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Living unspecified kidney donation around the world: Gaps and best practice

Żywe nieokreślone dawstwo nerki na świecie: Luki i najlepsze praktyki

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STRESZCZENIE

ŻYWE NIEOKREŚLONE DAWSTWO NERKI NA ŚWIECIE: LUKI I NAJLEPSZE PRAKTYKI

Wprowadzenie. Przeszczep nerki jest preferowaną formą leczenia pacjentów ze schyłkową niewydolnością nerek (w porównaniu z dializami). Wiele państw zezwala na transplantację nerek od żywych dawców w celu rozwiązania problemu niedoboru narządów od dawców zmarłych. Istnieje kilka rodzajów donacji w zależności od relacji żywego dawcy z biorcą. Sekcja do spraw Etycznych, prawnych i psychospołecznych aspektów transplantacji narządów (ELPAT) Europejskiego Towarzystwa Transplantacji Narządów (ESOT) klasyfikuje altruistyczne dawstwo nerki dla osoby nieznajomej jako „nieokreślone" (unspecified). Nieokreślone dawstwo nerki od żywego dawcy nie stanowi nowej formy donacji, jednak możliwe jest jedynie w niewielkiej liczbie państw.

Cel pracy. Celem pracy jest porównanie praktyki żywego nieokreślonego dawstwa nerki na świecie. Niniejszy artykuł zestawia wiedzę na temat częstości występowania nieokreślonego dawstwa nerek, procesu oceny kandydatów na dawców, wsparcia okołooperacyjnego dla dawców oraz dylematów etycznych jakie towarzyszą tej procedurze.

Słowa kluczowe: **przeszczep nerki, żywy dawca, niepowiązany dawca, altruizm**

ABSTRACT

LIVING UNSPECIFIED KIDNEY DONATION AROUND THE WORLD: GAPS AND BEST PRACTICE

Introduction. Kidney transplantation is the preferred form of treatment for patients with end-stage renal disease (compared to dialysis). Many countries allow living donor kidney transplantation to address organ shortage from deceased donors. There are several types of donation depending on the relationship of the living donor to the recipient. The Ethics, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) section of the European Society for Organ Transplantation (ESOT) classifies altruistic kidney donation to a stranger as "unspecified". Unspecified living donation is not a new form of donation, but it is only legal in a small number of countries.

Aim. The aim of the study is to compare the practice of live unspecified kidney donation in the world. This article summarizes the knowledge of the prevalence of unspecified kidney donation, the donor candidate evaluation process, perioperative donor support, and the ethical dilemmas that accompany this procedure.

Key words: **kidney transplantation, living donors, unrelated donors, living donors, altruism**

INTRODUCTION

Clinically and financially, kidney transplantation is the preferred form of treatment for patients with end- stage renal disease (ESRD), compared to dialysis [1-3]; yet, kidney donation shortfall is a global problem. Many countries permit living kidney donation to address the shortage of deceased donors and there are several categories of these donor according to their relationship with the intended recipient. The Ethical, Legal and Psychosocial Aspects of Transplantation (ELPAT) section of the European Society for Organ Transplantation (ESOT) categorises altruistic kidney donation to a stranger as "unspecified" [4,5]. The idea of unspecified living kidney donation (ULKD) is not new; however, it is legal in a relatively small number of countries.

AIM

The objective of this article is to compare ULKD among across North America, Europe, Oceania, and the Middle East. Existing research reports are based on the experience of one or more centres in a given, particular country. From a global lens, this article collates knowledge about the prevalence of unspecified kidney donation, the donor candidate assessment process, perioperative support for the donors, and ethical dilemmas. A global lens can shed light on gaps as well as best practices.

MATERIALS AND METHODS

PubMed, Lilacs, and Google Scholar were searched using several keywords: "altruistic kidney donation," "unspecified kidney donation," "nondirected kidney donation," "Good Samaritan donor" "anonymous kidney donor," and "unrelated kidney donor." The articles were limited to English and full-text accessibility, any published date. Articles, which address the issue of the prevalence of unspecified kidney donation, descriptions of the process, support for the donors, donor anonymity, and dilemmas, were selected for analysis. Articles describing individual cases of donation were excluded. The authors also conducted a manual search of online documents of country health departments and associated organ procurement organisations for content pertaining to ULKD.

RESULTS

Content satisfying the inclusion criteria was retrieved from 11 countries across North America, Europe, Oceania, and the Middle East (Tab. 1). Italy, Malaysia, Singapore, and South Korea permit ULKD; however, their content was excluded from study due to languages other than English. Specifically, the initial search yielded a total of 775 journal articles. After exclusions, 123 potentially relevant publications remained. A manual search provided an additional 17 documents from health departments and organ procurement organisations. An additional 81 documents were excluded from our analysis because of duplicates, outdated and/or recurring content. The 42 remaining documents were selected for analysis (Fig. 1).

Prevalence of unspecified kidney donation

Tab. 1. reports the worldwide prevalence of unspecified kidney donation [1-3,6-15]. The highest numbers of ULKD are observed in the USA, the United Kingdom, and Saudi Arabia.

Description of the procedure

Globally, the donor candidate assessment/screening process takes between 3 to 18 months. The donor must be able to provide legally valid informed consent. Screenings include the opinion of various experts [1,2,16-20]: nephrologists, ethicists, psychologists, psychiatrists, transplant surgeons, social workers, etc. The similarities and differences among the countries are described according to their particular continent.

North America

In the United States, the hospital begins the donor candidate screening process usually with a telephone questionnaire to applicants about their lifestyle, donation motives, and the financial aspects of non-medical costs, such as travel to the transplant centre. The next stage of the evaluation ("diagnostic") consists of psychological and laboratory tests, as well as radiology exams. In the US, an independent living donor advocate also screens all living donor candidates. This person is not involved with the Transplant Team and works only with the Donor Team [21]. Also, many US donation programs have a Donor

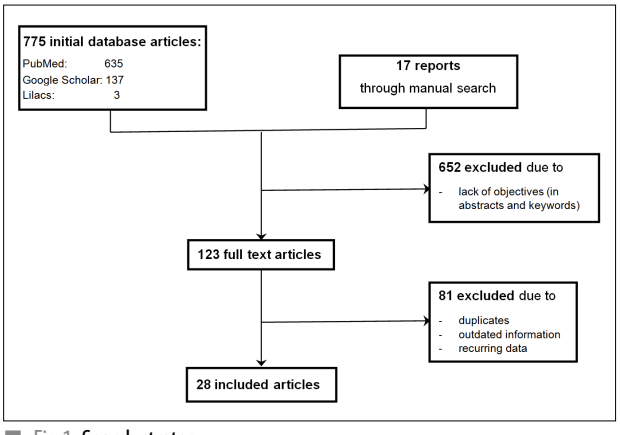


Fig 1. Search strategy

Tab. 1. Prevalence of unspecified kidney donation

Country	First procedure	Number of donors	Years of donation
Iran	1988	Data not available	Data not available
USA	1998	2908	1998- July 2019
New Zealand	1998	77	1998- July 2019
Netherlands	2000	104	2000- 2014
Sweden	2004	26	2004- 2016
Australia	2004	52	1998- July 2019
United Kingdom	2006	557	2007- March 2019
Saudi Arabia	2007	563	2009- 2017
Israel	2008	Data not available	Data not available
Canada	2009	Data not available	Data not available
Spain	2010	13	2010- 2017

Tab. 2. Comparison of donor support in studied countries

Country	Financial support	Medical support	Social support
Australia	refunds lost income during stay and convalescence for 9 weeks after donation	N/A	N/A
	refunds travel and accommodation		
Canada	refunds travel	N/A	N/A
	refunds salary		
	refunds childcare costs		
Iran	USD 1200 from the government	free annual medical insurance	N/A
	negotiated payment from the recipient		
Israel	refunds lost income	extra psychological care	certificate of recognition
	exempt from fees for health insurance contributions for 3 years		
	refunds the benefit for a week's convalescence		free admission to national parks
Netherlands	refunds lost income	priority on the waiting list in case of a need of transplant	N/A
	refunds additional hospital costs and/or extra costs at home		
	travel expenses		
	the cost of additional medical care		
New Zealand	refunds lost remuneration during the stay and convalescence for 12 weeks after donation	N/A	N/A
	refunds travel and accommodation		
Saudi Arabia	refunds lost income	medical care for the amount of 50,000 riyals (approx. USD 13,500)	national medal
	discounts with Saudi Airlines for donor and family		college entrance assistance for donor's family
Spain	No data	No data	No data
Sweden	full compensation for expenses and lost earnings associated with the donation	N/A	N/A
United Kingdom	refunds lost income	priority on the waiting list in case of a need of transplant	donor medal of honor
	refunds travel and accommodation		
United States (New York)	refund of lost income	medical support is specified by the insurer	state and national donor medal of honor
	tax deduction of up to USD 10,000		

N/A - not applicable

Buddy system which allows donor candidates to meet others who have been organ donors to learn first-hand of their experience as part of the informed consent process. After successfully completing the above, including consults with physicians and surgeons, the candidate is asked to confirm his/her willingness to proceed with donation [20].

In Canada, the candidate assessment process, as in the US, includes laboratory tests and psychosocial assessment, together with donation motives. Two weeks after donation, the donor undergoes surgical consultation, as well as laboratory tests 6-9 weeks post-donation. In Canada, the donor is provided with an annual check-up at the general practitioner or transplant centre (compared to only 2 years of total follow up by US transplant hospitals) [16,20].

Europe

In the Netherlands, the donor candidate receives donation information materials after contacting the transplant centre. If he/she still desires to donate, he/she undergoes a detailed examination process. The tests are conducted by a nephrologist and a nurse-specialist in kidney transplantation. A social worker also interviews the candidate. After completing this stage, the candidate is screened by a nephrologist, transplant surgeon and anaesthesiologist. After qualifying, the donor is entered on an approved list awaiting matching to patients with ESRD. The waiting time is between one to four months. After donation, a follow-up visit to the transplant centre takes place within 2-3 weeks and 3 months after the procedure. Then, donors have an annual check-up [17].

In Sweden, the preliminary stage of dealing with a potential organ donor is a phone interview about the individual's general health conditions. Candidates admitted to the next stage of the procedure receive an information package about the donation process. If the candidate renews contact, he/she is invited to a meeting with an interdisciplinary team consisting of a nephrologist, social worker, transplant coordinator, and psychiatrist. After qualifying as a kidney donor, the candidate still has the possibility of changing his/her decision for a period of 3 months. The donors have two follow-up visits at the transplant centre, usually 2-4 weeks and 6-12 months after surgery. A follow-up visits is then required every 5 years [1].

In the United Kingdom, as in Sweden, the process begins with a telephone conversation between the donor candidate and the transplant coordinator. If the coordinator considers the person to be a suitable donor candidate, they meet with staff from the Office for Human Tissues, followed by a psychosocial and surgical assessments at the hospital. At the last stage of the qualification procedure, the candidate's motivation is verified and the transplant is approved by the human tissue authority. After donation, the donor undergoes annual health checks [18].

In Spain, the program for unspecified donation consists of three stages: an introductory telephone interview and hospital evaluations with a kidney transplant program as well as a crossover kidney exchange program [9]. Crossover exchange programs allow unmatched donor-recipient

pairs to find matches by exchanging the planned pairing of donors and recipients (often relatives) with new donors [22].

Oceania

In Australia and New Zealand, similar to Europe, an interview is conducted followed by diagnostic tests and verification of the donors' motivation [23-24]. Of note, unspecified donation is not performed in the state of Queensland, Australia and donors wishing to participate must travel to other states or territories within the country.

Middle East

In Israel, according to the law, ULKDs must be at least 25 years old [19] and must obtain consent for donation from an independent state commission [2]. Pre-donation proceedings involve a number of examinations similar to those in other countries. After donation, the donor is given an annual visit to the transplant centre or a general practitioner for a health check [2, 19, 25]. In Saudi Arabia, the Saudi Centre For Organ Transplantation (SCOT) is responsible for coordinating the entire ULKD screening and registration process, ensuring potential donor candidates undergo a detailed medical and psychological assessment [10].

In Iran, the process is very different compared to other countries. Donors must be within a narrow age range (18-35 years) and informed consent must be provided by the donor as well as a member of the donor's immediate family. Donors are allowed to receive a financial payment for the organ, with the donor candidate and intended recipient negotiating the fee. When financial conditions are accepted by both parties, the date of surgery is set. After the donation, the donor presents his/her donation confirmation certificate to the Charity Foundation for Special Diseases to obtain annual health insurance. In the situation of female living donors, there are known problems of abuse whereby women are coerced to donated and their consent is not voluntary (e.g. pressure from their own family or the intended recipient/their family) [26]. In such cases a nephrologist can be asked to provide a medical excuse for the donor candidate, facilitating a disqualification from the donation process [27].

Donor Support

There are substantial differences in the support for donors in all studied countries (Tab. 2). This support can be divided into three categories: financial, medical and social [3,10,11,16-20,22-25, 28].

Donor Anonymity

ULKD contributes to the increase of the pool of live kidney donors, yet it raises some ethical dilemmas. For example, the issue of anonymity of donors and recipients varies by country. In the USA it is possible for mutually consenting donors and recipients to meet after a waiting period. If desired, the hospital helps to arrange these meetings, often in a neutral place such as a park or cafe [29]. In the Netherlands, Australia and Spain, contact between recipients and donors is prohibited [6,30,31]. Notably, in Great Britain and Sweden, anonymity is only maintained before and during transplantation; however, six months after transplantation, it can be cancelled by mutual agreement so that the parties can meet [12,29]. There are also countries such as Israel where this matter is unregulated. The Israeli organization Matnat Chaim (which encourages ULKD, with particular emphasis on donors from the orthodox Jewish community) reports that in most cases the donor and recipient will meet in a hospital before the transplant, and almost everyone will meet before hospital discharge. In New Zealand there are cases of mediation between donor and recipient at the explicit request of both parties. Anonymous letters, written in a way that makes it impossible to identify each party, are a form of communication [32]. In Iran, anonymity is not possible due to the financial negotiations that occur between donors and recipients [27].

DISCUSSION

As shown, there is a lack of harmonization regarding ULKD globally. Donor follow up in countries where there is no national health insurance creates an ethical dilemma. For example, in the United States many ULKDs do not have health insurance, thus they are required to self-pay the costs of any late or lengthy complication occurring after the 6-month period after donation [33]. The same issue may concern potential donors living in countries that do not allow or offer ULKD when they travel to countries which permit such donations but yet may lack their own health care insurance or treatment access when they return home. While all countries provided support to ULKDs for lost income, countries differed on refunding such expenses as travel, accommodation, childcare costs, additional health care, and medical insurance. One of the states within the US grants a tax deduction to living donors (New York), and one country gives discounts for national airlines (Saudi Arabia). Some countries grant free national park access (Israel), others provide assistance with a donor's family members entering college (Saudi Arabia) [28].

The Iranian system permits coerced female donations as well as financial payments for organ donation deeming it ethically problematic and not best practice. Koplin [34] criticizes the Iranian system because donor motivation is financial, not altruistic. The main reason for the decision to sell organs in Iran is the need of paying debts. It is worrying that more than 90% of donors experience sadness, depression and regret after donation and 86% reported negative financial consequences of donation [30]. Worldwide, it is generally accepted that organs are a gift [donation] and not a commodity that is bought/sold, and in many countries payments such as this are illegal [35]. Additionally, coerced female donations could be viewed as a form of human trafficking and this is a violation of human rights [36]. Payments can seem like a "benefit" of organ donation and could cause potential donors to disregard the risks of donation. To tackle the ethical dilemmas of the Iranian model of paid kidney donation, in 2015,

the Iranian Health Minister for the first time in the history of the program expressed concerns about the current system [37]. While the Iranian system is a way to increase the number of available organs, it does so amid a monetary payment system, as well as a system that facilitates female human trafficking. The latter is ethically reprehensible.

With ULKD, sometimes grafts go to identified wait--listed patients (e.g. Facebook or other social media posts about patients needing transplant), while other donations go to the person at the top of the waiting list. They can also be used for triggering donation chains or supporting paired exchange programs [5]. Choosing the recipient can raise ethical concern as donations can be made without considering factors such as waiting time, illness severity, and capacity to benefit. It produces another dilemma which is advertising the need of a kidney [38], including truth-telling and other matters [39]. These issues are unique to ULKD and are not addressed in a uniform manner globally. They remain for ethical exploration and research.

Meghan et al. [40] show that for many donors the decision of meeting the recipients is difficult. Bramstedt [41] and Slaats et al. [42] indicate that the vast majority of donors are satisfied with the anonymity of such a relationship. Interestingly, donors want to remain anonymous more often than the recipients. Mamode et al. [29] described the following potential risks associated with the cancellation of anonymity: disappointment when reality differs from the idealized image of the beneficiary or the outcome of the operation, a sense of pressure to make a donation, the possibility of withdrawal from the donation and violation of privacy and the potential for solicitation.

Limitations of the study

Only articles in English with full-text availability were analyzed, thus limiting the global reach of our research efforts, as well as the potential to gather documents within some of the regions that were explored in our study. Also, there is the possibility that other ULKD documents exist but are not published for public access (i.e. confidential or otherwise restricted internal/hospital staff access only).

CONCLUSIONS

In summary, the gaps and dilemmas related to ULKD mainly concern the anonymity of donors and financial incentivization; however, Iran has the additional serious concern of human trafficking. Overall, due to its demonstrated safety and effectiveness, ULKD is a valuable technology that should continue (and expand worldwide) with ethical safeguards.

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