MINISTRY OF HEALTH MALAYSIA

INDEPENDENT DONOR ADVOCATE TEAM

IDAT

INDEPENDENT DONOR ADVOCATE TEAM

Training Module

a Gift of Life

Pusat Sumber Transplan Nasional
KUALA LUMPUR

2023

First published in Malaysia in 2023 by

Pusat Sumber Transplan Nasional
Lot B.5-1, Aras 5,
Menara Wisma Sejarah,
Jalan Tun Razak,
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National Library of Malaysia Cataloguing in Publication Data
A catalogue record for this module is available from the National Library of Malaysia

ISBN 978-629-98613-0-0

9 786299 861300

Printed in 2023 by

Percetakan PMI
43-4, Jln. PJU 1/39, Dataran Prima, 47310 Petaling Jaya, Selangor.

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FOREWORD

BY THE DEPUTY DIRECTOR GENERAL OF HEALTH (MEDICAL)

DATO' DR ASMAYANI BINTI KHALIB
Deputy Director General of Health (Medical)

There is a demographic shift in the Malaysian population indicating an increased life-expectancy and simultaneously, the prevalence of non-communicable diseases (NCD) has also become a compelling public health challenge resulting in increased number of end-organ failure patients. Consequently, a rise in healthcare needs and expenditure, socio-economic challenges, decreased productivity and economic losses ensues. Organ transplantation is a life-saving/ life-enhancing procedure which can improve the quality of life and healthcare outcomes amongst these end-organ failure patients. However, therein lies the challenge of finding suitable donors especially from deceased organ donors. Hence, living organ donation from related or unrelated individual is performed. In Malaysia, living organ donation, especially from unrelated organ donors are strictly governed through various guidelines and policies to prevent organ commercialization, trafficking and unethical transplant practices.

The pursuit of unrelated living donation introduces a set of unique challenges that must be navigated with utmost care to safeguard the donors' rights, protect against exploitation and ensure that every donation is made willingly without coercion. All cases of living-unrelated donation must undergo assessment by donor advocates, evaluation from the Unrelated Transplant Approval Committee (UTAC) and finally the approval by the Director General of Health.

Thus, it is with great pleasure that I introduce the Independent Donor Advocate Team (IDAT) module. This training module serves as a testament to the commitment by this Program to ensure the highest standards of medical care and ethics is delivered by a group of well trained and knowledgeable healthcare professionals in conducting the donor advocacy assessment for potential organ donors.

I extend my heartfelt congratulations to the team at the National Transplant Resource Centre, Transplantation Services of the Medical Development Division and all the healthcare professionals involved in producing this training module. Finally, to all healthcare professional in the past, present and future who has been or will be part of this exceptional group, I would like to personally express my deepest appreciation for your commitment and support for the National Transplantation Programme.

FOREWORD

BY THE DIRECTOR OF NATIONAL TRANSPLANT RESOURCE CENTRE

DR ABDUL GHANI BIN ABDUL JALIL
Director
National Transplant Resource Centre

Organ transplantation has long been considered the gold standard of treatment for end-stage organ disease, offering a higher graft survival rate from living donors and a lower treatment cost compared to haemodialysis.

The emergence of organ transplantation involving unrelated donors and paired exchange has necessitated the development of a national policy aimed at safeguarding ethical informed consent for a unique population—the unrelated living donors—who do not derive any medical benefit from the donation.

In line with Malaysia's policy and guidelines, it is imperative to establish an independent body tasked with evaluating prospective donors. This ensures that the act of donation is altruistic, autonomous, and based on a fully informed decision.

The unrelated transplant approval process entails conducting an interview with the prospective donor by the Independent Donor Advocate Team (IDAT) panel members. The latter's responsibility is to assess the prospective donor's understanding of the transplant procedure, their motivation to donate, and the relationship they have with the recipient undergoing transplantation. This step is crucial in ensuring that the prospective donor has received comprehensive information about the pre-, intra-, and post-transplant procedures during counselling sessions with the healthcare professionals at the transplant center. It also establishes that the prospective donor's decision to donate is not influenced by external factors. The IDAT's finding will be presented to the Unrelated Transplant Approval Committee (UTAC) for further evaluation before a recommendation is made to the Director General of Health for final approval.

In April 2023, ten IDAT panel members convened to develop a training module for future panel members. The objective is to equip them with the necessary knowledge to provide living donor advocacy service in our country. We hope that the publication of this module will not only promote but also expand this area of service to a higher level, thus contributing to the creation of a healthier population with improved healthcare quality.

IDAT

INDEPENDENT DONOR ADVOCATE TEAM

The unsung heroes of transplantation – the donor advocates. They are the compassionate catalysts, bridging hope with reality, connecting patients in need with the gift of life. Their dedication turns dreams into second chances, proving that humanity's greatest strength lies in giving. The above picture shows the IDAT Panel Members and Secretariats for the May 2023's full-day Independent Donor Advocate Team (IDAT) Training Module Development workshop, held in the heart of Kuala Lumpur.

a Gift of Life

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Chapter
4

The Role of Medical Social Workers in Psychosocial Assessment for Unrelated Living Donation

OUTLINE

I. INTRODUCTION

The field of organ transplantation relies on the generosity and altruism of donors, contributing their organs to save the lives of others. Living donor transplantation offers significant advantages in terms of patient outcomes and reduced wait times compared to deceased donor transplantation. There is a critical need for comprehensive training for healthcare professionals to address the gaps and challenges in donor advocacy:

i. *Knowledge gap*. Limited awareness about the benefits, risks and eligibility criteria associated with living organ donation hampers the ability of healthcare professionals to educate prospective donors about the life-saving opportunities of transplantation;
ii. *Inadequate training and donor advocate pool*. Currently, there is a lack of standardized training programs dedicated to donor advocacy. The low potential pool of donor advocates across healthcare facilities in the country hampers expansion for a better donor advocacy service.
iii. *Communication challenge*. Healthcare professionals need effective communication strategies for engagement with prospective donors. Without adequate training, healthcare professionals may feel ill-equipped to address sensitive topics and navigate complex conversations on living donation, potentially discouraging the prospective donors from making informed decision.

This training module will equip healthcare professionals the necessary knowledge, skills and resources to understand, educate and support prospective living donor's decision-making process upon opting for transplantation. The benefits of this training module include:

i. *Increased awareness*. This module will enhance the understanding of living organ donation, providing with knowledge and key skills to correctly assess prospective donor's understanding about organ transplantation;

ii. *Improved donor advocacy*. Healthcare professionals equipped with comprehensive knowledge and skills in donor advocacy will be tactful in addressing misconceptions and communicate effectively with prospective donors;

iii. *Enhanced patient outcomes*. Through improving the engagement of prospective living donors and increasing donor advocate pools, the module will lead to improved patient outcomes including reduced waiting times and improved organ quality.

iv. *Standardized and consistent practice*. A standardized training module shall ensure consistent practices in donor advocacy across healthcare facilities, streamlining the application process, increasing efficiency and providing better care for prospective living donors.

The Independent Donor Advocate Team Training of Trainers (IDAT TOT) is a one-day training course that is part of requirement upon appointment as a Donor Advocate (DA). Prospective donors and recipients requiring Unrelated Transplant Approval Committee's (UTAC's) recommendation prior proceeding for transplantation will require evaluation by IDAT.

The role of IDAT in general is to carefully evaluate the prospective unrelated living donor's understanding of the risks and benefits carried in the transplant procedure and provide them with the necessary information required to make an informed consent. This ensures that the act of donation is altruistic and the donor has made an informed decision to donate autonomously.

The team consists of primarily three DAs from three disciplines – Physicians from Internal Medicine Department (DA-M), Psychiatrists from Psychiatry Department (DA-PSY) and Medical Social Workers from Medical Social Work Department (DA-SW). The National Transplant Resource Centre (NTRC) acts as a secretariat for both IDAT and the Transplantation Unit is involved in the secretariat role for UTAC.

This training module for healthcare professionals is pivotal in addressing the existing knowledge gaps and barriers in fostering effective engagement of prospective living donors. It is hoped that it will equip healthcare professionals with the necessary knowledge and skills, enabling for an effective donor advocacy and ultimately improving patient outcomes in the field of organ donation and transplantation.

II. OBJECTIVES

a. Main objective

To empower the Independent Donor Advocate Team (IDAT) panel members in performing evaluations on the unrelated living donor, where the findings of the evaluation will be presented to the Unrelated Transplant Approval Committee (UTAC) for further recommendation prior final approval by the Director General (DG) of Health.

b. Specific objectives

i. **To introduce knowledge and skills among newly appointed IDAT panel members** in delivering a comprehensive evaluation for unrelated living donation.

ii. **To identify, train and appoint physicians, psychiatrists and medical social workers as IDAT panel members**, capable of performing evaluation on unrelated living donor.

iii. To decentralize the service to other states/regions, **providing better accessibility for prospective donor** who will be attending IDAT evaluation.

iv. To **decrease the waiting time** for IDAT evaluation and UTAC approval recommendation.

III. TARGET GROUPS

i. Physicians
ii. Psychiatrists
iii. Medical Social Workers

IV. OUTCOMES

At the end of this course, participants will be able to:

i. Describe the role of UTAC and the approval process in unrelated living transplant;
ii. Describe the composition of IDAT panel and its function in the approval process;
iii. Describe the process of medical, psychiatrist and psychosocial assessments in donor advocacy;
iv. Perform the evaluation of prospective donor in unrelated living donation and provide recommendation to the UTAC;
v. Become a certified IDAT member and attend donor assessment as required by the secretariat.

V. BASIC FACILITY REQUIREMENT

a. Room layout

i. A comfortable, well-lit, and ventilated room with adequate quantity of tables and seatings to accommodate the expected number of participants.
ii. An adequate space for the speaker to stand during their presentation in front of the participants as well as for skill building activity.
iii. The room should have/able to accommodate an overhead projector and a projection screen including the audio-visual equipment listed below.

b. Audio-Visual Technical Requirement

i. Laptop
ii. Audio Speaker
iii. Microphone (2)
iv. LCD projector
v. Projection screen
vi. Ensure a technician in charge is available on standby to troubleshoot any potential technical problems

c. Course Materials

i. Digital copy of the presentation slides will be distributed prior to the workshop.

ii. A printed materials for skill building activity will be provided during the session.

VI. MODULE ACTIVITY

For lecture component module, activities for trainers and participants are as follows:

i. TRAINER

- Lecture/discussion/interactive activity

ii. PARTICIPANT

- Interactive discussion

iii. AUDIO VISUAL AIDS/TEACHING MATERIALS

- PowerPoint presentation slides prepared by the trainer

iv. ASSESSMENT/EVALUATION

- None

v. TIME

- Refer to item VII: Programme.

VII. PROGRAMME

TIME	ACTIVITY	DURATION
8.00 am – 8.30 am	Registration	30 Minutes
8.30 am – 9.00 am	Introduction to Unrelated Transplant Approval Committee (UTAC)	30 Minutes
9.00 am – 9.30 am	Introduction to Independent Donor Advocate Team (IDAT)	30 Minutes
9.30 am – 9.45 am	Q&A Session	15 Minutes
9.45 am – 10.00 am	Tea Break	15 Minutes
10.00 am – 11.00 am	The Role of Physicians in Unrelated Living Donor Advocacy	1 Hour
11.00 am – 12.00 pm	The Role of Psychiatrist in Psychological Assessment for Unrelated Living Donation	1 Hour
12.00 pm – 1.00 pm	The Role of Medical Social Worker in Psychosocial Assessment for Unrelated Living Donation	1 Hour
1.00 pm – 2.00 pm	Lunch	1 hour
2.00 pm – 3.30 pm	IDAT Panel Skill Building	1 hour 30 minutes
3.30 pm – 4.45 pm	Group Presentation & Discussion	1 hour 15 minutes
4.45 pm – 5.00 pm	Closing	15 minutes

Pusat Sumber Transplan Nasional
KUALA LUMPUR

Chapter 1

IDAT
INDEPENDENT DONOR ADVOCATE TEAM

The Unrelated Living Transplant

The Unrelated Living Transplant

A. Introduction to the Unrelated Transplant Approval Committee (UTAC)

i. LEARNING OBJECTIVES

1. To understand the living transplant program in Malaysia.
2. To understand the roles and responsibilities of UTAC.
3. To understand the unrelated living transplant approval process.

ii. CONTENTS

1. OVERVIEW OF TRANSPLANT SERVICES

1.1. BACKGROUND

a. Performed by Datuk Dr Hussein Awang on 15 December 1975 in Hospital Kuala Lumpur.
b. Living organ donation from a donor-recipient brothers from Sarawak.
c. Both surgeries were uneventful.
d. Renal transplant recipient survived for 31 years.
e. Died in 2006 following a cat bite.

1.2. ORGAN AND TISSUE DONATION

a. Living Donation:

i. Organs: One kidney, part of liver.
ii. Consanguinity: Related, unrelated.

b. Deceased Donation:

i. Organs: Heart, lungs, whole liver, both kidneys, bone, skin.

1.3. THE STAKEHOLDERS

a. The Recipients and the Donor.

i. Patient engagement and education regarding the transplantation process;
ii. Understanding the process and being well informed prior decision making.

b. The Transplant Physicians.

i. Participation in education & training;
ii. Capability at point of care;
iii. Quality management and safe practices;
iv. Communication & teamwork.

c. Transplant Advocates.

i. Education & training;
ii. Complete, objective assessment of living donor;
iii. Communication & teamwork.

d. Approval Committee.

i. Evaluation of applications, advocate reports, documents & clinician reports.
ii. Propose & recommend committee findings to the DG of Health.

1.4. THE TRANSPLANT CENTRES

Centres	Heart	Lung	Kidney	Liver	Cornea
Hospital Kuala Lumpur			✓	✓	✓
Hospital Selayang			✓	✓	✓
Hospital Sungai Buloh					✓
IJN, KL	✓	✓			
Hospital Tunku Azizah, KL				✓ (Paediatric Liver)	
UMMC			✓	✓	✓
Prince Court Medical Centre			✓	Living Renal Transplants	
Sunway Medical Centre			✓		
Mahkota Medical Centre			✓		
Island Hospital Penang			✓		

2. ABOUT UTAC

2.1. UTAC main function is described under Section 8 of the Unrelated Living Organ Donation: Policy & Procedures (2011).

2.2. Recommendation for approval by UTAC has also been stated in the MOH Circular (2012).

2.3. The Purpose of UTAC:

a. *To safeguard the interest of living organ donors*
   i. Assessing willingness and ensuring free from coercion;
   ii. Ensuring donors are competent towards decision making to give consent;
   iii. Ensuring donor and recipient are fully informed of the risk and benefit of the transplant procedure;
   iv. Adequately evaluated.

b. *Preserve the ethical standards in organ donation and transplantation.*

c. *WHO Guiding Principles of Human Cell Tissue and Organ Transplantation 2010;*

d. *The Declaration of Istanbul on Organ Trafficking and Transplant Tourism 2008.*

2.4. The Committee is:

a. *Independent* – The committee is not affiliated to any person(s) with interest of the cases;

b. *Appointed by the DG of Health* – Chairperson & members are appointed by the DG of Health consisting of doctors and non-doctors;

c. *To fulfil their Role* – Assess, evaluate and advise on the appropriateness for approval of all applications for Living Unrelated Organ Transplant.

2.5. Degree of Relationship.

Degree of Consanguinity	Example	
First degree relative	Mother Daughter Full sister (including heterozygous twin/multiple twins)	Father Son Full brother (including heterozygous twin/multiple twins)
Second degree relative	Grandmother Granddaughter Aunt Niece Half sister	Grandfather Grandson Uncle Nephew Half brother
Third degree relative	Great grandmother Great granddaughter Great aunt First female cousin Grand niece	Great grandfather Great grandson Great uncle First male cousin Grand nephew

2.6. Unrelated Living Donation

Types of Living Donor			UTAC Approval
Malaysian Citizen	Genetic relationship	Homozygous twin	No
		First degree	No
		Second degree	No
		≥ Third degree	Yes
	Emotional relationship	Spouse	Yes
		Others	Yes
Non-Malaysian Citizen (Both related and not related)			Yes

a. All applications for unrelated living organ donation **MUST** undergo assessment and evaluation by the Unrelated Transplant Approval Committee (UTAC).

b. All applications for unrelated living organ donation **MUST** fulfil the following criteria:

   i. No available cadaveric donors;

   ii. No suitable living related organ donor from the recipient close relatives.

c. All living organ transplantation involving foreign nationals (Non-Malaysians) **MUST** undergo assessment and evaluation by the Unrelated Transplant Approval Committee.

d. All transplant clinicians are responsible to determine the degree of relationship between potential donor-recipient pair. If the relationship between the potential donor-recipient pair cannot be determined, the case **MUST** be referred to the UTAC.

e. All living organ donation **MUST** be reported to the National Transplant Resource Centre monthly.

2.7. Cases requiring UTAC authorization.

a. Organ transplant involving non-Malaysians;

b. Organ transplant involving unrelated living donor:

   i. Genetic relationship beyond 2nd degree;

   ii. Emotional relationship other than spousal;

   iii. Doubtful cases/difficulty to ascertain relationship status.

3. ABOUT THE PROCESS

3.1. The application process.

No	Description	Acting Secretariat
1	Application from Transplant Centres	National Transplant Resource Centre (IDAT)
2	IDAT assessment	
3	UTAC Committee Meeting	Transplant Services, MOH (UTAC)
4	DG's Approval to applicants	

3.2. UTAC evaluation

a. 5 – 7 team members are appointed (3-5 UTAC members, 2-7 Technical Advisors);

b. Confidential process;

c. Declaration of Conflict of Interest and Confidentiality;

d. Review application and all relevant documents;

e. Review report by the IDAT team.

3.3. Principle

a. UTAC is not responsible for judging clinical appropriateness of any transplant;

b. Approval of UTAC does not clear clinicians from the clinical responsibility towards patient management;

c. UTAC approval is only valid if patient's condition remains the same at the time of transplant with what was reported to UTAC.

3.4. Challenges in evaluations.

a. Legibility of handwriting;

b. Completeness of information & Donor Advocate assessment;

c. Final recommendation from Donor Advocates;

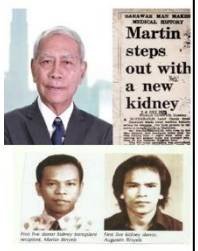
d. Ethical consideration.

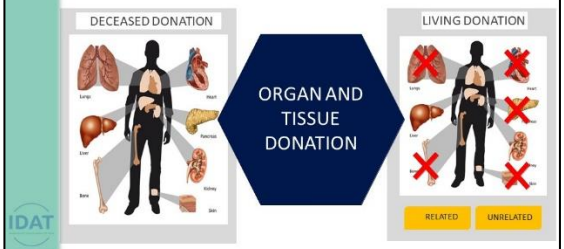
Unrelated Transplant Approval Committee: An Introduction

Overview of Transplant Services

Background

- Performed by Datuk Dr Hussein Awang on 15 December 1975
- Hospital Kuala Lumpur
- Living organ donation from a donor-recipient brothers from Sarawak
- Both surgeries were uneventful
- Renal transplant recipient survived for 31 years
- Died in 2006 following a cat bite





The Stakeholders

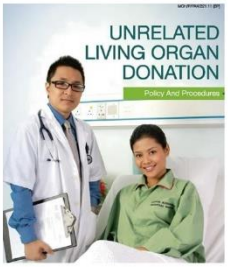
Transplant Centres

Centres	Heart	Lung	Kidney	Liver	Cornea
Hospital Kuala Lumpur			✓	✓	✓
Hospital Selayang			✓	✓	✓
Hospital Sungai Buloh					✓
IJN, KL	✓	✓			
Hospital Tunku Azizah, KL				✓ Paediatric Liver	
UMMC			✓	✓	✓
Prince Court Medical Centre			✓		
Sunway Medical Centre			✓		
Mahkota Medical Centre			✓		
Island Hospital Penang			✓		

Living renal transplants

About UTAC

Unrelated Living Organ Donation: Policy & Procedures



CONTENT

KETUA PENGARAH KESIHATAN MALAYSIA
DIRECTOR-GENERAL OF HEALTH MALAYSIA

Rujukan Kami : KKM/BP(JP2)/1366 (15)
Tarikh : 4 Januari 2012

Semua Pengarah Kesihatan Negeri
Pengarah Hospital Kuala Lumpur

Yang Berbahagia Tuan/Puan,

SURAT PEKELILING KETUA PENGARAH KESIHATAN BILANGAN 1 TAHUN 2012: GARISPANDUAN PENDERMAAN ORGAN DARI PENDERMA HIDUP TIADA KAITAN KEKELUARGAAN

Dengan segala hormatnya saya merujuk kepada perkara di atas.

2. Sebagai sebahagian dari komitmen Kementerian Kesihatan di dalam melaksanakan ***WHO Guiding Principles on Human Cell Tissue and Organ Transplantation*** tahun 2010 dan **Polisi Transplantasi Organ Tisu dan Sel Kebangsaan** tahun 2007, Program Perubatan telah menerbitkan satu garispanduan mengenai pendermaan organ dari penderma hidup tiada kaitan kekeluargaan, ***"Unrelated Living Organ***

4. Dasar pendermaan organ dari penderma hidup adalah seperti berikut:

a. Semua pendermaan organ dari penderma hidup yang tidak mempunyai hubungan kekeluargaan perlu dinilai terlebih dahulu oleh Jawatankuasa Bebas "Unrelated Transplant Approval Committee (UTAC)";
b. Pendermaan organ dari penderma hidup yang tidak mempunyai hubungan kekeluargaan perlu memenuhi kriteria seperti berikut:
   i. ketiadaan penderma kadaverik;
   ii. ketiadaan penderma hidup yang bersesuaian dari kalangan ahli keluarga terdekat;
c. Semua pembedahan transplan yang melibatkan warganegara asing juga perlu dinilai terlebih dahulu oleh UTAC.
d. Adalah menjadi tanggungjawab pakar yang terlibat untuk membuat kepastian mengenai status hubungan di antara penderma dan penerima untuk setiap kes. Sekiranya status hubungan kekeluargaan untuk sesuatu kes diragui atau sukar untuk dipastikan, pakar yang berkenaan bertanggungjawab untuk merujuk kes tersebut kepada UTAC.
e. Semua kes transplan dari penderma hidup perlu dilaporkan kepada Pusat Sumber Transplan Nasional setiap bulan. Semua kes transplan dari penderma hidup juga perlu dilaporkan kepada Registri Transplan Nasional.

IDAT

The **Purpose**

- Safeguard the interest of living organ donors
  - ✓ Willingness, free from coercion
  - ✓ Competent
  - ✓ Fully informed of the risk and benefit (donor and recipient)
  - ✓ Adequately evaluated
- Preserve the ethical standards in organ donation and transplantation
  - WHO Guiding Principles of Human Cell Tissue and Organ Transplantation 2010
  - The Declaration of Istanbul on Organ Trafficking and Transplant Tourism 2008

IDAT

The **Committee**

IDAT

DEGREE OF RELATIONSHIP

Degree of Consanguinity	Example	
First degree relative	Mother Daughter Full sister (including heterozygous twin/multiple twins)	Father Son Full brother (including heterozygous twin/multiple twins)
Second degree relative	Grandmother Granddaughter Aunt Niece Half sister	Grandfather Grandson Uncle Nephew Half brother
Third degree relative	Great grandmother Great granddaughter Great aunt First female cousin Grand niece	Great grandfather Great grandson Great uncle First male cousin Grand nephew

Table 1: Summary on Degree of Consanguinity

IDAT

UNRELATED LIVING DONATION

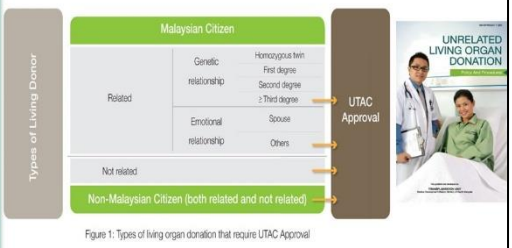


Figure 1: Types of living organ donation that require UTAC Approval

IDAT

Unrelated Living Organ Donation

- All applications for **unrelated-living organ donation MUST** undergo assessment and evaluation by the **Unrelated Transplant Approval Committee**
- All applications for living-unrelated organ donation **MUST** fulfill the following criteria:
  - No available cadaveric donors
  - No suitable living-related organ donor from the recipient close relatives

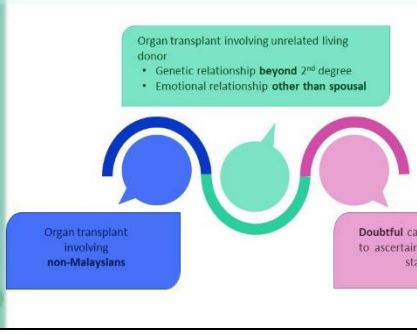
IDAT

Unrelated Living Organ Donation

- All **living organ transplantation involving foreign nationals** (Non- Malaysians) MUST undergo assessment and evaluation by the Unrelated Transplant Approval Committee
- All transplant clinicians are responsible to determine the degree of relationship between potential donor-recipient pair. **If the relationship between the potential donor-recipient pair cannot be determined**, the case MUST be referred to the UTAC
- All living organ donation MUST be reported to the National Transplant Resource Centre monthly

IDAT

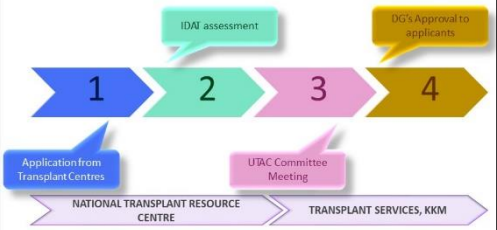
Cases requiring UTAC authorization



IDAT

About The Process

Application Process



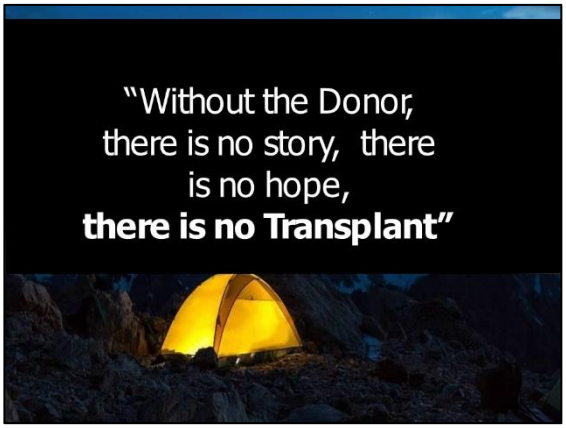
UTAC evaluation

Principle

- UTAC is not responsible for judging clinical appropriateness of any transplant
- Approval of UTAC does not clear clinicians from the clinical responsibility towards patient management
- UTAC approval is only valid if patient condition remain the same at the time of transplant with what was reported to UTAC

Challenges in evaluations

- Legibility of handwriting
- Completeness of information & Donor Advocate assessment
- Final recommendation from Donor Advocates
- Ethical consideration



B. Introduction to the Independent Donor Advocate Team (IDAT)

A. LEARNING OBJECTIVES

i. To understand the general concept of Donor Advocates in unrelated living transplant in Malaysia.

B. CONTENTS

1. SITUATION AND CHALLENGE

1.1. In our line of work, we witness the complexities and challenges faced by patients and their families as they navigate the organ transplant journey. There is a delicate balance between preserving life and respecting an individual's autonomy.

1.2. Living donors are a ***special group of population***. They are healthy people exposed to surgical procedures that pose risks but offer no physical benefits to them.

1.3. Currently, living donors contribute to the majority of kidney and liver transplantations in Malaysia.

1.4. The rights and well-being of potential organ donors need to be ***safeguarded*** throughout the process. Without a safeguard mechanism, living donors are ***exposed to coercion*** by other parties and may be unable to exercise autonomy and informed consent.

1.5. Healthcare workers can ensure informed consent and avoid potential conflict of interest for the prospective living donors through Independent Donor Advocate Team. The Policy and Guidelines on Unrelated Living Donation was introduced by the Ministry of Health (MoH) Malaysia in 2011 outlining the application process for unrelated living donation approval.

2. INTRODUCTION

2.1. IDAT is a group of at least three (3) donor advocates, specially appointed for the evaluation process of prospective donors

2.2. The donor advocates are (i) Medical (Physician), (ii) Psychiatrist and (iii) Medical Social Worker.

2.3. The donor advocate shall be independent and are not involved in the care of prospective recipient.

2.4. This is to minimize potential conflict of interest

3. ROLE

3.1. IDAT panel's role is to carefully evaluate the prospective donor and provide him/her with necessary information required to make an informed consent.

4. GOAL

4.1. The IDAT panel's goal is to verify that the fact of donation is:

1. Altruistic, and;
2. Autonomous and informed decision by the prospective donor.

5. THE DONOR ADVOCATE: MEDICAL

5.1. Physicians build trust and rapport with patients to educate and guide them through the complex process of organ donation. The former provides the prospective donors with necessary information to make informed decisions, all while ensuring their well-being and autonomy are respected.

5.2. The DA: Medical shall be a specialist doctor

5.3. The Donor Advocate: Medical's role is to ensure that the nature of the transplant procedure has been explained in depth to the potential donor, including:

a. Donor evaluation procedure;
b. Surgical procedure;
c. Recuperative period;
d. Short- and long-term follow-up care;
e. Alternative donation and transplant procedure;
f. Potential psychological benefits to the donor;
g. Transplant centre and surgeon specific statistics of donor and recipient outcome;
h. Confidentiality of donor's information and decision
i. Donor's ability to withdraw at any point in the process;
j. Information on how the transplant centre will attempt to follow up on the health of the donor for life.

5.4. Shall ensure that the prospective donor understands the explanation, including the risks of the operation and any wider implications, which include:

a. Potential for surgical complications including risk of donor death;
b. Potential for medical complications including long-term complications;
c. Scars, pain, fatigue, abdominal symptoms.

5.5. Shall be satisfied that the consent for the removal of the organ was not obtained by coercion or the offer of an inducement.

5.6. Shall ensure that the donor has been made aware of the right to change his mind at any time.

5.7. Assistance by an interpreter may be required in certain cases – difficulties in communicating.

6. THE DONOR ADVOCATE: PSYCHIATRIST

6.1. Psychiatrists addresses the emotional and psychological aspects of organ transplantation. They provide invaluable support by understanding and addressing the fears, anxieties, and ethical dilemmas that may arise during the donation process. Their expertise in mental health will help ensure the holistic well-being of both donors and recipients.

6.2. The DA: Psychiatrist makes an in-depth evaluation of the potential donor to assess his emotional and psychosocial stability and capability to make an informed decision.

6.3. They shall determine the motivation to donate, presence of anxiety or conflict in decision to donate.

6.4. Shall also ensure that the donor's decision was not made under any duress or coercion.

6.5. Shall identify and help the prospective donor to consider various option in preparing him/herself for any potential problems such as:

a. Potential problems with body image;
b. Possibility of recipient death;
c. Possibility of recipient rejection and loss of organ;
d. Impact on donor's family including position from relatives;
e. Possibility of adjustment disorder post-surgery and post-surgery depression
f. Potential impact of donation on lifestyle

6.6. May also interview family members of the prospective donor when necessary.

7. THE DONOR ADVOCATE: MEDICAL SOCIAL WORKER

7.1. Medical Social Work Officers are the backbone of patient support, navigating the complex healthcare systems and providing vital resources to patients and families. As advocates, they are involved in ensuring the concerns of donors are heard and addressed.

7.2. The DA: MSW obtains a detailed social history of the potential donor and recipient to confirm the nature of their relationship.

7.3. They also assess education background, financial status and social support available in the event of problems.

7.4. They determine the financial stability of the potential donor so as to preclude financial incentives as a motivating factor for donation.

7.5. Issues of reimbursement and potential financial hardships should be considered include:

a. Hospitalization costs and out-of-pocket expenses;
b. Losses incurred from time off-work;
c. Loss of income and possible loss of employment;
d. Potential impact on ability to obtain future employment;
e. Impact on ability to obtain medical and life insurance in the future.

8. AN OVERVIEW OF THE APPLICATION PROCESS FOR THE LIVING UNRELATED TRANSPLANT

Step	Action	Description
1	Applicant sends application forms to NTRC HKL (IDAT Secretariat)	Applicant is either a doctor responsible for the prospective donor or the prospective recipient. Applicant to submit: **a. Form A** Application for Living Unrelated Transplant; **b. Form B** Declaration by the Prospective Living Donor; **c. Form C** Declaration by the Prospective Recipient; d. Other documents as per **Checklist B**
2	Evaluation of the prospective donor by IDAT	IDAT will fill in: **a. Form D** Donor Evaluation- Medical; b. **Form E** Donor Evaluation – Psychiatrist; c. **Form F** Donor Evaluation- Medical Social Worker
3	Evaluation of the case by UTAC	Secretariat will prepare documents as per **Checklist A** for the UTAC member
4	DG of Health will inform the applicant about the decision	

IDAT

THE INDEPENDENT DONOR ADVOCATE TEAM (IDAT)

Content

Situation & Challenge

- Navigating the organ transplant process
- Special population group
- Contributes to the solid organ transplant in Malaysia
- Ensuring rights and well-being are safeguarded
- Exposure to coercion, preventing autonomy and informed consent
- How to ensure informed consent and avoid COI?

Introduction

- Is a group of at least three donor advocates specially appointed for the evaluation process of prospective donors

- Donor advocate shall be independent and are not involved in the care of prospective recipient
- To minimize conflict of interest

GOAL

IS TO VERIFY THAT THE FACT OF DONATION IS ALTRUISTIC, IS AN AUTONOMOUS AND INFORMED DECISION

IDAT

The Donor Advocate: MEDICAL

IDAT

- Educate and guide prospective donors through the donation process
- Provide necessary information to make informed decisions
- All while ensuring donor's well-being and autonomy are respected

IDAT

- Shall be a specialist doctor.
- Role is to ensure that the nature of the transplant procedure has been explained in depth to the potential donor, including:
  a. Donor evaluation procedure;
  b. Surgical procedure;
  c. Recuperative period;
  d. Short and long term follow-up care;
  e. Alternative donation and transplant procedure;
  f. Potential psychological benefits to the donor;
  g. Transplant centre and surgeon specific statistics of donor and recipient outcome;

IDAT

h. Confidentially of donor's information and decision;
i. Donor's ability to withdraw at any point in the process;
j. Information on how the transplant centre will attempt to follow up on the health of the donor for life.

IDAT

- Shall ensure that the prospective donor understands the explanation, including the risks of the operation and any wider implications
  a. Potential for surgical complications including risk of donor death
  b. Potential for medical complications including long-term complications
  c. Scars, pain, fatigue, abdominal symptoms
- Shall be satisfied that the consent for the removal of the organ was not obtained by coercion or the offer of an inducement
- Shall ensure that the donor has been made aware of the right to change his mind at any time
- Assistance by an interpreter may be required in certain cases – difficulties in communicating

IDAT

The Donor Advocate: PSYCHIATRIST

- Address emotional and psychological aspects
- Fears, anxieties, and ethical dilemmas that may arise during the process
- Expertise in mental health – ensure holistic well-being

- Must make an in-depth evaluation of the potential donor to assess his emotional and psychosocial stability and capability to make an informed decision.
- Shall determine the motivation to donate, presence of anxiety or conflict in decision to donate
- Shall also ensure that the donor's decision was not made under any duress or coercion.

Shall identify and help the prospective donor to consider various option in preparing himself/herself for any potential problem such as:

a) Potential problems with body image;
b) Possibility of recipient death;
c) Possibility of recipient rejection and loss of organ;
d) Impact on donor's family including position from relatives;
e) Possibility of adjustment disorder post surgery and post surgery depression;
f) Potential impact of donation on lifestyle.
   - May also interview family members of the prospective donor when necessary

The Donor Advocate: MEDICAL SOCIAL WORKER

- Backbone of patient's support
- Provide vital resources to patients and families
- Ensures the voices and concerns of donors are heard and addressed.

- Must obtain a detailed social history of the potential donor and recipient to confirm the nature of their relationship
- Also assess education background, financial status and social support available in the event of problems
- Determine the financial stability of the potential donor so as the preclude financial incentives as a motivating factor for donation

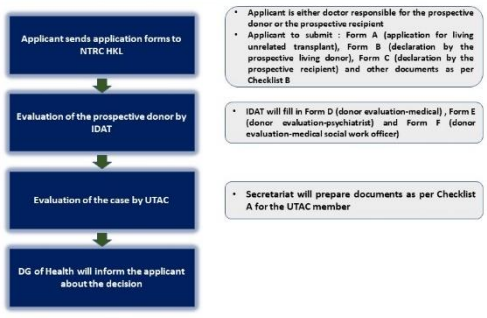
IDAT

Issues of reimbursement and potential financial hardships should be considered include:

a. Hospitalization costs and out of pocket expenses;
b. Losses incurred from time off work;
c. Loss of income and possible loss of employment
d. Potential impact on ability to obtain future employment;
e. Impact on ability to obtain medical and life insurance in the future.

IDAT

An Overview of the Application Process for the Living Unrelated Transplant



IDAT

IDAT

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KUALA LUMPUR

Chapter 2

The Role of Physicians in Unrelated Donor Advocacy

Chapter 2

The Role of Physicians in Unrelated Living Donor Advocacy

A. LEARNING OBJECTIVES

i. To understand the living donation program in Malaysia
ii. To understand the application process for unrelated living donation
iii. To understand and describe the function and role of Donor Advocate: Medical in IDAT for evaluation

B. CONTENTS

1. INTRODUCTION

1.1. Burden of the Problem

a. According to the 2007 OPTN/SRTR annual report, new candidates for kidney transplantation in the United States – 22, 337 in 2001 to 31, 495 in 2006.

b. With annual growth of 8-9% in the number of new registrants without a parallel increase in the number of organs, these figures mean prolonged waiting time for kidney transplantation.

1.2. Local

a. As reported by the WHO through the Global Observatory in Donation and Transplantation (GODT), Malaysia's deceased organ donation rate is equivalent to 0.64 donations per million population.

b. On the other hand, it was estimated that as many as 11,000 patients were waiting for organs in our country.

c. Therefore, current organ donation rate is unable to meet the increasing demands.

2. BENEFITS OF LIVING DONATION

2.1. Shorter waiting time
A patient with kidney failure usually waits for several years to receive deceased donor kidneys. However, with a suitable living donor such transplant can be done within weeks.

2.2. Living donation is an elective surgery
This means the transplant surgery can be done when both donor and recipient are in the best of health for surgery. Living donor transplant surgery can be electively scheduled to suit the donor and recipient.

2.3. Organs from living donors work better
Most of the time the kidney from living donor works immediately after surgery and continues to work better and longer than kidney from a deceased donor.

3. TRANSPLANT CENTRES

3.1. The major public transplant centres in this country are;
a. **Hospital Kuala Lumpur** – Kidney Transplantation
b. **Hospital Selayang** – Kidney Transplantation, Liver Transplantation
c. **University Malaya Medical Centre** – Kidney Transplantation
d. **National Heart Institute** (in collaboration with Respiratory Medicine Institute) – Heart & Lungs Transplant

4. OBJECTIVES

4.1. To safeguard the interest and welfare of living organ donors.

4.2. To preserve ethical and professional standards in organ donation and transplantation in the country.

4.3. To ensure living donors are adequately and appropriately informed about the surgical procedures in line with the principle of informed consent.

4.4. To ensure living donors receive adequate and appropriate medical, psychiatric and psycho-social evaluation before the surgical procedures.

5. UNRELATED TRANSPLANT APPROVAL COMMITTEE (UTAC)

5.1. UTAC is an independent committee set up by the Ministry of Health to evaluate every application for unrelated living organ donation.

5.2. The donor cannot apply directly to UTAC; only the doctor responsible for the potential donor or a doctor responsible for the potential recipient can apply to UTAC

5.3. The doctor needs to do a preliminary assessment on the potential donor to determine the suitability to be a living donor. If the doctor is satisfied with the suitability, he/she will then apply to UTAC by filling in some official forms.

5.4. The prospective donor will then have to undergo a series of interviews with independent donor advocates.

6. THE ROLE OF THE ADVOCATE

6.1. Ensures the donor knows the risk and benefits of donor process.

6.2. Ensures the rights of the donor.

6.3. Ensures the process of organ procurement is free of exploitation, monetary gains/involvement and is truly voluntary.

7. MORTALITY RISK

7.1. Mortality risk for organ donation differs between kidney and liver donation:

Type of organ donation		Donor Mortality risk
i.	Kidney donation	3.1 deaths in 10,000 donations
ii.	Liver donation	Right lobe liver: 1 death in 200 donations Left lobe liver: 1 death in 1000 donation

8. PREREQUISITES REQUIRING APPROVAL

8.1. Prior authorisation shall be obtained from the Unrelated Transplant Approval Committee (UTAC) before any organ transplantation involving unrelated living donor can take place. Such organ donation must fulfil the following criteria:

a. No available cadaveric donor;

b. No compatible donor by genetics or;

c. Emotionally related individuals.

9. DONOR SOURCE FOR UTAC

Degree of Consanguinity	Example	
i. 1° relative	Mother Daughter Full sister (including heterozygous twin/multiple twins)	Father Son Full brother (including heterozygous twin/multiple twins)
ii. 2° relative	Grandmother Granddaughter Aunt Niece Half sister	Grandfather Grandson Uncle Nephew Half brother
iii. 3° relative	Great grandmother Great granddaughter Great aunt First female cousin Grand niece	Great grandfather Great grandson Great uncle First male cousin Grand nephew

10. THE INDEPENDENT DONOR ADVOCATE TEAM (IDAT)

10.1. IDAT is a group of at least **three** (3) donor advocates specifically appointed for the evaluation process of prospective donors.

10.2. It shall consist of a medical donor advocate, a psychiatrist and a medical social work officer. Donor advocates shall be independent and are not involved in the care of the prospective recipient. This is to minimise conflict of interest.

10.3. The role of IDAT in general is to carefully evaluate the prospective living donor and provide him/her with necessary information required to make informed consent.

10.4. The goal of IDAT is to verify that the act of donation is altruistic, is an autonomous and informed decision.

10.5. IDAT shall submit and independent report to the UTAC using Form D, Form E and Form F. Each donor advocate shall evaluate the prospective donor separately.

11. CLINICAL INVESTIGATIONS

11.1. The prospective donor's blood and the recipient's blood will be taken for compatibility test:

a. Blood type: O, A, B or AB
b. HLA cross match
c. HLA typing

11.2. Once the initial tissue typing has been completed and a compatible potential donor is identified, the medical evaluation of that potential donor can continue.

11.3. Compatibility test will help to determine the risk of organ rejection. This will guide the transplant team on the level of anti-rejection drugs or immunosuppression to be used in the recipient.

11.4. This evaluation can take place at the transplant centers, or if the donor lives far away, many of these tests can be performed at the nearby hospital. These additional tests include:

i.	**Additional Blood Test**	This is to screen for transmissible diseases like HIV, Hepatitis B and others. This is also to assess your medical status such as presence of diabetes, heart disease and others.
ii.	**Urine Test**	In particular for kidney donation, 24 hours urine sample will be taken to assess your kidney function or presence of kidney stones. Usually, three samples are taken.
iii.	**Chest X-Ray**	This is to assess your lungs and your heart.
iv.	**Electrocardiogram (ECG)**	This is to screen for heart disease. Based on the ECG finding and other clinical reasons, further test may be required for evaluation of the heart such as stress test.
v.	**Ultrasound and Other Imaging e.g., CT scan**	This is to assess your liver and/or your kidney.
vi.	**Cancer Screening**	Types of tests will be determined by your transplant team.

vii.	**Psychosocial and Psychological Evaluation**	This is to assess your mental health, your ability to understand all information given and make and informed decision. The team will also asses your daily life circumstances.
viii.	**Consultation**	The transplant team including surgeon will give you further consultation and perform physical examination. Surgeon will explain about the nature of the surgery and risks.
ix.	**Others**	Some doctors may do liver biopsy for liver donation.

12. DONOR ADVOCATE: MEDICAL

12.1. The donor advocate for medical (**DA-M**) shall be a specialist doctor.

12.2. The DA-M's role is to ensure that the nature of the transplant procedure has been explained in depth to the potential donor. This should include:

a. Donor evaluation procedure;
b. Surgical procedure;
c. Recuperative period;
d. Short and long-term follow-up care;
e. Alternative donation and transplant procedures;
f. Potential psychological benefits to the donor;
g. Transplant centre and surgeon-specific statistics of donor and recipient outcomes.

12.3. DA-M also has to ensure the:

a. Confidentiality of donor's information and decision;
b. Donor's ability to withdraw at any point in the process;
c. Information on how the transplant centre will attempt to follow up on the health of the donor for life

12.4. DA-M shall ensure that the prospective donor understands the following explanations:

a. Risks of the operation and any wider implications e.g., the potential effects it may have to his work, family life and insurability.
b. Physical risks including:

i. Potential for surgical complications including risk of donor's death
ii. Potential for medical complications including long-term complications
iii. Scars, pain, fatigue, abdominal symptoms

12.5. Other risks associated with the surgery include:

a. Pain or numbness around the incision area.
b. Lung, urinary tract and wound infection. The chances of developing a lung infection can be reduced by breathing exercise.
c. Bleeding is uncommon. However, you may require a blood transfusion if necessary. It is important you also understand the risks associated with blood transfusion.
d. Blood clots may occur in your legs (Deep Vein Thrombosis) which may travel to the lung. This can be life threatening. You will be advised to wear compression stockings and ambulate early after surgery to prevent this from happening.
e. Anaesthetic complication including allergic reactions to anaesthetic drugs.
f. Injury to surrounding tissue or other organs.
g. Hernia. You should not do heavy lifting for four to six weeks after surgery to avoid this problem.

12.6. The DA-M shall be satisfied that the consent for the removal of the organ was not obtained by coercion or the offer of an inducement.

12.7. The DA-M shall ensure that the donor has been made aware of the right to change his mind at any time.

12.8. It is also important for the DA-M to report any difficulties in communicating with the potential donor (e.g., language, literacy level) and how this was overcome. Assistance by an interpreter may be required in certain cases.

13. NEGATIVE PSYCHOLOGICAL EFFECTS

13.1. Negative psychological symptoms are possible during the healing process and even years after the donation.

13.2. Your donated organ may not function in the recipient after it is transplanted.

13.3. Scarring or other aspects of the donation process could possibly contribute to problems with body image.

13.4. You may have feelings of regret, resentment or anger.

13.5. You may also develop anxiety and depression.

13.6. Treatment of these conditions can be lengthy and you may experience side effects of the medications used.

14. NEPHRECTOMY FOR KIDNEY DONATION

14.1. There are two (2) types of surgery for kidney donation; laparoscopic and open flank approach surgery.

14.2. An open flank surgery is a traditional approach which involves a flank incision about 15-20 cm on either your right or left side.

14.3. Both the skin and muscle need to be cut in order to reach the donor's kidney.

14.4. Laparoscopic surgery involves the use of tube-like instruments. The use of laparoscopic instruments allows the kidney to be removed through a smaller incision. The major benefits of this type of surgery are faster recovery time and less discomfort for the donor.

14.5. The surgical team will suggest to the donor types of surgery depending on the level of expertise and suitability of the donor and/or kidney.

15. HEPATECTOMY FOR KIDNEY DONATION

15.1. The surgeon will make an incision on your abdomen approximately 2 fingers width below the rib cage.

15.2. The length will depend the donor's body size. Either the left or right lobe will be taken depending on the size of the recipient (usually the right lobe is for adult recipients and the left lobe is for the paediatric recipients).

15.3. The incision will be closed with either stitches or staples.

15.4. Your surgeon and anaesthetist will explain to you further on what you should do before and after the surgery.

16. IDAT EVALUATION FORMS

16.1. Required forms to be filled by IDAT Members

	Form	Description	Signatories
i.	**Form D**	Donor Evaluation: Report by Donor Advocate (**Medical**) Risk benefit assessment	Donor Advocate (Medical)
ii.	**Form E**	Donor Evaluation: Report by Donor Advocate (**Psychiatrist**) Psychiatrist Evaluation	Donor Advocate (Psychiatrist)
iii.	**Form F**	Donor Evaluation: Report by Donor Advocate (**Medical Social Work Officer**) Psycho-social evaluation	Donor Advocate (Medical Social Work Officer)

17. UTAC APPLICATION PROCESS

Applicant send application forms to NTRC HKL

Applicant is either doctor responsible for the prospective donor or the prospective recipient

Applicant to submit: Form A, Form B, Form C and other documents as per Checklist B

Evaluation of the prospective donor by IDAT

IDAT will fill in Form D, Form E and Form F

Evaluation of the case by UTAC

Secretariat will prepare documents as per Checklist A for the UTAC member

DG of Health will inform the applicant about the decision

The Role of Physicians in Unrelated Living Donor Advocacy

Introduction

Burden of the Problem

- USA - new candidates for kidney transplantation – 22, 337 in 2001 to 31, 495 in 2006. (2007 OPTN/SRTR annual report)
- With annual growth of 8-9% in the number of new registrants without a parallel increase in the number of organs, these figures mean prolonged waiting time for kidney transplantation.

Local

- As reported by the WHO through the Global Observatory in Donation and Transplantation (GODT), Malaysia's deceased organ donation rate is equivalent to 0.64 donations per million population.
- On the other hand, it was estimated that as many as 11,000 patients were waiting for organs in our country.
- Therefore, current organ donation rate is unable to meet the increasing demands.

Benefits

1. Shorter waiting time

- A patient with kidney failure usually waits for several years to receive deceased donor kidneys. However, with a suitable living donor such transplant can be done within weeks.

2. Living donation is an elective surgery

- This means the transplant surgery can be done when both donor and recipient are in the best of health for surgery. Living donor transplant surgery can be electively scheduled to suit the donor and recipient.

3. Organs from living donors work better

- Most of the time the kidney from living donor works immediately after surgery and continues to work better and longer than kidney from a deceased donor.

Objectives

1. To safeguard the interest and welfare of living organ donors.
2. To preserve ethical and professional standards in organ donation and transplantation in the country.
3. To ensure living donors are adequately and appropriately informed about the surgical procedures in line with the principle of informed consent.
4. To ensure living donors receive adequate and appropriate medical, psychiatric and psycho-social evaluation before the surgical procedures.

Role of The Advocate

1. Ensure donor knows the risk and benefits of donor process
2. Ensure the rights of the donor
3. Ensure the process of organ procurement is free of exploitation, monetary gains/involvement and is truly voluntary

*Advocate to directly ask the donor his/her right/ risk & benefits

Mortality Risk

	Type of organ donation	Donor Mortality risk
i.	Kidney donation	3.1 deaths in 10,000 donations
ii.	Liver donation	Right lobe liver: 1 death in 200 donations Left lobe liver: 1 death in 1000 donation

Prerequisites Requiring Approval

Prior authorisation shall be obtained from the Unrelated Transplant Approval Committee (UTAC) before any organ transplantation involving unrelated living donor can take place. Such organ donation must fulfil the following criteria:

a. No available cadaveric donor;

b. No compatible donor by genetics or;

c. Emotionally related individuals.

Clinical Investigations

Donor and recipient's blood screening

- ABO grouping
- HLA cross match & typing

- Compatible donor will proceed with further medical evaluation

i.	Additional Blood Test	This is to screen for transmissible diseases like HIV, Hepatitis B and others. This is also to assess the prospective donor's medical status such as presence of diabetes, heart disease and others.
ii.	Urine Test	In particular for kidney donation, 24 hours urine sample will be taken to assess the prospective donor's kidney function or presence of kidney stones. Usually, three samples are taken.
iii.	Chest X-Ray	This is to assess the prospective donor's lungs and your heart.
iv.	Electrocardiogram (ECG)	This is to screen for heart disease. Based on the ECG finding and other clinical reasons, further test may be required for evaluation of the heart such as stress test or other screening modalities .
v.	Ultrasound and Other Imaging e.g., CT Scan	This is to assess the prospective donor's liver and/or kidneys.
vi.	Cancer Screening	Types of tests will be determined by the transplant team.
vii.	Psychosocial and Psychological Evaluation	This is to assess the prospective donor's mental health, the ability to understand all information given and make and informed decision. The team will also assess the daily life circumstances.
viii.	Consultation	The transplant team including surgeon will give the prospective donor further consultation and perform physical examination. Surgeon will explain about the nature of the surgery and risks.
ix.	Others	Some doctors may do liver biopsy for liver donation.

Donor Advocate: Medical

The donor advocate for medical (DA-M) shall be a specialist doctor.

The DA-M's role is to ensure that the nature of the transplant procedure has been explained in depth to the potential donor. This should include:

a. Donor evaluation procedure;
b. Surgical procedure;
c. Recuperative period;
d. Short and long-term follow-up care;
e. Alternative donation and transplant procedures;
f. Potential psychological benefits to the donor;
g. Transplant centre and surgeon-specific statistics of donor and recipient outcomes.

DA-M also has to ensure the:

a. Confidentiality of donor's information and decision;
b. Donor's ability to withdraw at any point in the process;
c. Information on how the transplant centre will attempt to follow up on the health of the donor for life

DA-M shall ensure that the prospective donor understands the following explanations:

a. Risks of the operation and any wider implications e.g., the potential effects it may have to his work, family life and insurability.
b. Physical risks including:
   i. Potential for surgical complications including risk of donor's death
   ii. Potential for medical complications including long-term complications
   iii. Scars, pain, fatigue, abdominal symptoms

Other risks associated with the surgery include:

a. Pain or numbness around the incision area.
b. Lung, urinary tract and wound infection. The chances of developing a lung infection can be reduced by breathing exercise.
c. Bleeding is uncommon. However, a blood transfusion may be required if necessary. It is important the prospective donor to understand the risks associated with blood transfusion.
d. Blood clots may occur in the legs (Deep Vein Thrombosis) which may travel to the lung. This can be life threatening. The prospective donor will be advised to wear compression stockings and ambulate early after surgery to prevent this from happening.
e. Anaesthetic complication including allergic reactions to anaesthetic drugs.
f. Injury to surrounding tissue or other organs.
g. Hernia. The prospective donor should not do heavy lifting for four to six weeks after surgery to avoid this problem.

The DA-M shall be satisfied that the consent for the removal of the organ was not obtained by coercion or the offer of an inducement.

The DA-M shall ensure that the donor has been made aware of the right to change his mind at any time.

It is also important for the DA-M to report any difficulties in communicating with the prospective donor (e.g., language, literacy level) and how this was overcome. Assistance by an interpreter may be required in certain cases.

Negative Psychological Effects

Negative psychological symptoms are possible during the healing process and even years after the donation.

The donated organ may not function in the recipient after it is transplanted.

Scarring or other aspects of the donation process could possibly contribute to problems with body image.

The donor may have feelings of regret, resentment or anger.

The donor may also develop anxiety and depression.

Treatment of these conditions can be lengthy and the donor may experience side effects of the medications used.

Nephrectomy for Kidney Donation

There are two (2) types of surgery for kidney donation; laparoscopic and open flank approach surgery.

An open flank surgery is a traditional approach which involves a flank incision about 15-20 cm on either right or left side.

Both the skin and muscle need to be cut in order to reach the kidney.

Laparoscopic surgery involves the use of tube-like instruments. The use of laparoscopic instruments allows the kidney to be removed through a smaller incision. The major benefits of this type of surgery are faster recovery time and less discomfort for the donor.

The surgical team will suggest to the prospective donor the types of surgery depending on the level of expertise and suitability of the donor and/or kidney.

Hepatectomy for Liver Donation

The surgeon will make an incision on the donor's abdomen approximately 2 fingers width below the rib cage.

The length will depend on the donor's body size. Either the left or right lobe will be taken depending on the size of the recipient (usually the right lobe is for adult recipients and the left lobe is for the paediatric recipients).

The incision will be closed with either stitches or staples.

The surgeon and anaesthetist will explain to the prospective donor further on what they should do before and after the surgery.

IDAT Evaluation Forms

Form	Description	Signatories
i. Form D	Donor Evaluation: Report By Donor Advocate (Medical) Risk benefit assessment	Donor Advocate (Medical)
ii. Form E	Donor Evaluation: Report By Donor Advocate (Psychiatrist) Psychiatrist Evaluation	Donor Advocate (Psychiatrist)
iii. Form F	Donor Evaluation: Report By Donor Advocate (Medical Social Work Officer) Psycho-social evaluation	Donor Advocate (Medical Social Work Officer)

IDAT

Thank You

Pusat Sumber Transplan Nasional
KUALA LUMPUR

Chapter 3

IDAT
INDEPENDENT DONOR ADVOCATE TEAM

The Role of Psychiatrists in Psychological Assessment for Unrelated Living Donation

Chapter 3

The Role of Psychiatrists in Psychological Assessment for Unrelated Living Donation

A. LEARNING OBJECTIVES

i. To understand the importance of psychiatric evaluation in living donation
ii. To understand and describe the function and role of Donor Advocate: psychiatrist in IDAT for evaluation
iii. To provide knowledge about the possible psychological issues related to prospective donor and recipient
iv. To provide knowledge about the pre/intra/post-operative anticipations of the prospective donor and recipient
v. To provide training on IDAT psychological assessment

B. CONTENTS

i. The Rationale of Psychiatric Evaluation
ii. The Role of Psychiatrist as the Donor Advocate
iii. Domains of Psychiatric Evaluation

1. RATIONALE OF PSYCHIATRIC ASSESSMENT

1.1. Noticeable drastic growth in transplant technology for the past 3 decades.

1.2. Requirement of adequate preparedness for the affected parties in order to enhance the successful long-term victory.

1.3. Importance of psychiatric evaluation is recognized and valuable[2].

1.4. Supported evidences regarding high rates of psychiatric co-morbidity among patients with end-organ dysfunction[3]:

a. Depression 20 – 40% (heart disease);

b. 50% psychiatric disorder in lung transplant patients;

c. 5 – 22% MDD (Major Depressive Disorder) among dialysis patient.

1.5. Overall surgical success requires significant behavioural change to implement healthy lifestyle.

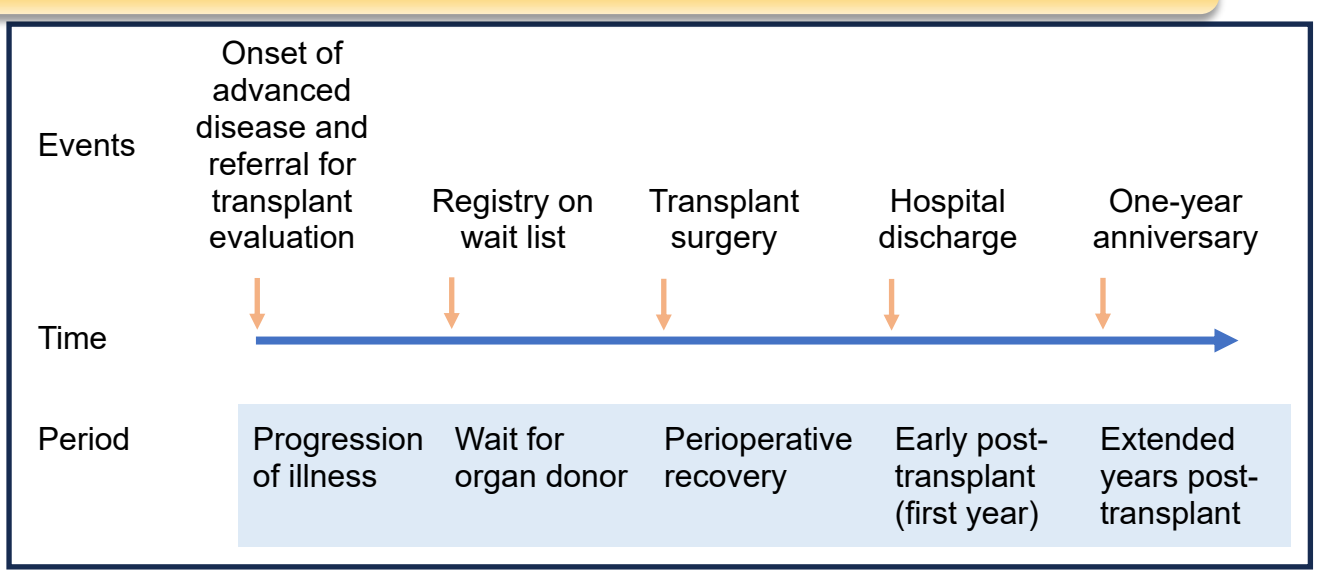
1.6. Patients may face negative outcome including mental health issues.

1.7. Psychiatrists are typically asked to predict the likelihood of patient compliance after transplantation.

1.8. To assess preoperative and postoperative psychiatric syndromes.

1.9. Crucial assessment to include relationship dynamics between affected parties.

2. POTENTIAL MEDICAL AND PSYCHOSOCIAL STRESS INHERENT IN EACH PHASES OF TRANSPLANT



Adapted from Dew MA et al. Encyclopaedia of stress 2007

Period	Progression of illness	Wait for donor organ
Health Stressors for transplant patients in each period	• Continued deterioration of organ function • Acute health crises • Hospitalization • Treatment and sequalae of treatment in end-stage disease	
Psychological stressors for transplant patients in each period	• Adaptation to losses in function • Adaptation to increasing health demands • Decrements in QOL (quality of life) • Loss of autonomy and reliance on others • Concerns over acceptance for or survival to transplant • Financial strain/loss of work/disability • Fear of death	
Caregiver issues and stresses in each period	• Adaptation to caregiving needs • Adaptation to increasing responsibility for patients and adoption of prior patient's roles • Possible need for time off work to perform caregiving or transportation • Fear of patient's death	

Period	Perioperative recovery
Health Stressors for transplant patients in each period	• Adequacy of organ function • Sequalae of major surgery • Physical function impairment • New medication adverse effects
Psychological stressors for transplant patients in each period	• Elation over transplant • Fear of organ rejection • Immunosuppressive medication adverse effects • Lingering cognitive symptoms or delirium
Caregiver issues and stresses in each period	• Elation over survival • Stress of ICU experience • Fear of organ rejection • Concerns about transition to home

Period	Early post-transplant (first year)
Health Stressors for transplant patients in each period	• Acute organ rejection • Infection • Hospitalization • Physical rehabilitation
Psychological stressors for transplant patients in each period	• Adjusting to demands of transplant directives • Recognition of limits of transplant • Frustration over recovery process • Fear of rejection
Caregiver issues and stresses in each period	• Realizing magnitude of post op caregiving • Anxiety or being overwhelmed with caregiving needs • Gradual transitioning of responsibility to recipient as he/she recovers

Events **One-year anniversary**

Time

Period	Extended years post-transplant
Health Stressors for transplant patients in each period	• Chronic organ rejection • Graft failure and its treatment • Complications of long term immunosuppressive (eg, diabetes, renal failure, cancer) • Recurrent organ disease • New/worsening concurrent health problems • Physical function decline
Psychological stressors for transplant patients in each period	• Stress with maintenance treatment • Adjusting to a new normal QOL • Concerns over returning to prior responsibilities or roles • Concerns over disability status and return to work • Concerns over future health issues • Financial issues with medications and clinical treatments
Caregiver issues and stresses in each period	• Relinquishing caregiving roles • Resuming more normalcy • Concerns over recipient's future health or need for treatment

3. DEVELOPMENT IN RENAL TRANSPLANT SURGERY

3.1. Increasing campaigns and awareness, hence increasing potential donors;

3.2. Recipients of young age;

3.3. Technology for incompatible donors;

3.4. Health tourism from neighbouring countries.

4. THE ROLES OF DONOR ADVOCATE: PSYCHIATRIST

4.1 The Donor Advocate: Psychiatrist (**DA-Psy**) must make an in-depth evaluation of the potential donor to assess his emotional and psychosocial stability and capability to make an informed decision.

4.2 The DA-Psy shall determine the motivation to donate, presence of any psychological issues or conflict in decision to donate.

4.3 DA-Psy shall also ensure that the donor's decision was not made under any duress or coercion.

4.4 DA-Psy shall identify and help the prospective donor to consider various options in preparing himself/herself for any potential problems such as:

a. Potential problems with body image;
b. Possibility of recipient's death;
c. Possibility of recipient rejection and loss of organ;
d. Impact on donor's family including opposition from relatives;
e. Possibility of post-operative psychological issues;
f. Potential impact of donation on lifestyle.

4.5. The DA-Psy may also interview family members of the prospective donor when necessary.

4.6. Assessment of the recipient is also an important integral part of the evaluation.

5. PRE-OP ASSESSMENT

5.1. It is best practiced that the donor to be offered the best possible environment for making a voluntary informed choice.

5.2. Donor to feel at ease to make decision by non-treating team.

6. CONTENT OF ASSESSMENT: INDIVIDUAL

6.1. Assess motivation and expectations;

6.2. Determine understanding of process;

6.3. Explore difficulty and challenges;

6.4. Freedom of expression;

6.5. Ascertain decision making;

6.6. Lifestyle and psychosocial issues.

7. CONTENT OF ASSESSMENT: JOINT ASSESSMENT

7.1. Establish opportunity to discuss about issues.

7.2. Background and response of other family members.

7.3. Relationship before and since offer;

7.4. Expectations of each other.

8. DOMAINS OF PSYCHIATRIC EVALUATION

8.1. **Informed consent**.

a. Understand illness, prognosis and treatment options (pros and cons);
b. Understand the procedure, possible pre-, intra- and post-transplant complications;

c. Post-transplant requirements.

8.2 The Domain of assessment – Donor

a. Purpose
b. Pre-operative anticipations and arrangement
c. Intra-operative risks and complications
d. Post-operative anticipations
e. Medications
f. Lifestyle modification
g. Social support
h. Financial implication
i. Past psychiatric illness
j. Current mental health issues
k. Coercion
l. Unresolved conflicts
m. Rewards/gains
n. Substance use

8.3 The domain of Assessment – Recipient

a. Purpose
b. Pre-operative anticipations and arrangement
c. Intra-operative risks and complications
d. Post -operative anticipations
e. Antirejection therapy
f. Compliance
g. Lifestyle modification
h. Social support
i. Financial implication
j. Past psychiatric illness
k. Current mental health issues
l. Unresolved conflicts
m. Substance use
n. Behavioural challenges

9. PRE-, INTRA- AND POST-OP ANTICIPATIONS - DONOR

- Risk during surgery – bleeding, infection, graft thrombosis 1 in 100, thromboembolic event (PE, DVT, CVA, MI, arrythmia);
- Mortality risk: 1 in 3000, morbidity rate: 1-2%;
- GA risk: intubation, chipped tooth, aspiration pneumonia;
- Post op: lung atelectasis, pneumonia, DVT, pain, neuralgia;
- Incidental finding during op e.g., stone, lesion;
- Long term risk: CKD in the future, higher than age gender match control, HPT, proteinuria;

- Risk during pregnancy with single kidney – HPT, proteinuria, ↑ creatinine, early delivery, SGA, etc. (doubled than normal population);
- May affect buying a new insurance;
- MC for 4-6 weeks and first 4 weeks not advisable to drive or lift heavy object, after that can live a normal life;
- Donor may withdraw at any stage.

10. PRE-, INTRA- AND POST-OP ANTICIPATIONS - RECIPIENT

- Transplant benefit over dialysis;
- Surgical risk - bleeding, infection, graft thrombosis 1 in 100, thromboembolic event (PE, DVT, CVA, MI, arrythmia), injury to other organs, urine leak;
- Mortality risk: <1%
- GA risk: intubation, chipped tooth, aspiration pneumonia, allergy;
- Post-op: lung atelectasis, pneumonia, DVT, pain, neuralgia, blood transfusion;
- Risk of graft dysfunction: graft thrombosis, primary graft failure, delayed graft function;
- Graft failure within 1 year: 2-3%
- Need of long-term immunosuppressive therapy;
- Side effect of immunosuppressant: infection, malignancy, metabolic

11. SPECIAL CONSIDERATIONS

11.1. **Minor pair.**

11.2. **Fertility.**

11.3. **Relationship obligation.**

12. COMMON RELATIVE CONTRAINDICATIONS

12.1. Active clinical symptoms;

a. Suicidal;
b. Psychotic.

12.2. Severe mental retardation (IQ < 50);

12.3. Significant dementia / cognitive deficits;

12.4. Ambivalent to give consent;

12.5. Personality disorder;

a. Antisocial / borderline;
b. Significant medical non-compliance.

12.6. Heavy substance abuse.

13. POST-OP ASSESSMENT

13.1. **Donor:**

a. Well-being;
b. Fear;
c. Lifestyle modification;
d. Self-esteem;
e. Expectation to recipient.

13.2. **Recipient:**

a. Well-being;
b. Side effects of treatment;
c. Treatment adherence;
d. Goal achievement.

IDAT

PSYCHOLOGICAL ASSESSMENT IN UNRELATED LIVING DONATION

The Role Of Independent Donor Advocate Team (IDAT)

CONTENTS

LEARNING OBJECTIVES

- To understand the importance of psychiatric evaluation in living donation
- To understand and describe the function and role of Donor Advocate: Psychiatrist in IDAT for evaluation
- To provide knowledge about the possible psychological issues related to prospective donor and recipient
- To provide knowledge about the pre/intra/post-operative anticipations of the prospective donor and recipient
- To provide training on IDAT psychological assessment

Rationale of psychiatric assessment

- Noticeable drastic growth in transplant technology for the past 3 decades
- Requirement of adequate preparedness for the affected parties in order to enhance the successful long term victory
- Importance of psychiatric evaluation is recognized and valuable[1]
- Supported evidences regarding high rates of psychiatric co-morbidity among pts with end-organ dysfunction[2]
  - depression 20%–40% (heart disease)
  - 50% psy disorder in lung transplant patient
  - 5%-22% MDD among dialysis patient

1. Dilch et al. Psychological evaluation of heart transplant candidates: an international survey of process, criteria and outcomes. J Heart Lung Transplant. 1995; 10:94-55
2. Frasure et al. Depression following myocardial infarction. Impact on 6-month survival. JAMA. 1999; 281:1159-26

Overall surgical success requires significant behavioural change to implement healthy lifestyle

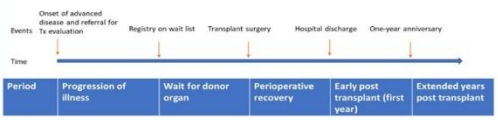
Patients may face negative outcome including mental health issues

Psychiatrists are typically asked to predict the likelihood of patient compliance after transplantation

To assess preoperative and postoperative psychiatric syndromes

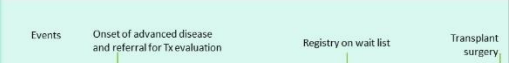
Crucial assessment to include relationship dynamics between affected parties

POTENTIAL MEDICAL AND PSYCHOSOCIAL STRESSES INHERENT IN EACH PHASES OF TRANSPLANT



Period	Progression of illness	Wait for donor organ	Perioperative recovery	Early post transplant (first year)	Extended years post transplant

Adapted from Dew MA et al. Encyclopaedia of stress 2007



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Caregiver issues and stresses in each period	• Adaptation to caregiving needs • Adaptation to increasing responsibility for patients and adoption of prior patient's roles • Possible need for time off work to perform caregiving or transportation • Fear of patient's death	

Events: Transplant surgery → Hospital discharge
Time

Period	Perioperative recovery
Health Stressors for transplant patients in each period	• Adequacy of organ function • Sequalae of major surgery • Physical function impairment • New medication adverse effects
Psychological stressors for transplant patients in each period	• Elation over transplant • Fear of organ rejection • Immunosuppressive medication adverse effects • Lingering cognitive symptoms or delirium
Caregiver issues and stresses in each period	• Elation over survival • Stress of ICU experience • Fear of organ rejection • Concerns about transition to home

IDAT

Events: Hospital discharge → One-year anniversary
Time

Period	Early post transplant (first year)
Health Stressors for transplant patients in each period	• Acute organ rejection • Infection • Hospitalization • Physical rehabilitation
Psychological stressors for transplant patients in each period	• Adjusting to demands of transplant directives • Recognition of limits of transplant • Frustration over recovery process • Fear of rejection
Caregiver issues and stresses in each period	• Realizing magnitude of post op caregiving • Anxiety or being overwhelmed with caregiving needs • Gradual transitioning of responsibility to recipient as he/she recovers

IDAT

Events: One-year anniversary
Time

Period	Extended years post transplant
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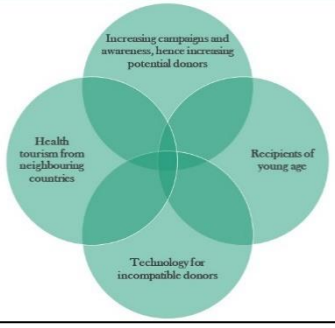
Caregiver issues and stresses in each period	• Relinquishing caregiving roles • Resuming more normalcy • Concerns over recipient's future health or need for treatment

IDAT

Development in Renal Transplant Surgery



IDAT

Roles of Psychiatrist as a Donor Advocate

IDAT

The Role of Psychiatrist as a donor advocate

- DA-Psy shall identify and help the prospective donor to consider various options in preparing himself/herself for any potential problems such as:
  - Potential problems with body image;
  - Possibility of recipient's death;
  - Possibility of recipient rejection and loss of organ;
  - Impact on donor's family including opposition from relatives;
  - Possibility of post operative psychological issues;
  - Potential impact of donation on lifestyle.
- The DA-Psy may also interview family members of the prospective donor when necessary.
- Assessment of recipient is also an important integral part of the evaluation.

IDAT

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- The DA-Psy may also interview family members of the prospective donor when necessary.
- Assessment of recipient is also an important integral part of the evaluation.

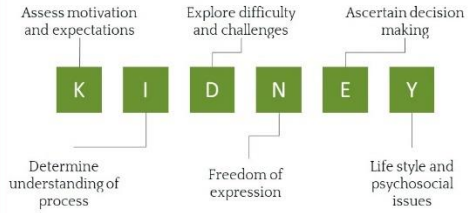
IDAT

Pre-op assessment

- It is best practiced that the donor to be offered the best possible environment for making a voluntary informed choice
- Donor to feel at ease to make decision by non treating team

IDAT

Content of assessment: individual



Content of assessment: joint assessment

- Establish opportunity to discuss about issues
- Background and response of other family members
- Relationship before and since offer
- Expectations of each other

Domains of psychiatric evaluation

INFORMED CONSENT

Understand illness, prognosis and treatment options (pros and cons)	Understand the procedure, possible pre-, intra- and post-transplant complications	Post-transplant requirements

Domain of assessment - Donor

- Purpose
- Pre-operative anticipations and arrangement
- Intra-operative risk and complications
- Post-operative anticipations
- Medications
- Lifestyle modification
- Social support
- Financial implication
- Past psychiatric illness
- Current mental health issues
- Coercion
- Unresolved conflicts
- Reward/gain
- Substance use

Domains of assessment - Recipient

- Purpose
- Pre-operative anticipations and arrangement
- Intra-operative risk and complications
- Post-operative anticipations
- Antirejection therapy
- Compliance
- Lifestyle modification
- Social support
- Financial implication
- Past psychiatric illness
- Current mental health issues
- Unresolved conflicts
- Substance use
- Behavioural challenges

PRE, INTRA, POST-OP ANTICIPATIONS - DONOR

- Risk during surgery – bleeding, infection, graft thrombosis 1 in 100, thromboembolic event (PE, DVT, CVA, MI, arrythmia)
- Mortality risk: 1 in 3000, morbidity rate: 1-2%
- GA risk: intubation, chipped tooth, aspiration pneumonia
- Post op: lung atelectasis, pneumonia, DVT, pain, neuralgia
- Incidental finding during op eg stone, lesion
- Long term risk: CKD in the future, higher than age gender match control, HPT, proteinuria.
- Risk during pregnancy with single kidney – HPT, proteinuria, ↑ creat, early delivery, SGA, etc (doubled than normal population)
- May affect buying a new insurance
- MC for 4-6/52 and first 4/52 not advisable to drive or lift heavy object, after that can live a normal life
- Donor may withdraw at any stage

PRE, INTRA, POST-OP ANTICIPATIONS - RECIPIENT

- Transplant benefit over dialysis
- Surgical risk – bleeding, infection, graft thrombosis 1 in 100, thromboembolic event (PE, DVT, CVA, MI, arrythmia), injury to other organ, urine leak,
- Mortality risk: <1%
- GA risk: intubation, chipped tooth, aspiration pneumonia, allergy
- Post op: lung atelectasis, pneumonia, DVT, pain, neuralgia, blood transfusion
- Risk of graft dysfunction: graft thrombosis, primary graft failure, delayed graft function.
- Graft failure within 1 year: 2-3 %
- Need of long term immunosuppressive therapy
- Side effect of immunosuppressant: infection, malignancy, metabolic

Special consideration

- Minor pair
- Fertility
- Relationship obligation

Common relative contraindications

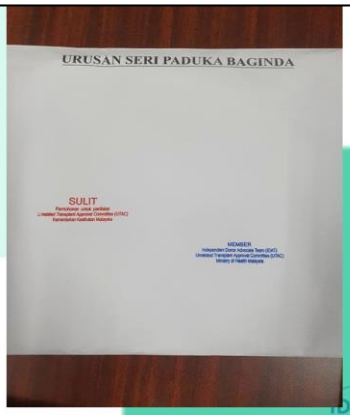
- Active clinical symptoms
  - suicidal
  - psychotic
- Severe mental retardation (IQ < 50)
- Significant dementia/ cognitive deficits
- Ambivalent to give consent
- Personality disorder
  - antisocial / borderline
  - significant medical non-compliance
- Heavy substance use

Post –op assessment

Donor
- Well being
- Fear
- Life style modification
- Self esteem
- Expectation to recipient

Recipient
- Well being
- Side effects of treatment
- Treatment adherence
- Goal achievement

Relevant documents



Relevant documents

Appendix 3 *Form A (UTAC)*
Application for Living Unrelated Transplant

Appendix 4 *Form B (UTAC)*
Declaration by the Prospective Living Donor

Appendix 5 *Form C (UTAC)*
Declaration by the Prospective Living Recipient

Appendix 7 *Form E (UTAC)*
Donor Evaluation: Report by Donor Advocate (Psychiatrist)

Reference

1. Chadban, S. J., Ahn, C., Axelrod, D. A., Foster, B. J., Kasiske, B. L., Kher, V., ... & Knoll, G. A. (2020). KDIGO clinical practice guideline on the evaluation and management of candidates for kidney transplantation. Transplantation, 104(4S1), S11-S103.
2. Sarkar, S., Grover, S., & Chadda, R. K. (2022). Psychiatric Assessment of Persons for Solid-Organ Transplant. Indian Journal of Psychiatry, 64(Suppl 2), S308.
3. Levenson, M. D. J. L. (2019). Chapter 29. In The American Psychiatric Association publishing textbook of Psychosomatic Medicine and Consultation-Liaison Psychiatry, third edition. essay, American Psychiatric Association.
4. Leigh, H., & Streltzer, J. (2015). Chapter 28-29. Handbook of consultation-liaison psychiatry, second edition. New York, NY: Springer.

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Chapter 4

IDAT
INDEPENDENT DONOR ADVOCATE TEAM

The Role of Medical Social Workers in Psychosocial Assessment for Unrelated Living Donation

Chapter 4

The Role of Medical Social Workers in Psychosocial Assessment for Unrelated Living Donation

A. LEARNING OBJECTIVES

i. To understand the role of Medical Social Worker as part of holistic transplant patient care
ii. To understand the general criteria for Psychosocial assessment referral
iii. To understand the processes involved in Psychosocial support service
iv. To understand the Donor Advocate: Medical Social Worker's role in living donor evaluation process
v. To understand the potential emotional and psychological and social issues in the context of living donation

B. CONTENTS

i. Introduction
   a. ESRF Patients' Issues
ii. Medical Social Worker in IDAT
iii. Assessment by the Donor Advocate: Medical Social Worker (DA-MSW)
   a. Components in Psychosocial Assessment
      i. Family details
      ii. Economic background
      iii. Social support
      iv. Home visit

1. INTRODUCTION

1.1. ESRF patients' issues
   a. Statistics of ESRF patients' referral to the Medical Social Work (MSW) department
   b. Treatment cost for dialysis (Haemodialysis/CAPD) and others
   c. Patient's social support system
   d. Lifestyle changes

2. MEDICAL SOCIAL WORKER IN IDAT

2.1 Medical social workers (MSWs) are involved in the assessment of the following:
   a. Recipient (pre-transplant)
   b. Donor
   c. **Unrelated Living Donor** (IDAT)

2.2 Donor advocates shall be independent and are not involved in the care of the prospective recipient.

2.3 This is to minimise conflict of interest.

2.4 The role of Independent Donor Advocate Team (IDAT) in general is to carefully evaluate the prospective living donor and provide him/her with necessary information required to make an informed consent.

2.5 The goal of IDAT is to verify that the act of donation is altruistic, is an autonomous and informed decision.

3. ASSESSMENT BY THE DONOR ADVOCATE: MEDICAL SOCIAL WORKER (DA-MSW)

3.1 Components in psychosocial assessment:

a. Family details:

i. Genogram of potential donor and recipient to confirm the nature of their relationship;

ii. Level of education among family members.

b. Economic background:

i. Household income and expenses;

ii. Issues of reimbursement and potential financial hardships should be considered;

iii. Potential financial issues include:

iv. Hospitalisation costs and out-of-pocket expenses;

v. Losses incurred from time off work;

vi. Loss of income and possible loss of employment;

vii. Potential impact on the ability to obtain future employment;

viii. Impact on the ability to obtain medical and life insurance in the future.

c. Social support:

i. Family support system – decision making, post-transplant care, emotional, spiritual support, etc.;

ii. Financial stability of the potential donor, so as to preclude financial incentives as a motivating factor for donation.

d. Prospective donor's house (Home visit, if possible)

i. Ownership status;

ii. Type of house;

iii. Facilities provided;

iv. Condition of the surrounding area.

THE ROLE OF MEDICAL SOCIAL WORKERS (MSW) PSYCHOSOCIAL ASSESSMENT FOR UNRELATED LIVING DONATION

INTRODUCTION

ESRF patients' issues :

- Statistic ESRF case refer to MSW department
- Treatment cost for Dialisis (Hemodialisis / CAPD) and others
- Patient social support system
- Lifestyle changes

MEDICAL SOCIAL WORKER IN INDEPENDENT DONOR ADVOCATE TEAM (IDAT)

MSWS are involved in the assessment of the following:

a. Donor (pre-transplant)
b. Recipient (pre-transplant)

MSWS as advocates shall be independent and are not involved in the care of the prospective recipient.

- to minimise conflict of interest.

PSYCHOSOCIAL ASSESSMENT

1. Family details

i. Genogram of potential donor and recepient to confirm the nature of their relationship

ii. Level of education in family members

2. Economic Background

i. Household income and expenses

ii. Issues of reimbursement and potential financial hardships should be considered.

Potential financial issues include:

- Hospitalisation costs and out of pocket expenses;
- Losses incurred from time off work;
- Loss of income and possible loss of employment;
- Potential impact on ability to obtain future employment;
- Impact on ability to obtain medical and life insurance in the future

3. Social Support

i. Family support system – decision making, post transplant care, emotional, spiritual support and etc.

ii. Financial stability - of the potential donor so as to preclude financial incentives as a motivating factor for donation.

4. Prospective Donor's House Home visit
(if possible)

- Ownership status
- Type of house
- Facilities
- Surrounding area

REFERENCE

1. Garis Panduan Laporan Penilaian Sosioekonomi Perkhidmatan Kerja Sosial Perubatan , Kementerian Kesihatan Malaysia. Cetakan : 25 April 2017
2. Kod Etika Pegawai Kerja Sosial Perubatan.
3. Prosedur Operasi Standard. Pengurusan Bantuan Praktik
Tarikh cetak : Jun 2018
4. Prosedur Operasi Standard. Pengurusan Bantuan Terapi Sokongan
Tarikh cetak : Jun 2018
5. Pelan Pengurusan Operasi Perkhidmatan Kerja Sosial Perubatan
Tarikh cetak : Jun 2018
6. Unrelated Living Organ Donation Policy and Procedure.. terbitan 2011 Kementerian Kesihatan Malaysia.

IDAT

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Activity

Activity

IDAT Panel Skill Building

A. LEARNING OBJECTIVES

i. To develop the skills to perform a structured donor advocacy assessment by utilizing real-life case scenarios.
ii. To consolidate the understanding of theoretical knowledge obtained from each respective donor advocate teams.

B. CONTENTS

i. Case scenario of IDAT assessment shall be prepared by the organizers/secretariats (Refer **Appendix A**).
ii. The trainers shall choose the case scenario number to be used during the activity and ensure that the same case scenario is discussed by each respective DA teams.

C. ACTIVITIES (TRAINER)

i. Assign participants into 3 groups (Group DA: Medical, Group DA: Psychiatry and Group DA: MSW).
ii. Distribute a copy of the same case scenario to respective groups.
iii. Brief the participants about the scenario given, summarizing necessary points for assessment of the prospective donor/recipient.
iv. Brief the participants for a role play to demonstrate the IDAT assessment. Participants will be assigned as characters provided in the scenario case that has been discussed.
v. Instruct the participants of respective groups to summarize the findings and outcome of the case scenario discussion through a brief presentation to the whole group.
vi. Advise participants on the conclusion for the case scenario.

D. ACTIVITIES (PARTICIPANT)

i. Read and understand the case scenario handout provided by the trainer
ii. Take note of the required points in preparation for the assessment of the prospective donor/recipient.
iii. Participate in a brief role play demonstrating the IDAT assessment process.
iv. Summarize the findings and outcome of the case and present them in a brief presentation to the whole group.
v. Conclude on whether the case could further proceed for UTAC recommendation, providing reasons to support this statement.

E. AUDIO VISUAL AIDS/TEACHING MATERIALS

i. Case scenario handouts
ii. 2 microphones with speakers

F. ASSESSMENT/EVALUATION

i. The trainer evaluates the participant's ability to plan, execute and analyse on the performed IDAT donor assessment during this training session.

G. TIME

i. 1 hour 30 minutes for skill building activity.
ii. 1 hour 15 minutes for discussion and presentation.

IDAT ACTIVITY

Hands on training consolidates the theoretical knowledge obtained through lectures, besides develops the practical skill in performing assessment.

*A trainer (**upper left picture**) is involved throughout the skill building activity while the trainee participates in case scenario discussions (**lower left picture**), role playing and case presentation.*

ACTIVITY

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Appendix

IDAT
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IDAT Skill Building Scenarios

SCENARIO 1

You are the Medical Donor Advocate and you are meeting Miss A and Miss B for renal transplant.

Miss A is a 45-year-old ESRF with unknown origin and currently on regular haemodialysis, and she is the recipient.

Both Miss A and Miss B are friends whom they met through an online social media few years back.

Kindly please assess both the recipient and donor.

Attention to trainer:

Relationship among Miss A and Miss B can be:

Colleagues, neighbours, friends since secondary school.

SCENARIO 2

Mr C is a known case ESRF due to DM nephropathy and currently on regular dialysis for past 5 years.

He has married with Ms D, who is a China citizen, 6 years ago.

They have come to meet you who is a Medical Donor Advocate for living non-related renal transplant.

Kindly please interview both the couple.

Attention to trainer:

The couple must be one is Malaysian, and the spouse is a foreigner.

The duration of marriage can be before/ after the commencement of recipient's haemodialysis.

SCENARIO 3

Mr E has ESRF secondary to unknown origin and currently on regular haemodialysis via cuff catheter due to poor vascular access.

He also has undergone recent PCI to his LAD 1 year ago with impaired heart function.

Mr F, who is Mr E's biological brother, keen to donate his kidney to Mr E and his kidney was found compatible for transplant.

Kindly please assess both siblings.

Attention to trainer:

Either Mr E or Mr F can have multiple or poorly controlled comorbid

Comorbid can be changed accordingly

SCENARIO 4

Mdm. G has underlying HPT, DM and ESRF secondary to DM nephropathy. She is on CAPD since 8 years ago.

She was advised by her nephrologist for renal transplant and she has undergone pre-transplant workout.

Her donor will be her sister, Mdm. H, who has HPT for past 4 years but well controlled with single anti-hypertensive agent.

You are the Donor Advocate from medical discipline, kindly please assess both the donor and recipient.

Attention to trainer:

To create missed clinical signs/ investigations for donor

e.g no ECG done for chest pain, has TIA episode but was not noticed during pre-transplant workout.

SCENARIO 5

Mr. Ahmad (29 years old) suffered from End Stage Renal Failure since he was 16 years old.

His sister-in-law (the brother's wife of the patient) has decided on donating one of her kidneys to Mr. Ahmad.

Later, both were referred to the National Transplant Resource Centre for further evaluation.

En. Ahmad adalah seorang pesakit berusia 29 tahun yang mengalami kegagalan buah pinggang sejak berusia 16 tahun.

Kakak ipar pesakit (isteri kepada abangnya) bermurah hati untuk mendermakan buah pinggang kepada En. Ahmad.

Kedua-dua pesakit dirujuk kepada Pusat Sumber Transplan Nasional untuk tindakan lanjut.

SCENARIO 6

Mr. Ong, a 45-year-old gentleman was diagnosed with kidney failure at the age of 32.

He has been married to his wife, a French citizen for 3 years and recently she has expressed her willingness to donate her kidney to Mr. Ong.

An application form was sent to the IDAT panel for further action.

En. Ong yang berusia 45 tahun telah mengalami kegagalan buah pinggang sejak berusia 32 tahun, isterinya seorang warganegara Perancis yang dikahwini sejak 3 tahun yang lalu telah terbuka hati untuk mendermakan buah pinggang kepada En. Ong.

Borang permohonan telah dirujuk kepada panel IDAT untuk tindakan lanjut.

SCENARIO 7

Mr. Ramesh who worked in a government agency, has expressed his kind intention to help his colleague, Mr. Chong, by donating his kidney.

Mr. Chong suffered from renal failure for the past 4 years, and recently both he and Mr. Ramesh were referred to the National Transplant Resource Centre (NTRC) and subsequently to the IDAT panel for further evaluation.

En. Ramesh yang berkerja di sebuah jabatan kerajaan telah bermurah hati untuk mendermakan buah pinggang kepada rakan sekerjanya, En. Chong.

En. Chong yang mengalami kegagalan buah pinggang sejak 4 tahun yang lalu telah dirujuk kepada Pusat Sumber Transplan Nasional bersama dengan En Ramesh dan seterusnya dirujuk kepada panel IDAT untuk tindakan lanjut.

SCENARIO 8

Mrs. Zulia (28 years old) works for an insurance company.

She has expressed her intention of donating one of her kidneys to her best friend's son (27 years old), who has been suffering from renal failure for 5 years.

Both have different blood groups based on the screening done at the National Kidney Transplant Centre (NKTC).

They were later referred to the National Transplant Resource Centre (NTRC) for the purpose of IDAT evaluation.

Pn. Zulia yang berusia 28 tahun bekerja di sebuah syarikat insurans.

Beliau bermurah hati untuk mendermakan buah pinggang kepada anak sahabat baiknya yang berusia 27 tahun yang mengalami kegagalan buah pinggang sejak 5 tahun yang lalu.

Pesakit dan penderma dari kumpulan darah yang berbeza, saringan telah dibuat di Pusat Transplan Buah Pinggang Kebangsaan (NKTC) dan seterusnya permohonan dirujuk kepada Pusat Sumber Transplan Nasional untuk tujuan penilaian IDAT.

SCENARIO 9

Mrs. Yati is a kind 48-year-old lady who wished to donate her kidney to her husband, a Dutchman who has been married to Mrs. Yati for 24 years.

The spouse was referred to the National Transplant Resource Centre (NTRC) and subsequently to the IDAT panel for further evaluation.

Puan Yati berusia 48 tahun telah bermurah hati untuk mendermakan buah pinggang kepada suaminya.

Suami kepada Puan Yati adalah warganegara Belanda yang telah dikahwini selama 24 tahun.

Pasangan ini telah dirujuk kepada Pusat Sumber Transplan Nasional dan seterusnya kepada panel IDAT untuk penilaian dan tindakan lanjut.

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There is no story,

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There is no **Transplant**"

ISBN 978-629-98613-0-0

2023