2. 陽明大學公共衛生研究所Faculty Seminar (2019. 11. 04)：「親屬間活體器官捐贈決策的自主、家庭與性別」			