

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

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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.

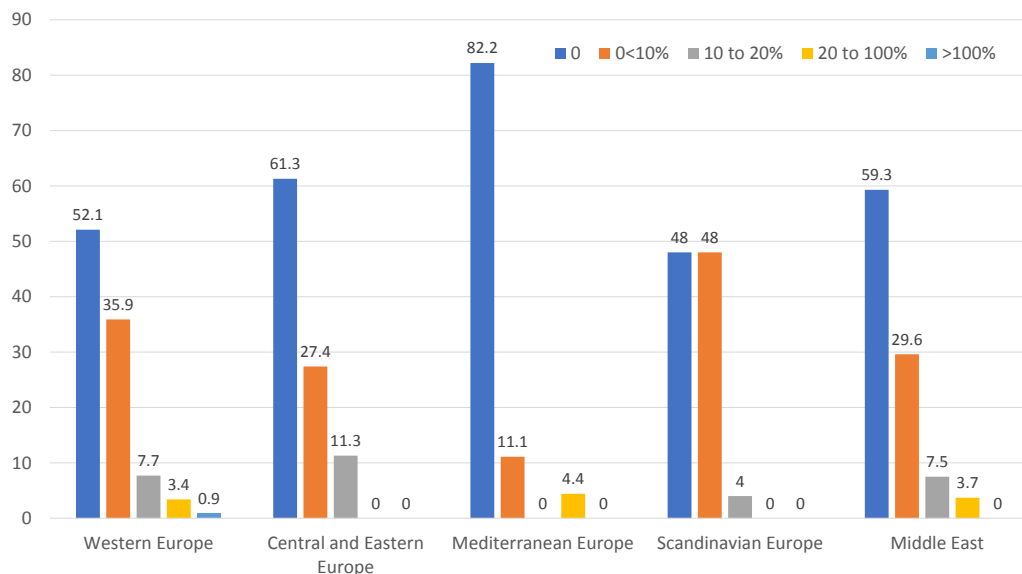


Figure 1. Prevalence of refugees as a function of a nonrefugee population receiving care in dialysis centers in Europe. Bars represent percentage of centers in that region having a given range of additional refugee patients over their regular population (expressed as a percentage) in their center.

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

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