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## The Effect of War on Syrian Refugees With End-Stage Renal Disease



**To the Editor:** The number of refugees in the world exceeds 20 million, with Syrians constituting close to a quarter of them,<sup>1</sup> including about 629,000 in Jordan in 2015.<sup>2</sup> Health care coverage of refugees varies by host country, but the United Nations High Commissioner for Refugees is the major payer. The United Nations High Commissioner for Refugees does not cover the expenses of many chronic diseases including end-stage renal disease (ESRD).<sup>3</sup> Studies from the Syrian War and other wars showed a major negative impact on the

populations with ESRD of the war-torn countries including excess death, loss of facilities, and diminution of the workforce.<sup>4,5</sup> As a result, many patients with ESRD seek refuge in other countries. The size and gravity of the problem of patients who need dialysis becoming refugees were recently highlighted in a survey of providers in Europe and the Middle East done by the Renal Disaster Relief Task Force of the International Society of Nephrology and European Renal Association/European Dialysis and Transplant Association. The survey estimated that 1.5% of patients who required dialysis in the surveyed facilities in Europe and the Middle East were refugees.<sup>6</sup>

Despite these publications, a significant lack of knowledge about the medical and psychosocial conditions of these refugees and how their renal replacement therapy is provided remains. In this letter, we report the results of a survey we conducted on the Syrian refugees in Jordan who required dialysis in 2015 with the goal of trying to estimate the prevalence of dialysis-treated ESRD and better understand the associated medical and psychosocial problems.

## METHODS

We identified Syrian patients receiving dialysis in Jordan in March 2015 by contacting nongovernmental organizations and the United Nations High Commissioner for Refugees. The prevalence of ESRD that required dialysis in the refugee population was calculated by dividing this number by the number of Syrian refugees in Jordan during the same period. Between July and September 2015, we attempted to interview these patients using a survey consisting of 47 demographic, clinical, and psychosocial questions. We obtained the value of each patient's most recent hemoglobin level before the interview. The interviews were conducted from July through September 2015. By then, 13 of the original 119 patients identified previously had left the country, 4 had died, and 3 had received living related donor kidneys funded by private donors and/or family. Fifty-seven of the remaining 99 patients participated in the survey (response rate: 58%). Consent was obtained from each interviewed patient or the parents if the patient was a minor.

## RESULTS

Demographic and additional psychosocial data are shown in [Table 1](#). The estimated prevalence of dialysis requiring ESRD was 189 patients per million refugees (119 divided by 629,000 and multiplied by a million). All patients were receiving hemodialysis. The mean duration of dialysis was 44 months. Thirty-one patients (54%) started receiving dialysis in the host country,

**Table 1.** Patients' characteristics and psychosocial findings

Variable	N (percent)
Average age (range)	47 (infants to 90 yr)
Female	32 (56%)
Diabetic	21 (37%)
Hepatitis C positive	8 (14%)
Hepatitis B positive	0 (0%)
Native fistula vascular access	46 (81%)
Feels severely sad and frustrated	20 (35%)
Feels that he/she is a major burden to family	21 (37%)
Considers dialysis discontinuation	15 (26%)
Lives in a tent	1 (2%)
Unable to get medications consistently	51 (89%)

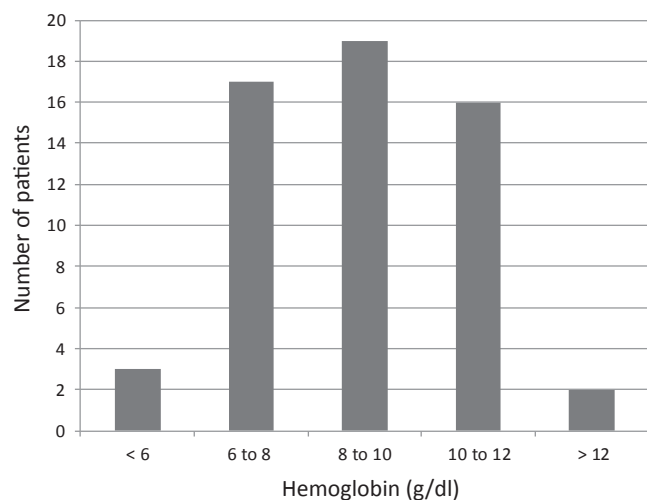
and the rest migrated as patients with ESRD. Thirty-nine patients (68%) received dialysis 3 times a week, 17 (30%) twice a week, and 1 patient once a week. The decision to provide dialysis less than 3 times a week was, in part, influenced by the funding entity protocols. Funding for the dialysis procedure was provided by Syrian diaspora organizations for 48 patients (84%) and other nongovernmental organizations for the rest. The dialysis procedures were done at certified Jordanian facilities that were directly reimbursed by the funding entities. The cost of the dialysis session without any anemia medications or vitamin D was about US \$85. Thirteen patients (23%) reported that they were not seen at all by a nephrologist. Fourteen patients (25%) reported at least 1 period of interruption of dialysis for a week or more, with financial reasons being the most common cause. The lack of a system that identifies funding agencies and coordinates their activities, the requirement of some funders to have the patient pay a fraction of the cost (copay), and shortages of available funds are the main reasons for the interruption of financial support. Twenty-six patients (46%) reported that they had to move to a different city 3 or more times to find a dialysis facility. Feeling psychologically exhausted was the most common reason for considering discontinuation of dialysis.

The distribution of the hemoglobin levels is shown in [Figure 1](#). Nine of the 20 patients with a hemoglobin level of less than 8 (45%) had no access to erythropoietic agents.

With regard to switching modality of renal replacement therapy, 38 patients (67%) were interested in receiving a kidney transplant. Lack of knowledge about peritoneal dialysis was reported by 39 patients (68%). Among those who knew about peritoneal dialysis but did not want to consider it, "fear of infection" was the most common reason for avoiding it.

## DISCUSSION

This study provides evidence of many aspects of inadequate care, including poor anemia control,<sup>7</sup> very



**Figure 1.** Distribution of hemoglobin values in the patients.

limited availability of medications, high prevalence of hepatitis C, and missed dialysis sessions.<sup>8</sup> Although prolonged intervals (1 week or more) without dialysis are life threatening, many of the other shortcomings are not unique to the refugees' situation and are somewhat typical for dialysis provision under limited resources.<sup>9</sup> The 14% prevalence of hepatitis C in our study is similar to that noted inside Syria in a recent survey of patients receiving dialysis by the World Health Organization.<sup>10</sup> The twice-a-week hemodialysis prescribed in 30% of cases in our study is not necessarily an indicator of poor quality of care if it is ordered in the appropriate setting.<sup>11</sup>

The negative emotions reported—including frustration, dissatisfaction with care, and consideration of dialysis discontinuation—are probably multifactorial in origin with contributions from the burden of ESRD itself<sup>12</sup> and the experiences of war and migration, in addition to the elements of inadequate care discussed previously. Amelioration of the latter element may help reduce the negative symptoms.

In 2005, the prevalence of dialysis-requiring ESRD in Syria was estimated to be 143 patients per million inhabitants.<sup>13</sup> Although in our study the prevalence in the Syrian population receiving dialysis was 189 per million, it is difficult to draw any solid conclusions about the impact of the war on the dialysis population survival, given many unknown facts about patients' migration patterns and the growth of this population over the 10 years between 2005 and 2015. Despite these limitations, it is fair to conclude that lifesaving dialysis, albeit substandard, is being provided. Although the United Nations High Commissioner for Refugees has not considered some chronic diseases, such as ESRD and cancer, a priority,<sup>3,14</sup> coverage of ESRD seems to have been considered a priority by nontraditional donors, such as diaspora nongovernmental organizations

and private donors. One interesting observation from inside Syria is that in the Idlib province, which was not under siege, the number of dialysis clinics increased after the start of the conflict.<sup>5</sup> These new facilities were funded by diaspora and international nongovernmental organizations. One can speculate that although agencies like the United Nations High Commissioner for Refugees make their decisions based on scientific methods such as cost-effectiveness, private donors and diaspora organizations involve more “emotions” in their decision-making process. This preference is known as the “rule of rescue,” which is defined as an “imperative people feel to rescue identifiable individuals facing avoidable death.”<sup>15</sup>

In this study, no patients were receiving peritoneal dialysis. This phenomenon is not unique to the Syrian refugee situation; the penetration of this modality was low in the country because of lack of adequate knowledge about the modality and false perceptions about its safety and effectiveness.<sup>13</sup>

Whether dialysis provision is or is not a priority in the scheme of health care management for refugees, it is clear from this study and others that funding for this provision exists. Regional and international renal professionals and organizations should play a major role in optimizing the provision of care, education, advocacy, and research.<sup>4</sup> Examples of such efforts include finding ways to get cheaper supplies, especially for peritoneal dialysis; lobbying governments and international organizations to provide protection for this vulnerable population; conducting research on cheaper alternatives, such as lower dialysis dose and low hemoglobin goals; and advocating palliative care.

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## DISCLOSURE

All the authors declared no competing interests.

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## United States Dialysis Facilities With a Racial Disparity in Kidney Transplant Waitlisting



**To the Editor:** Dialysis facilities are responsible for the majority of care provided to patients with end-stage renal disease (ESRD) in the United States (US).<sup>1,2</sup> US dialysis facilities are overseen by 18 ESRD networks and are tasked by the Centers for Medicare & Medicaid Services (CMS) to oversee quality ESRD care.<sup>3</sup> The CMS closely monitors dialysis facility performance related to many quality measures—such as patient mortality, patient hospitalization, vascular access, and other measures—and quantifies the facility's performance in a 5-star performance rating for patient interpretation.<sup>3,4</sup> The current quality metrics do not include measures for kidney transplantation access, which is the preferred treatment for the majority of patients with ESRD.<sup>5</sup> Variation in *transplant* rates across US dialysis facilities<sup>1</sup>, as well as racial and geographic disparities in kidney transplantation,<sup>1,6–8</sup> have been reported, but dialysis facility variation and prevalence of racial disparities in access to the deceased donor kidney waitlist remains unknown. Our aims were to describe (i) the variation in waitlisting and waitlisting racial disparities (African American vs. white) across US dialysis facilities and (ii) the geographic distribution of dialysis facilities with a waitlisting racial disparity. The identification of dialysis facilities with low waitlisting and the presence of racial disparities could help focus intervention efforts to improve access to kidney transplantation.

### METHODS

#### Study Data

To measure waitlisting variation and waitlisting racial disparities (African American vs. white), we analyzed United States Renal Data System data on dialysis facility characteristics, obtained by aggregating patient receiving dialysis (service dates from January 1, 2012 to December 31, 2014) by facility and year to obtain data on each facility in which a patient received dialysis. Each patient contributed 1 observation per facility per service period. Of a total of 9924 dialysis facilities, we included 5050 dialysis facilities with an ESRD network ID,  $\geq 5$  African American patients,  $\geq 5$  white patients, and  $\geq 11$  total patients with ESRD in every year (representing 987,046 patients) (Figure 1). Dialysis facility quality measures were obtained from the Centers for Medicare & Medicaid Services dataset used