

Barriers to kidney transplants in Indonesia: a literature review

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Background: People living with chronic kidney disease will require renal dialysis or a kidney transplant to maintain life. Although Indonesia has a developing healthcare industry, Indonesia's kidney transplant rates are lower than comparable nations.

Purpose: To explore the healthcare literature to identify barriers to kidney transplants in particular in relation to Indonesia.

Methods: Healthcare databases were searched (CINAHL, Medline, EBSCOhostEJS, Blackwell Synergy, Web of Science, PubMed, Google Scholar and Proquest 5000) using the search terms: transplant, kidney disease, renal, dialysis, haemodialysis, Indonesia and nursing. The search was limited to English and Indonesian language data sources from 1997 to 2007. Reference lists of salient academic articles were hand searched.

Results: The results of our search identified six articles that met our criteria. Costs are the major barrier to kidney transplant in Indonesia, followed by cultural beliefs, perception of the law, lack of information and lack of infrastructure. In addition, kidney disease prevention strategies are required.

Conclusions: There are many complex socio-economic, geographical, legal, cultural and religious factors that contribute to low kidney transplant rates in Indonesia. Although an increase in transplantation rates will require strategies from various agencies, healthcare professionals, including nurses, can play a role in overcoming some barriers. Community education programmes, improving their own education levels and by increasing empowerment in nursing we may contribute to improved kidney transplant rates in Indonesia.

Keywords: Dialysis, Indonesia, Kidney, Nursing, Renal, Transplant

Introduction

People living with chronic kidney disease stage 5 (CKD 5) require haemodialysis, peritoneal dialysis or transplantation to maintain life for an extended period. Transplantation is the treatment of choice as it has a lower mortality rate, improves a patient's quality of life and has cost benefits after the first year of the transplant (Davis & Delmonico 2005; Teerawattananon et al. 2007).

In Indonesia, kidney transplantation rates are low compared with other similar developing countries. The first kidney transplant in Indonesia was performed 30 years since ago in 1977 (Markum 2004). Subsequent transplant rates have remained lower than in similar countries. According to Ota (2004), only 247 kidney transplants were performed in Indonesia between 1997 and 2001. This is low compared with countries such as the Philippines (1246) and Thailand (757). Importantly, in Indonesia, all kidney transplants during this period were from living-related donors, not cadavers (Ota 2004) where in other countries cadaver donor organs were permitted.

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Why are kidney transplantation rates in Indonesia lower than other similar countries? What are the barriers to transplantation in Indonesia? How can these be improved? What is the role of the Indonesian nurse? These questions will be addressed through a review of healthcare literature. The purpose of this review is to explore the literature, identify barriers to kidney transplants and discuss the clinical implications where nurses (and other healthcare workers) can contribute to increasing the transplantation rates and improve the quality of life of people living with kidney disease.

Background

Health care in Indonesia

Indonesia has a population of over 206 million people spread over thousands of islands (Central Bureau of Statistics 2007). It is the fourth most populous country in the world with Islam as the major religion. The average life expectancy is 67 years with an under-5-year mortality of 34 (per 1000 live births) (WHO 2007). These rates compare favourably with other South East Asian Nations (WHO 2006a).

Spending on health has been increasing every year in Indonesia, although in 2004 it was 2.8% of national gross domestic product (GDP). This compares with similar developing countries such as Vietnam and Cambodia who spent more than 5% of GDP on health in the same year (Economic and Social Commission for Asia and the Pacific 2007).

Health care in Indonesia is available in both public and private hospitals (Shields & Hartati 2003) funded by the Indonesian government. The World Bank and the International Monetary Fund subsidize free healthcare services for the poorest. This is called Jaringan Pengaman Sosial Bidang Kesehatan and can be used only in public hospitals (Shields & Hartati 2003). Private hospitals are for profit and do not receive support from government.

There are two types of health insurance, social and commercial health insurance (Thabrany 2003). Social health insurance is paid by the government and is provided to public service employees. Commercial insurance is available for private employees who work in large companies. Although private insurance is available, it only makes up for 6% of health expenditure (WHO 2006b). This reflects the very low use of private health insurance in Indonesia.

Renal replacement therapy in Indonesia

Dialysis treatment is offered in Indonesia in both private and public hospitals. Unfortunately, Indonesia does not have a well-formed renal and transplant data registry so data may not be accurate (Prodjosudjadi 2006). It is believed that approximately

7000 people received haemodialysis treatment in 2006 (Ministry of Health of Indonesia 2006). From the latest available South East Asian data in 2003, Indonesia has the third largest number of CKD 5 patients treated with dialysis but a very low transplant rate (Markum 2004). Consequently, the number of patients requiring dialysis or dying from CKD 5 is increasing each year.

People living with CKD suffer related co-morbid conditions affecting the quality and quantity of life. Co-morbidities include cardiovascular-related diseases such as ventricular hypertrophy, hypertension, atherosclerosis and arteriosclerosis (Sarnak 2003). In addition, many patients live with renal osteodystrophy, anaemia, sleep apnoea, diabetes, anaemia and alterations in calcium/phosphorus metabolism (Eiam-Ong & Sitprija 2002; Johnson 2004). They are often fatigued, depressed and malnourished (Abraham et al. 2003). People living with CKD rate their quality of life as low (Odden et al. 2006), reflecting the life-changing effects kidney disease has on an individual and their families. Kidney transplantation has been shown to improve people's quality of life and can stop the progression of co-morbidities (Port et al. 1993).

Search strategies

Aim

To find and explore peer-reviewed publications that provide information on barriers to kidney transplantation in Indonesia.

Databases searched and keywords

In 2007 we searched major academic databases (CINAHL, Medline, EBSCOhostEJS, Blackwell Synergy, Web of Science, PubMed and Proquest 5000) using the search terms: transplant, kidney disease, renal, dialysis, haemodialysis, Indonesia and nursing. Figure 1 summarizes the search process.

Inclusion and exclusion criteria

We limited the search criteria from 1997 to 2007 and to English and Indonesian language articles. Only full text articles were included. On the first search step we included full text articles that had the potential to inform our aim.

Search results

Using the above initial criteria we found 29 full text articles. All were written in English, none in Indonesian. Both authors read each article fully to ascertain their applicability to our aim. Six articles met the criteria of informing our aim. The search yielded only one nursing article (Shields & Hartati 2003) and five articles written by physicians (Markum 2004; Ota 2004; Prodjosudjadi 2006; Puruhito 1998; Sitprija 2003).

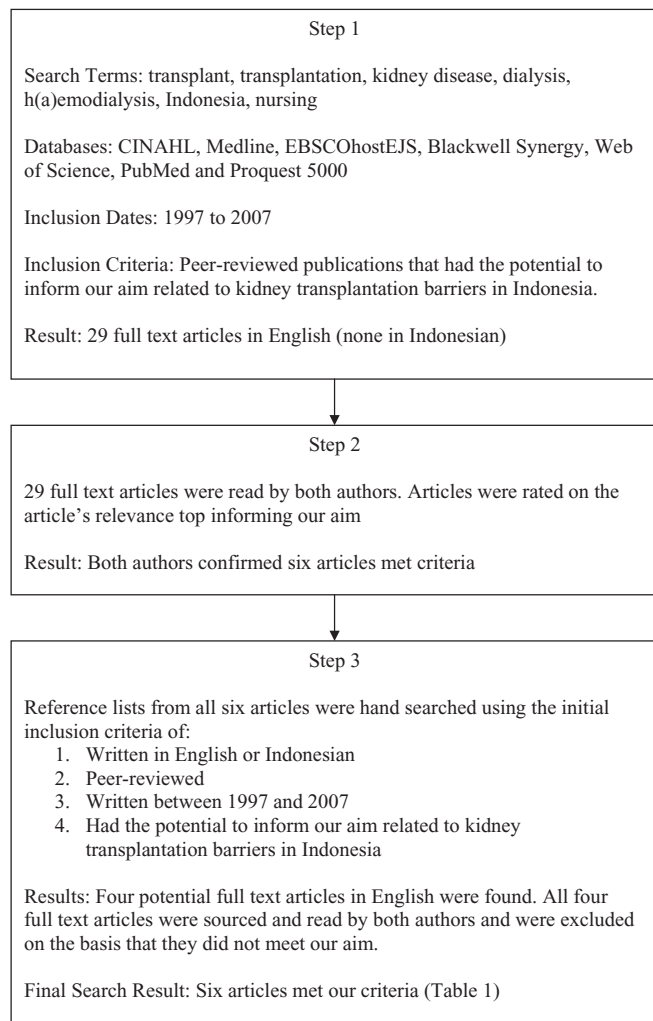


Fig. 1 Search strategy.

The third step was to hand search the reference lists of the above six articles. This resulted in four potential full text articles in English. All four were sourced and read by both authors and were excluded on the basis that they did not meet our aim. Thus, following our three-step search process we had identified the six articles summarized in Table 1.

Article methods

Two articles reported the results of targeted questionnaires directed at leading Asian nephrologists to ascertain the kidney disease and transplant status in Asia. Both included information relevant to Indonesia's low transplant rates.

Four articles were review articles written by nursing (1) and medical clinicians (3) who had worked in Indonesia. The articles

used previous literature, current practices, reported data and their own experience to develop their peer-reviewed publication.

Results

Results from our search supported the notion that the low rates of transplantation in Indonesia are multifactorial. The cost of dialysis and transplantation was the most reported barrier. However, other less economically driven influences were reported such as cultural issues, perception of the law, a lack of accurate information and a lack of supporting infrastructure (including human resources such as specialist nurses and nephrologists). These are discussed below.

Costs

For Indonesians with CKD 5, renal replacement therapy such as haemodialysis and transplantation is considered an expensive treatment. The cost of haemodialysis varies from US\$4900 to US\$6500 per year depending on the facility (Prodjosudjadi 2006). This is expensive when considering the average Indonesian earns US\$1280 per year (Central Bureau of Statistics 2007). One year's dialysis is equal to 5 years of the average Indonesian wage.

In Indonesia a kidney transplant costs approximately US\$15 000 for the first year but significantly decreases after year 1 (Prodjosudjadi 2006). As there is no health insurance that covers the high transplantation fee, it is problematic for most Indonesians to afford a transplant. The transplant is the equivalent of 15-year pay while the cost of post-transplant immunosuppressive drugs can be more than the average yearly salary (Burung Manyar Foundation 2003). Thus, the majority of Indonesians find the costs of transplantation prohibitive.

Lack of health insurance appears to be a significant barrier to transplantation in Indonesia; 85% of the population does not have health insurance (Thabrany 2003). Haemodialysis is covered by some health insurances, including insurance for the very poor. However, no health insurance covers kidney transplantation fee (Arifianto et al. 2005). It may appear reasonable that the government does not prioritize CKD 5 treatment when there are many demands on health insurance funds.

Culture and religion

Traditional cultural aspects, particularly religion, are highly valued by many Indonesians. A total of 88% of all Indonesians consider themselves to be practising Moslems with another 8% classified as Christian (Economic and Social Commission for Asia and the Pacific 2007).

The literature supports the idea that cultural and religious interpretation related to organ donation is a barrier to increasing rates. Although an official consensus in 1995 agreed that all

Table 1 Summary of peer-reviewed journal articles informing barriers to kidney transplantation in Indonesia

<i>Author (year)</i>	<i>Country (language)</i>	<i>Aim</i>	<i>Methods</i>	<i>Findings</i>	<i>Importance to Indonesian kidney transplant rates</i>
Prodjosudjadi (2006)	Indonesia (English)	Summarize incidence, prevalence and cost of CKD 5 in Indonesia	Questionnaire to targeted key Indonesian nephrology centres	Dialysis and transplantation costs too high for most Indonesians. Transplant rates low.	The quantity and quality of human and material resources for kidney transplantation need upgrading. More emphasis on prevention than cure. Needs improved data management. Needs improved health insurance. Improved understanding of definition of death.
Markum (2004)	Indonesia (English)	Summarize Indonesian kidney transplant barriers	Review	Barriers to transplants are cost, infrastructure, religion, custom and donor availability.	Needs improved data management. Needs improved health insurance. Improved understanding of definition of death.
Ota (2004)	Japan (English)	Summarize Asian transplant and dialysis status	Questionnaire to targeted key national leaders	Asian dialysis and transplant practices vary widely. Data registries vary widely.	Indonesian dialysis and transplant data are difficult to access. 247 kidney donations performed from 1997 to 2001.
Shields & Hartati (2003)	Indonesia/Ireland (English)	Describe nursing in Indonesia	Review	Indonesian nursing is low status. In 2003 Indonesia is developing a registration board, standardized accreditation and increased tertiary nurse education.	All were living related. Appropriate nurse education and improving nursing standards will improve health standards.
Sitprija (2003)	Thailand (English)	Describe medical care of kidney disease in South East Asia	Review	Workforce and clinical treatment are not adequate in many South East Asian countries.	Prevention strategies required. Provision of appropriate health services within economic and technological constraints.
Puruhito (1998)	Indonesia (English)	Address barriers to transplant	Review	The availability of technology has stimulated religious, cultural and economic barriers to transplantation.	Needs improved health insurance. Cost vs. benefit analyses required.

religions in Indonesia accepted organ transplantation, there is still significant resistance among both Moslem and Christian Indonesians (Markum 2004). This results in only donor kidneys coming from living relatives (Prodjosudjadi 2006). The very low use of kidneys coming from brain-dead sources (cadavers) limits both the supply of donor kidneys and transplant rates. In comparable countries, such as the Philippines and Thailand, cadaver kidneys have been a large source of kidney donation (Ota 2004).

Moslems may remain uncertain regarding organ transplantation (Aasi 2003). There is the notion that breaking the bone of a dead person is equal in sinfulness and aggression to breaking it while a person is alive. Conversely, kidney donation uncertainty is not so apparent in other Islamic nations. There are high transplant rates in countries such as Turkey (Bilgel et al. 2004), Saudi Arabia (Mani 2002), Iran (Broumand 1997) and Malaysia (D'Cruz & Chandrasekharan 2002). Subsequently, there have been efforts to clarify Islamic interpretations of organ transplantation led by the Middle East Society for Organ Transplantation. Twenty-nine Moslem countries in the world participating in this organization, such as Iran, Turkey, Pakistan have increased transplant rates significantly since the year 2000 (Shaheen & Souqiyeh 2004). These findings suggest that resistance to the use of cadaver organs in Indonesia is more an interpretation of their religious and cultural beliefs and values that differ from other Islamic nations.

Law

Legislation around organ donation in Indonesia is not widely understood (Markum 2004). There have been few well-known and understood legal processes for donating an organ. An example is the debate around the law that prohibits a transplant using an organ from an unknown donor. If the donor's confidentiality is maintained, then the recipient does not know the source of the organ. Thus, it is argued that it may not be acceptable to use an organ from a cadaver (Aasi 2003).

There is a general worldwide lack of understanding among non-health professionals regarding the diagnosis of brain death. Markum (2004) reports that this is no different in Indonesia where misconceptions can be held over the process of brain-death determination and the transplant process that follows. Improvement in these processes, as has been the case in Spain (Miranda et al. 1999) and Iran (Zargoosh 2001), can improve transplant rates. It is important to note, however, that these two countries have very different wealth profiles and health systems to Indonesia.

Lack of information

Lack of information about organ donation could contribute to the low number of donations and may require education to

address people's fears (Markum 2004). This leads to lack of information regarding the limited availability of donor organs in Indonesia. Insufficient information in the community can also lead to misconceptions related to live donor transplantation. Living with one kidney can be an unsettling fear in the community and may require education. Indonesians believe that kidney donation can affect their daily lives adversely (Markum 2004) contributing further to the lack of donors. This will only be addressed by utilizing healthcare worker and community workers in a very large targeted government education programme to allay misconceptions related to kidney donation.

Infrastructure factors

Low kidney transplant rates are certainly related to a lack of infrastructure, an inadequate transplant data registry, inadequate number of skilled practitioners and a lack of transplant centres. A universal, standardized method of data collection is vital for the further development of quality dialysis and transplant practices (Markum 2004; Ota 2004; Prodjosudjadi 2006). Data collection registries are important for local, national and international comparisons which lead to improved practices and improved patient outcomes (Schena 2000). The need for a high-quality transplant registry in Indonesia is a consistent recommendation from our findings.

A shortage of specialist nephrologists, transplantation facilities and specialist nephrology nurses contribute to the low kidney transplant rates (Prodjosudjadi 2006). Indonesia has a much lower rate of nephrologists compared with other Asian countries (Sitprija 2003). Indonesia's 43 nephrologists compares poorly with Thailand where the number of nephrologists in 2003 (the most recent accessible data) was 268. The population of Thailand is one-fifth of Indonesia's. The Philippines had 155 and Vietnam 60 nephrologists, respectively, both much higher ratios than Indonesia's (Sitprija 2003). Together with Myanmar, Indonesia has the lowest number of nephrologists per patient population in South East Asia (Sitprija 2003). Although no data on shortages of specialist nephrology nurses could be found, the low rates of tertiary educated nurses (Shields & Hartati 2003) suggest that advanced nephrology nurses would be scarce. No evidence of formal specialist nephrology nurse education was identified.

Distance to access kidney care centres is a major factor contributing to the low transplantation rates (Churak 2005). Transplant facilities are available in only a few centres in Indonesia, most on the island of Java. In 2004, there were only 10 hospitals able to perform organ transplantation (Markum 2004). Only one of these is located in Sumatra (the second most populated island), while the other nine are in Java (Prodjosudjadi 2006). Thus, the patients who live in remote areas or on poorly accessed islands are limited by transportation and higher costs. These

people also have difficulty accessing dialysis treatment and this contributes further to their inability to access transplantation information and resources. This ultimately leads to death from a disease that is highly treatable.

Discussion

Although the healthcare needs of developing countries such as Indonesia are different than wealthier nations, there are some similarities that are important to this discussion. In both developing and wealthier nations, kidney disease epidemiology and clinical features are similar (Luvira et al. 1998), transplantation has lower mortality rates (Port et al. 1993) and transplantation has improved quality-of-life outcomes (Cameron et al. 2000). Thus, low transplant rates lead to poorer outcomes for those living with CKD 5 whether in Indonesia or other nations.

Given the high costs of transplantation and the competing health priorities in Indonesia, the encouragement of expensive treatments such as kidney transplants may be questionable. The International Council of Nurses' (ICN 2000) statement relating to developing countries promotes 'the attain[ment of] a level of health that will permit them to lead a socially and economically productive life'. This starting point to the ethics of kidney transplantation in Indonesia leads to fundamental healthcare ethical principles such as autonomy, beneficence, non-maleficence and justice as well as ethical consequentialist or utilitarian approaches (Kerridge et al. 2005). Most developing nations accept organ donation on the ethical grounds related to consequentialist (the consequences of the intervention will be good) and beneficence (beneficial) grounds. The consequences of organ donation, i.e. the donated kidney being used to improve a person's health status rather than the kidney not being used, are an ethical perspective that supports organ transplantation. In addition, the principle of beneficence where the transplant benefits the individual without detrimental effects is also an ethical principle that supports transplantation.

Conversely, providing financial resources for kidney transplantation at the expense of other healthcare needs may not be beneficent to the majority of Indonesians. Markum (2004) suggested that more dialogue with health insurance agencies highlighting the savings of kidney transplants over dialysis is needed. Even so, the utilitarian argument favouring all Indonesians may not be consistent with the ICN's (1998) commitment to sustainable programmes which is incorporated in its 1998 vision statement. Therefore, in a developing country with competing healthcare resources, the question of health for the greatest good may be in question when it comes to sustaining expensive kidney transplant programmes. This is also complicated by individual and cultural ethical beliefs, which are influenced by religion, education, gender, law and social status (Tschudin 2003). The

cultural beliefs in Indonesia thus influence the ethical beliefs that they hold. This in turn may influence their reluctance to accept or donate an organ and may limit transplant rates, exacerbating the low transplant rates that already exist in Indonesia.

Discussion of kidney transplantation in the context of wider renal health care is necessary here. Prevention of kidney disease is more desirable than treatments such as dialysis and transplantation and should be the target of developing countries (Hafez et al. 2006; Prodjosudjadi 2006). Although a desirable target, there have been few studies supporting the successful implementation of mass screening to reduce kidney disease (Johnson 2004). Although there has been evidence of successful programmes in selected populations (Hoy et al. 2000), there is still much debate on the best screening methods and whether they are actually cost-effective (Hallan et al. 2006). Nwankwo (2006) supports the notion of untargeted general population kidney disease screening in developing countries. This has been taken up to some extent through Indonesia's National Kidney Foundation's Early Detection Program (National Kidney Foundation of Indonesia 2008). There remains a need for more research to inform the balance of prevention and treatment in order to contribute to the best use of Indonesia's limited healthcare resources.

Nursing practice implications

What can nurses do, if anything, to contribute to improved kidney transplantation rates in Indonesia? Given that there are many contributing factors how can nurses possibly contribute? We believe that the response is not to declare the 'situation impossible' but to suggest some ways in which nurses in Indonesia may contribute. These will be discussed under the headings of increased community education, nurse education and nurse empowerment.

Community education

Lack of awareness of kidney disease (causes, prevention, transplant issues) could be associated with low kidney donation rates in Indonesia. A study conducted by Gaston (2005) verified that early education to CKD 5 patients about transplantation and early referral to a transplant centre can increase access to transplantation rates. Participation by nurses may improve transplant rates by educating patients and their families' communities about kidney disease, prevention and treatment. This includes pre-transplant procedures. Discussion around the impact of living with one kidney, legal aspects and support mechanisms are important for a person on whether to decide to donate or receive a kidney.

There is evidence that discussion around prevention and health promotion in the community is already being encouraged

(Prodjosudjadi 2006). Some Indonesian health professionals and advocates have been involved in World Kidney Day in Indonesia (National Kidney Foundation of Indonesia 2008). We propose that nurses may play an important role in the prevention of CKD and an increase in transplant rates to improve quality of life of people living with kidney disease in Indonesia.

Nurse education

The low rate of university-prepared nurses can be recognized as a major contributing factor to low levels of health and high mortality (Shields & Hartati 2003). These low rates can specifically impact on restricting the roles of nurses at all levels of health care. In the area of kidney disease nurses can be involved at the primary through to the tertiary stages of care (Bonner 2003). In the community, nurses can contribute to preventing kidney disease by being involved in blood pressure, diabetes and kidney disease screening programmes. In addition they can encourage stakeholders to discuss their understanding of the benefits of organ donation. Intensive care, theatre and transplant coordinator nurses in the tertiary sector can play a role in the logistical aspects to improve donation practices. We agree with Shields & Hartati (2003) that educated nurses can help to increase the quality of health care in Indonesia, specifically the health care of Indonesians living with kidney disease. With further development of tertiary education for nurses, a shift in attitudes is occurring (Shields & Hartati 2003). More educated nurses can bring higher standards of care resulting in improved outcomes for patients. This may lead to better education of patients, community, and an improved understanding of the value of both disease prevention and organ transplantation.

Nurse empowerment

To improve the nation's health, nurses can contribute in health policy and public policy (Rains 2001). In making healthcare policies, governments cannot make the policies solely according to their own needs; they also need the health professionals who are involved in practice settings so the policies can benefit all. Nurses' participation in policy making should play an important role (Cherry & Jacob 2005).

In 2003 (the latest available figures in Indonesia), the number of nurses was 135 705 with a density of 6.2 nurses per 1000 population (Ministry of Health of Indonesia 2006). Although they are a major resource, nurses are still considered as non-professional (Shields & Hartati 2003). The stigma of the nurse as doctor's maid or doctor's helper is still strongly believed in community.

In Indonesia, nurses are hesitant to talk about change because it is usually associated with a negative attitude or a bad impression. Mason & Talbott (1985) stated that politics may not be acceptable for nurses, because it is thought to be related to 'dirty

games' and not to the Florence Nightingale image of the traditional helping nurse. Although this can be viewed as a dated opinion, it can certainly be relevant to Indonesia today. There are major differences between the educational preparation of medical doctors and nurses in Indonesia (Shields & Hartati 2003).

An increase in the educational quality of nurses could contribute to an increased professionalism. Nurses can be the advocates and speak for patients, families and communities' needs, or those who need care but have limited power (Gebbie et al. 2000). People with kidney disease would benefit from an increase in nursing professionalism and educational quality. Nurses can give their voices to help CKD patients continue their lives.

In Indonesia, there is still no well-communicated policy ruling relating to organ donors. Davies (2004) suggests that nurses can pass the message to the politicians and community, speak to the media and influence policy makers. Nurses can cooperate with other medical professionals to increase the low transplantation rate. Empowered nurses should be in a position to lobby for a greater per cent of GDP to be spent on health so that CKD patients can be supported to have improved therapy and improved health outcomes.

International relevance

Although the context of this paper is Indonesia, which has many complex and unique features, aspects of our findings may have international relevance. Aspects featured in this review such as costs, cultural, religious, data and information, infrastructure, geography, nursing's role in community awareness, nurse education and empowerment may have relevance to other healthcare issues in other nations.

Study limitations

Given rapid economic development in many parts of Indonesia, the process of literature review may have not identified important recent changes. Limited registry data were available. The review was confined to Indonesia and comparisons with Indonesia's immediate neighbours. We make no attempt to generalize these findings given that the review was geographically specific. Nevertheless, the finding that it is not just cost alone that prevents increased donation rates may be applicable to other nations.

Conclusion

Kidney transplantation is the treatment of choice for most people suffering from CKD 5. The results of this review identified that Indonesia's transplant rates are much lower than other comparable countries. Furthermore, there is a paucity of literature addressing low kidney transplant rates in Indonesia in both Indonesian and English language literature. The literature

identified costs as the major barrier to kidney transplant in Indonesia followed by cultural and religious beliefs, perception of the law and poor infrastructure related to kidney transplant requirements. We believe that there is great potential in Indonesia for empowered, educated nurses to lower some of these barriers and contribute to quality healthcare practices for people living with kidney disease.

Author contributions

Paul N. Bennett and Alfrina Hany contributed to the study concept, data collection/analysis, drafting of the manuscript and critical revisions.

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