

Caring for Migrants and Refugees With End-Stage Kidney Disease in Europe

Wim Van Biesen, Raymond Vanholder, Thomas Hernandez, Daniel Drewniak, and Valerie Luyckx

With the number of migrants and refugees increasing globally, the nephrology community is increasingly confronted with issues relating to the management of end-stage kidney disease in this population, including medical, logistical, financial, and moral-ethical questions. Beginning with data for the state of affairs regarding refugees in Europe and grounded in moral reasoning theory, this Policy Forum Perspective contends that to improve care for this specific population, there is a need for: (1) clear demarcations of responsibilities across the societal (macro), local (meso), and individual (micro) levels, such that individual providers are aware of available resources and able to provide essential medical care while societies and local communities determine the general approach to dialysis care for refugees; (2) additional data and evidence to facilitate decision making based on facts rather than emotions; and (3) better information and education in a broad sense (cultural sensitivity, legal rights and obligations, and medical knowledge) to address specific needs in this population. Although the nephrology community cannot leverage a change in the geopolitical framework, we are in a position to generate accurate data describing the dimensions of care of refugee or migrant patients with end-stage kidney disease to advocate for a holistic approach to treatment for this unique patient population.

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Introduction

Humanitarian crises have occurred throughout history, with displacement of groups of people and even of entire societies. In 2015 alone, the United Nations High Commission on Refugees (UNHCR) estimates that 65.3 million people were displaced from their homes due to conflicts and persecution.¹ In 2016, it is estimated that 347,000 refugees and migrants arrived in Europe, adding to the more than 1 million refugees and migrants who entered Europe in 2015.²

For the health care community, management of refugees and migrants is particularly challenging. Many medical therapies are expensive, and dilemmas arise around whether to extend these treatments to migrant and refugee populations. In nephrology practice, the need to care for refugees with end-stage kidney disease, including those treated with dialysis and kidney transplantation, will increase with the increasing number of refugees and migrants fleeing to countries where kidney replacement therapy is available. The immediate life-saving effect, the life-long need, and the financial challenges associated with maintenance kidney replacement therapy bring the ethical questions surrounding health care provision to these vulnerable populations into sharp focus. It is clear that

the micro level challenges of contacts between individual health care workers and migrants and refugees in need of end-stage kidney disease care also reflect what is happening on the macro, or societal, level, for which the increasing number of refugees trying to reach the European continent is causing substantial political tensions and societal distress. With regard to dialysis, the situation is less dramatic than may be perceived in popular culture: a recent international survey demonstrated that refugees constitute only 1.5% of the dialysis population and the majority of dialysis centers have no refugees at all (Fig 1).³ However, depending on center and region, the percentage of refugee patients is very variable, with the patient population in some centers having increased by >20% (and in occasional centers, by 50%) due to refugees seeking dialysis care.

In this Policy Forum Perspective, we present some of the ethical, moral, and social questions raised when refugees require end-stage kidney disease care, using deidentified clinical case vignettes to highlight situations faced by individuals with kidney failure, by their families, and by health care workers involved with their care. For simplicity, we use the terms migrants and refugees essentially interchangeably.

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Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients.

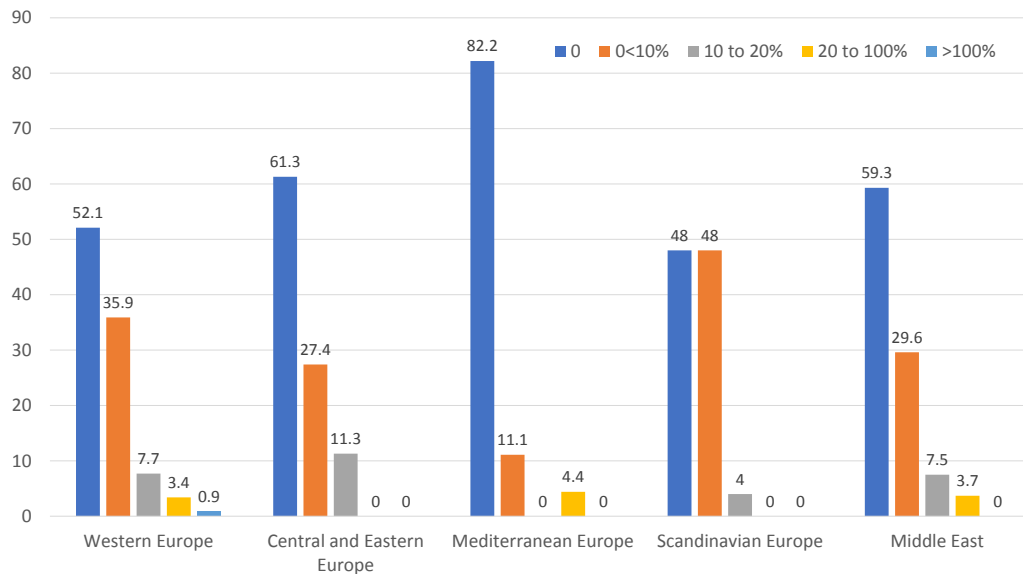


Figure 1. Prevalence of refugees as a function of a nonrefugee population receiving care in dialysis centers in Europe. Bars represent percentage of centers in that region having a given range of additional refugee patients over their regular population (expressed as a percentage) in their center.

Moral Dilemmas Posed by End-Stage Kidney Disease Care for Refugees in Europe

Case Vignette 1: A young refugee is admitted to the emergency department in a Western European country with dyspnea and weakness. He has a nontunneled internal jugular dialysis catheter in place, and an accompanying person explains that dialysis therapy was initiated in his homeland 3 weeks earlier due to chronic kidney failure. His last dialysis session was 5 days prior. The patient has muscle weakness and dyspnea. He has not yet registered to seek asylum, and his itinerary is unclear. It is therefore unclear what his legal status is and if and by whom medical costs will be reimbursed. However, it is clear that without further dialysis he will die soon.

Who Decides Whether Refugees Can Obtain Kidney Replacement Therapy?

Most moral frameworks agree that if you can do good to another person without causing harm to yourself or your next of kin, you should do so, highlighting that there is a “duty of rescue.”⁴ Accordingly, it is difficult to find a solid moral justification for not providing care to this patient: dialysis is life-saving, and Western Europe has the means to provide it without jeopardizing local patients or society. As mentioned, only ~1.5% of the broader European dialysis population are refugees,³ with peaks of 4.8% in Geneva and >30% in some Greek and Turkish dialysis centers. Although most nephrologists would dialyze a patient such as the one described in the vignette, 30% of surveyed nephrologists reported that this topic created tension within their team, partly because of reluctance to openly discuss the management of refugees.³ Reports of

tension were more prevalent (49% vs 28%, $P = 0.03$) in centers that also reported financial constraints on managing refugees. This finding is consistent with a systematic review that described that professional norms among physicians and nurses drove them to deliver care even if doing so went against regulations imposed by the authorities. This contrasted with support staff, who were less willing to make such deviations.⁵

Health care professionals are not always aware of the legal requirements for delivering care to migrants.⁶ Restriction of urgent care involving uninsured patients has been reported, although it is explicitly against the law in most countries.⁷ Furthermore, rules and laws regulating access to health care for migrants are open to interpretation and thus to biases or prejudice. For example, the construct “medical emergency” can be applied in different ways in the case of patients with end-stage kidney disease. Social perceptions and constructs have been found to unconsciously bias behavior and treatment decisions of health care professionals.^{8,9} It is likely that such implicit biases also occur toward refugees. For example, one study in which general practitioners were presented with vignettes found that their decision making on preferred medical actions was not only influenced by the medical condition, but also by patients’ social factors such as migration history, residential status (with or without permission), and economic situation.¹⁰

Some might distinguish between moral obligations to those who are refugees and either have pre-existing kidney failure or develop kidney failure versus those who are refugees because they have end-stage kidney disease and are looking for medical care that might not be available in their own region. In the former case, the refugee status is likely political and duties to the person may be clear. In the latter

case, the principle of solidarity could be considered weaker because criminal organizations exist that specifically arrange travel for patients with end-stage kidney disease from countries with low or no access to kidney replacement therapy to countries where it is widely available. At the University Hospital of Geneva, among 29 migrant patients starting hemodialysis therapy between 2000 and 2014, a total of 34% were already on dialysis therapy or started dialysis within 30 days of their arrival in Switzerland.¹¹

There is a need for strong well-constructed moral frameworks to support humanitarian medical practice.^{12,13} Moral frameworks are intended to provide tools outlining how to act in a given situation and also to supply a rationale for why one should aspire to act in that way.¹⁴ For a moral code to work, it is important that people can also understand how the tools will logically lead to the aspired goal. As a nephrology community, our goal may be to help patients with chronic kidney disease (CKD), whatever their origin. Making right choices also requires accurate facts on what is happening and understanding what the consequences of certain choices will be. Evidence and data for humanitarian health care are unfortunately very limited, with only one article dealing with CKD.¹⁵

Who Pays for Kidney Replacement Therapy for Refugees?

Among European nephrologists who participated in the aforementioned survey, responses about sources of funding for dialysis sessions for refugees were highly discrepant even within the same country, indicating a lack of knowledge regarding this topic.³ For registered refugees, some form of national or regional reimbursement of end-stage kidney disease care was often reported, but for nonregistered refugees, this number was substantially lower (59% vs 77%; $P < 0.01$). In most countries, reimbursement of health care depends on the legal status of the patient. For patients with a pending asylum request or permission to stay, health care is reimbursed up to the level of that of local patients. However, the actual source of reimbursement might differ among countries.⁶ In Switzerland, for example, health insurance is mandatory for everyone irrespective of residence status. Consequently, health insurance companies must accept anyone who can prove residency in the country for more than 3 months, including unregistered refugees requiring kidney replacement therapy. In contrast, in Belgium, health care costs for those with a pending asylum request are covered by the federal agency for refugees (Federal Agency for the Reception of Asylum Seekers [FEDASIL]), and dialysis units must reclaim costs from this agency. However, when an asylum request is accepted, reimbursement of costs to the hospital falls to the local community. Patients whose asylum requests are declined usually go underground and no longer have official health insurance. For these individuals, health care is reimbursed only in emergencies. To add to the complexity, it is unclear whether maintenance dialysis should be considered an emergency. The

World Health Organization (WHO) strongly condemns the provision of emergency care only, and the devastating physical and emotional effects of this practice on patients with end-stage kidney disease have been well described.¹⁶ The ethical foundation for tolerating such inequalities in access to care remain contested because some argue that even unequal access remains far better than what is available in the refugee's home country.

As mentioned, the number of refugees actually receiving kidney replacement therapy in Europe is far lower than often assumed. This discrepancy is deeply rooted in our biology. The human brain uses 2 decision-making systems: one (older) very fast system that is driven by immediate (visceral) emotions, and a second slow energy-consuming rational system.¹⁷ Neglecting emotions is impossible, but the tendency to develop fear of or anger toward refugees is irrational and unfair. When viewed on a factual basis, it becomes apparent that adding 1.5% more patients on dialysis therapy will not bankrupt existing health care systems. To promote a rational approach to refugees with kidney failure, the nephrology community has an obligation to document as many aspects of end-stage kidney disease care for refugees as possible. This should include establishing registries to record the incidence, prevalence, and other key factors relating to the care and well-being of refugee patients with end-stage kidney disease. Such information should be disseminated to educate health care workers and society to confront the pervasive emotional reactions to this issue. All nephrology centers should have easy access to accurate and up-to-date information about local legal and financial regulations on the management of refugees. Education of health care workers should also include a standardized framework for cultural competence training to tackle potential inequities in health care provision for patients with different social, linguistic, and cultural needs.¹⁸⁻²⁰

From an ethical point of view, it is important to ensure that decisions regarding health care reimbursement policies, including payment for dialysis care, remain at the political (macro) level so that individual providers, including nephrologists and nurses (the micro level), can focus on individual patients and their immediate needs (Fig 2; Table 1). Establishment of transparent guidance on reimbursement issues, including who can and cannot receive which forms of medical care, with an accompanying rationale on how to manage nonmedical issues in these patients, may reduce moral distress among health care workers confronted with rationing decisions when attempting to provide care for individual patients.²¹ The ethical values at stake are different at these 2 levels: at the macro level, safeguarding sustainability, fairness, and equity might be more important; however, for individual providers, delivery of optimal care based on medical needs of the individual patient should prevail. Forcing individual providers to consider sustainability or fairness of treating refugees is ethically hard to defend, particularly if sufficient resources exist to provide similar care for nonrefugee patients.



Figure 2. Responsibilities relating to end-stage kidney disease care for refugees and migrants at different societal levels of decision making and organization.

Ethical Challenges in Transplantation for Refugees

Case Vignette 1, Continued: *On account of the patient's young age, good health, and social support because of integration into the local society over the prior 2 years, the patient described previously is listed for kidney transplantation from a deceased donor. After 1 year, he receives a transplant. He is adherent to his medication, graft function remains excellent, and he is physically well 3 years later. However, because his refugee status is still pending, he remains on social assistance and is not allowed to work.*

Although kidney transplantation is the optimal kidney replacement therapy modality for many patients with end-stage kidney disease and in the longer run, is more cost-effective, the ethical aspects of transplantation in refugees and migrants are complex (Table 2). Patients with end-stage kidney disease who have been granted permission to remain in the host country should be considered equal to other members of the society and managed accordingly. Much more controversy surrounds refugees for whom such permission is not granted or still pending. Figure 3 depicts practices regarding transplantation for refugees in different regions of Europe and the Middle East. In Switzerland, kidney transplantation from deceased donors is only offered to refugees who have obtained a temporary admission, which also permits work and usually leads to a prolonged stay in the country. At the University Hospital of Geneva, 38% of migrant patients receiving maintenance

hemodialysis have gone on to undergo transplantation. However, given the paucity of available organs, this may increase the ethical tension of allocating a scarce resource to a newcomer—the challenge of distributive injustice.

Some countries promote living donation to decrease the burden of refugee patients requiring dialysis and reduce

Table 1. Approach to Refugees With End-Stage Kidney Disease

Goal	Relevant Actions
Place decision making at the right level	<ul style="list-style-type: none"> • Clear demarcations of responsibilities between the macro, meso, and micro level (Fig 2)
Provide data and evidence to facilitate decision making based on facts rather than emotions and hype	<ul style="list-style-type: none"> • Study epidemiology of kidney disease and ESKD among refugee and migrant populations • Investigate clinical outcomes among refugee and migrant populations • Examine well-being of refugee and migrant populations • Study health economic consequences of migration
Improve information and education	<ul style="list-style-type: none"> • Investigate epidemiology of diseases in subpopulations • Assess medical knowledge on specific diseases in this population • Learn about legal rights and responsibilities • Become familiar with reimbursement rules • Complete training in cultural sensitivity

Abbreviation: ESKD, end-stage kidney disease.

Table 2. Ethical Challenges Relating to Transplantation in Refugees and Migrants

Scenario	Moral Approach or Challenges
Living Donation With Donor Already in Country	
Acceptor and donor granted permission to remain	<ul style="list-style-type: none"> • Should be managed as regular citizens
Either acceptor or donor not (yet) granted permission to remain	<ul style="list-style-type: none"> • Is donation a justification to grant permission to stay for the donor and/or the acceptor? • Who is responsible for further medical follow-up in case permission to stay is refused later on? • Should we distinguish medical tourists from true refugees? • Who pays for the procedures? • How to avoid coercion for donation (ie, how to ensure free choice)?
Living Donation With Donor Not Yet in Country	
Would-be recipient granted permission to remain	<ul style="list-style-type: none"> • Is donation a justification to grant permission to stay for the donor? • How to ensure medical safety of the donation procedure for donor and recipient (pretransplantation workup)? • Who pays for the workup of the donor? • Who is responsible for further medical follow-up of the donor after donation? • How to avoid organ trafficking? • How to avoid coercion for donation (ie, how to ensure free choice)?
Would-be recipient not (yet) granted permission to remain	<ul style="list-style-type: none"> • Is donation a justification to grant permission to stay for the recipient and/or the donor? • How to ensure medical safety of the donation procedure for donor and recipient (pretransplantation workup)? • Who is responsible for further medical follow-up of the donor after donation? • Who is responsible for future medical follow-up of recipient in case permission to remain is refused? • How to avoid organ trafficking? • How to avoid coercion for donation (ie, how to ensure free choice)?
Deceased Donation	
Would-be recipient granted permission to remain	<ul style="list-style-type: none"> • Should be managed as regular citizens
Would-be recipient not (yet) granted permission to remain	<ul style="list-style-type: none"> • Issues of fairness and solidarity: 1 patient of local population is deprived of 1 kidney • Issues of fairness if refugees are accepted as potential donors but not as recipients or vice versa • Who is responsible for medical follow up in case permission to remain is refused? • Is transplantation a reason to grant permission to remain? • How to avoid medical tourism?

the allocation dilemmas with deceased donors.²² Although this approach seems attractive from the utilitarian point of view, it also is not free from ethical concerns, including a potentially greater risk for coercion and possibly even organ trafficking. Under such a scheme, there must be a clear action plan on how medical complications will be managed in the living donor, and it should be ensured that immunosuppressive agents will remain available to the recipient in the long run. In the absence of these assurances, including resource availability should repatriation occur, transplantation may be inappropriate.²³

Accepting for transplantation refugees or immigrants remaining in the country illegally can also create paradoxical situations in which people are allowed a sophisticated medical intervention, but are denied basic human rights. Transplantation is performed largely to improve quality of life and allow greater independence, including patients' ability to work and contribute to their own success and that of their families. Being restricted in these endeavors due to refugee status, even following transplantation, seems counter to the principles of dignity (being an accepted

member of society) and autonomy (ability to obtain sufficient financial means and the right to work).

Other Social and Cultural Challenges in Delivering Effective Care to Refugees

Case Vignette 2: A middle-aged legalized refugee treated with maintenance peritoneal dialysis is employed at a farm on a day-to-day contract basis. He has relapsing bouts of peritonitis with uncommon bacteria, but refuses to come to the hospital for fear of losing his job. Treatment of peritonitis episodes is therefore sometimes delayed for days. The patient needs the income to survive and to send to his son, who remains in a refugee camp on the border of his homeland. There is a suspicion that the son is kept hostage to ensure that the father pays outstanding debts for his journey to Europe. The man does not speak the local language and is close to illiterate. He struggles to understand the concepts of kidney disease and dialysis despite attempts to explain through a translator. He lives on his own in a room of 4 × 3 m. Lack of money and the need to work flexible shifts impede regular social contact.

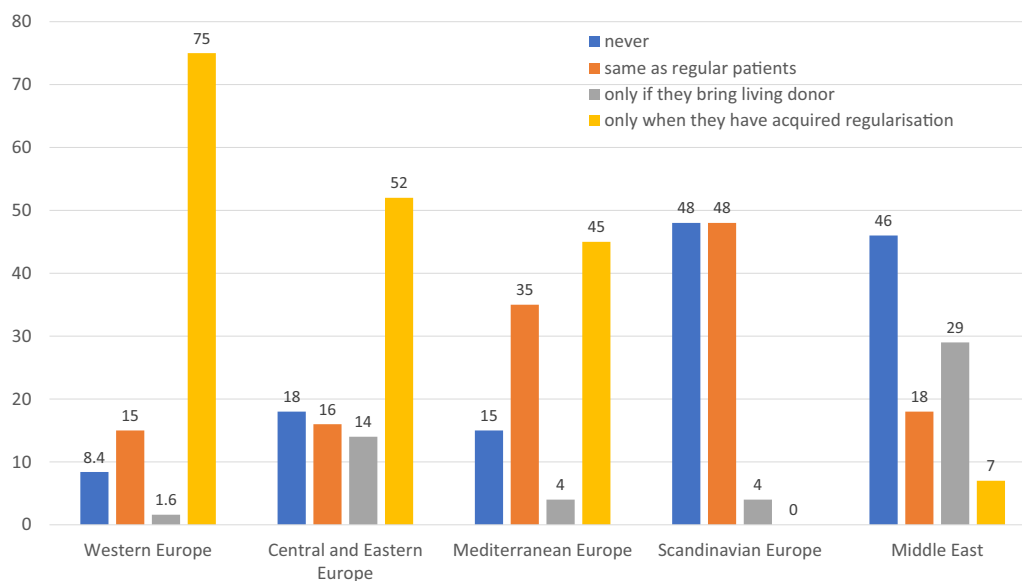


Figure 3. Approaches to transplantation of refugees in different regions of Europe and Middle East.

Refugees generally are among the more socioeconomically deprived segments of the host populations, increasing their risk for both communicable and non-communicable diseases.²⁴⁻²⁸ Although data specifically for CKD risk in refugees and migrants are lacking, type 2 diabetes, the leading risk factor for CKD in developed countries, is more common among refugees residing in neighborhoods with high as compared to low social deprivation.²⁹ Similarly, both hypertension and diabetes are associated with lower health literacy and lesser access to primary health care. Not surprisingly, both diabetes and hypertension are highly prevalent in refugee populations^{30,31} and provide potential treatment targets to reduce the risk for CKD and kidney failure.

Language barriers occur frequently, but they are probably often used too readily as an excuse to explain a lack of equitable access to care for migrants given the availability of interpreters and software platforms to enable communication.³² Of note, even when interpreter services are available, health care professionals do not always make full use of them.³³

Social, sex, and cultural mismatches between patients and treatment teams may prove further barriers to care.^{5,19} Both differences in perception and false expectations of health care can reduce mutual trust between refugees and medical providers.³⁴ For example, differences in approach to health care can lead to frustration among health care providers, who may deem a patient “nonadherent” while these same factors may result in a feeling of deprivation and even discrimination among patients, who may feel denied of dignity and respect as an individual.⁵ These challenges are often addressed through health care provider education in the cultural traditions of the specific population. Notably, although some qualitative work suggests that refugees experience treatment by some health

care professionals as unfriendly, humiliating, and disrespectful, other studies report that refugees value and appreciate the kindness and sincerity of their health care providers.¹⁶

Psychosocial problems are common in refugees, with at least half experiencing mental illness, most often post-traumatic stress syndrome or depression.³⁵ Sleep disturbances, concentration problems, increased vigilance and alertness, and panic disorder are also common.³⁶ Financial problems and uncertainty around their legal rights and future further add to the psychological burden. Fear of authorities based on previous experiences in their homelands or during their travels might create conflicts in families when urgent care is necessary. For many refugees, even small out-of-pocket costs for medical treatment are above what they can spend without depriving their families of other essential needs. For patients with end-stage kidney disease, this creates dilemmas that jeopardize not only the health of the affected patient, but also that of whole families. Accordingly, health care needs to be provided within a broader social context that will promote health both of the patient and of that patient’s family (Fig 4).³⁷

End-Stage Kidney Disease in Refugees in the Middle East

In terms of the current crisis in Syria and humanitarian crises elsewhere, only a minority of refugees reach Europe, while most are concentrated in countries surrounding geopolitically unstable areas. According to the UNHCR, 25% of refugees worldwide are currently in Turkey, Jordan, Libya, Egypt, or Iraq.² In Jordan, for example, 30% of the nation’s population are refugees. In addition, within Syria, the number of internally displaced persons is high. In these countries, up to 84% of dialysis sessions are paid for by nongovernmental charitable organizations, the

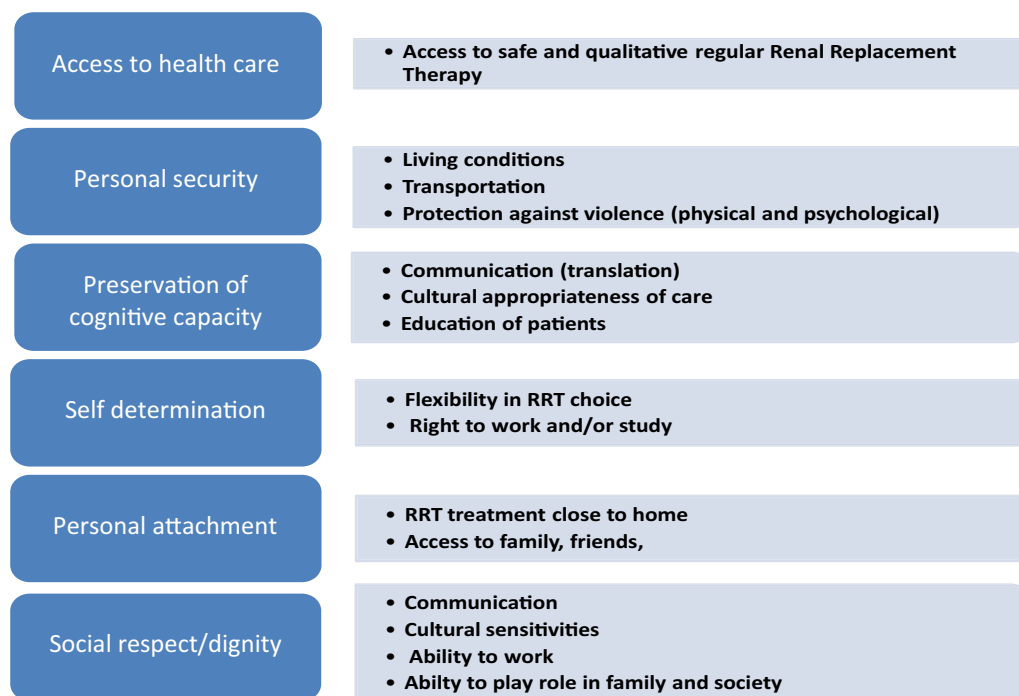


Figure 4. Requirements for equity-based management of refugees in need of kidney replacement therapy. (Based on the theory of Social Justice [Faden and Powers³⁷], as applied to provision of renal replacement therapy [RRT] to refugees).

WHO, or UNHCR because local authorities lack the means to do so.³⁸

Investment by international organizations in refugee health care appears to be positive, but external funding shifts the focus of care away from the local people toward the refugees. For medical problems such as hypertension or diabetes, refugees have been reported to have better access to health care and lower out-of-pocket costs than host country citizens.³⁰ Similarly, a retrospective analysis of reproductive health in 52 refugee camps in 7 countries demonstrated that refugees and internally displaced persons had better outcomes for all measured domains than host country citizens.³⁹ Whereas these results underline the effectiveness of some refugee health care programs, they also painfully highlight the created inequity in care. Such inequities are further exacerbated in dispersed health care settings, which rely on a variety of different actors and financing systems rather than one strong (state-driven) universal health care system.⁴⁰

For individuals dependent on maintenance dialysis, major problems described in Syria include safely getting to a dialysis facility, safety while in the dialysis facility (for both patients and dialysis staff), staffing and technical issues, and insufficient access to pure water.³⁸ New dialysis facilities have been established in safer areas in Syria, but access to disposables and spare parts for machines remains challenging. In these settings, the daily tensions among moral, ethical, medical, and financial aspects of dialysis care for refugee and migrant populations are far more stark than for refugee populations

in Europe. In these settings, care for end-stage kidney disease may be at the expense of other health care needs of the local population, but data are lacking.¹⁵ In Jordan, most dialysis sessions are funded by nontraditional donors such as diaspora nongovernmental organizations or private donors, and not by UNHCR.⁴¹ Nongovernmental organizations and private donors may feel an emotional “duty of rescue,” whereas UNHCR may have a more utilitarian approach driven by opportunity costs and cost-effectiveness. Consequentialists would point out that if they wanted to, European countries should be able to support the cost of dialysis in these countries (estimated at \$85 per session) in any valid candidate irrespective of his or her civil status, and that they omit to do so is thus a deliberate choice.⁴ At the same time, it behooves the nephrology community to develop kidney replacement therapy strategies at more affordable prices, which may also reduce migration driven by the need for dialysis.

Conclusion

Sustainable solutions for refugees with kidney failure depend on actions at the global geopolitical level. The international community should understand that hermetically closing borders while offering no support is ethically debatable and unrealistic. The nephrology community has the obligation to generate reliable and accurate data describing the many dimensions and challenges posed by provision of kidney replacement therapy for refugees and

migrants to inform relevant decision making. Such data should be disseminated, discussed, and used to advocate for appropriate treatment of migrant patients with kidney failure. It is imperative that individual health care workers are not forced to withhold available and essential treatment from patients who need these treatments regardless of their status as refugees or migrants. Rather, society needs to establish and disseminate transparent, definitive, and fair policies for kidney failure care for these vulnerable individuals.

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