Renal replacement therapy for refugees with end-stage kidney disease: an international survey of the nephrological community

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Provision of health care for refugees poses many political, economical, and ethical questions. Data on the prevalence and management of refugees with end-stage kidney disease (ESKD) are scant. Nevertheless, the impact of refugees in need for renal replacement can be as high for the patient as for the receiving centers. The International Society of Nephrology and the European Renal Association/European Dialysis and Transplant Association surveyed their membership through Survey Monkey questionnaires to obtain data on epidemiology and management practices of refugees with ESKD. Refugees represent 1.5% of the dialysis population, but their geographic distribution is very skewed: ±60% of centers treat 0, 15% treat 1, and a limited number of centers treat >20 refugees. Knowledge on financial and legal management of these patients is low. There is a lack of a structured approach by the government. Most respondents stated we have a moral duty to treat refugee patients with ESKD. Cultural rather than linguistic differences were perceived as a barrier for optimal care. Provision of dialysis for refugees with ESKD seems sustainable and logistically feasible, as they are only 1.5% of the regular dialysis population, but the skewed distribution potentially threatens optimal care. There is a need for education on financial and legal aspects of management of refugees with ESKD. Clear guidance from governing bodies should avoid unacceptable ethical dilemmas for the individual physician. Such strategies should balance access to care for all with equity and solidarity without jeopardizing the health care of the local population.

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The recent refugee crisis is considered one of the largest humanitarian and political challenges of recent decades. This crisis is a strenuous real practice test for the ethical concepts we take to be well established.[1] In our globalized society with omnipresent social media, we cannot ignore the crisis and the choices it brings. How we choose to respond directly affects the destiny of other human beings. In this era of sophisticated medical technology, a special consideration should go to those depending on that technology for their health and their lives, from very basic needs such as transplant patients for availability of their medication, to patients sustained on sophisticated life support in intensive care. In this setting, the global nephrological community is challenged with providing medical care to patients in need of renal replacement, a task with substantial ethical and financial consequences.

To the best of our knowledge, reports on kidney care in refugees until now have been scarce. Already in 1993, a report on the fate of end-stage kidney disease (ESKD) patients during the war in Iraq indicated that during conditions of war, insufficient access to dialysis and substantial shortening of treatments resulted in higher than expected mortality.[2] During this war, one-half of the patients fled the country as refugees. In a study on Afghan refugees in Iran, Otoukesh *et al.*[3] pointed out that a large proportion of referrals for kidney problems were for ESKD imposing an important financial burden on the hosting country.[4] Among Syrian

refugees in Jordan, the prevalence of chronic disorders that are at the origin of chronic kidney disease (diabetes, hypertension, cardiovascular disease) was found to be high. In addition to fleeing their country because of conditions of war, refugees also sought care for these ailments. It is also reported that poor social status and substantial changes in lifestyle predispose refugees to develop chronic conditions such as hypertension, cardiovascular disease, or diabetes,[5] which are all risk factors for chronic kidney disease.

The Renal Disaster Relief Task Force (RDRTF) of the International Society of Nephrology (ISN) and the European Renal Association/European Dialysis and Transplant Association (ERA-EDTA) surveyed the nephrological community on practical aspects of renal replacement therapy and nephrological care for refugees with ESKD. Our objective was to collect information on the size of the problem and on the views of the nephrological community on this topic.

RESULTS

Epidemiology

In total, 298 individual centers provided complete responses to the ISN survey (Figure 1, Table 1). Together, these centers had dialyzed 631 refugees in the 4 months before the survey. The total population of the centers who underwent regular dialysis was 40,378, so refugees represented about 1.5% of the represented dialysis population.

Of the responding centers, 177 (59.4%) reported that no refugees had been dialyzed in their unit over the preceding 4 months. Forty-two centers reported that they had treated 1 refugee, 21 centers had treated 2, 13 centers had treated 3, 8 centers had treated 4, 7 centers had treated 5, 5 centers had treated 6, and 3 centers had treated 7 refugee patients (Figure 2). Centers that reported to have treated >8 refugee patients had often substantially higher numbers, ranging up to 80 for a center in Yemen, where they provided once-weekly dialysis to maximize access for patients.

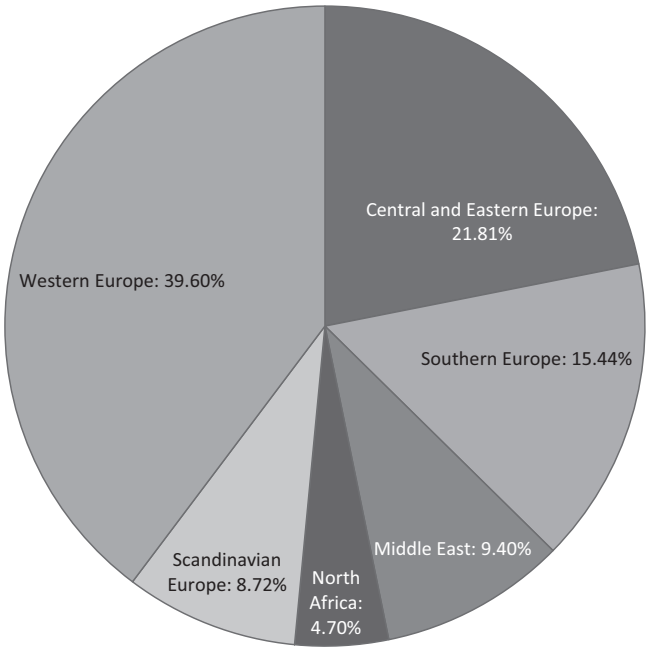

Figure 1 | Geographic distribution of respondents.

Thirty-three centers declared they refused dialysis to ≥1refugee. One center very close to an active war zone reported they had been obliged to refuse about 250 patients in need of dialysis because of a lack of resources. One center in Western Europe declined 25 refugee patients (but accepted 25 others) as the cost was to be supported by the nephrology department. Other centers reporting high refusal rates stated that they had requested patients to pay for their treatment.

Financial and legal regulations and policies

Reimbursement for dialysis for officially registered refugees with legal permission to stay in the country was covered by a national government in less than one-half of cases, and regional or local governments covered costs in about 25% of cases (Table 2). In a minority of cases, hospitals or nephrology units had to support the treatment themselves, or patients had to pay out of pocket.

There was a great deal of inconsistency in responses within the same country and even within the same region, where it was likely that legal regulations were similar. The cost of dialysis for refugees without official status was claimed to be covered by a government body by 40% of respondents. Up to 27.9% of the respondents admitted that they did not know who should pay for the dialysis of nonregistered refugee patients.

In many centers there was uncertainty and a lack of clear direction on how refugees with ESKD should be managed. Only about one-quarter of centers (24.5%) received clear instructions from their government that refugees who needed dialysis should receive it. About one-half the centers (46%) did not receive instructions from their government, but did obtain approval from their hospital administration to dialyze refugee patients if needed. Only one center stated that they received orders from the government not to treat refugee patients, and for 3.7% of centers, this order not to treat was issued by the hospital administration. One-quarter of centers reported that they were not aware of any instruction from their government or from the hospital administration, and of these, a large majority treated 0, 1, or 2 refugees (60, 8, and 2 centers of 74, respectively).

Attitudes toward transplantation for refugees

A small majority of centers (57.5%) listed refugees on their waiting list for renal (cadaveric) transplantation once they had obtained legal permission to remain in the country on a permanent basis. A substantial number (17.4%) declared that refugees were wait-listed irrespective of their official status, and one-quarter of centers never wait-listed refugee patients (15.7%), or only accepted them for a living donation transplantation if they provided a live donor and paid for the procedure themselves (9.1%).

How refugee status affects medical management

Financial constraints and cultural barriers seemed to have the greatest impact on the perceived adequacy of medical