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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,[1] including about 629,000 in Jordan in 2015.[2] 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).[3] 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.[4,5] 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.[6]

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, 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.

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%)

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 erythropoetic 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,[7] very