## Chapter 1 Introduction

## NKR and the Renal Replacement Therapy (RRT) Profile in Lebanon

The establishment of a Lebanese national kidney registry (NKR) is a cornerstone for the propagation of accurate and reliable data on the prevalence, incidence, patient management, practice patterns, clinical outcomes and survival among chronic kidney disease (CKD) patients of the Lebanese population. Unequivocally, this will generate information to be used by epidemiologists, public health officials, clinical researchers, service providers and physicians. Such information will be instrumental in prevention planning, continuous quality improvement in patient management, and monitoring of performance measures to assess these plans and processes. Many controversial issues will be highlighted and questions generated that constitute rich material for research in renal medicine practice in Lebanon.

*Hemodialysis* in Lebanon underwent rapid changes over the past few years. Between 2007 and 2012 the number of dialysis units increased from 51 to 64 and the number of HD patients from an estimated 2,400 to about 3,200, a 33% increase over 5 years. That increase in number of patients corresponded to an increase in prevalence of HD in Lebanon from 570 to over 700 patients per million people.

This increase in prevalence of HD is likely triggered by three factors that evolved concurrently:

- 1. Increased readiness by Nephrologists to initiate dialysis in older patients.
- 2. Higher alertness among physicians to diagnose renal disease, hence initiate RRT preparedness through referral to a nephrologist. This is shown by a higher percent of patients who saw a nephrologist prior to dialysis in patients who started HD in the past 18 months (Table 5.1).
- 3. Increased acceptance among patients to go into HD as an alternative they can live with rather than a "death sentence". Patients initiating dialysis over the past 18 months were about 8 years older (Table 4.1) and a higher proportion had comorbidity compared to prevalent patients (Table 5.1).

**Peritoneal dialysis** as a dialysis modality in adults appears to be gaining some momentum over the past three years. It is estimated that about 4% of patients are utilizing this modality compared to fewer than 3% three years ago. It will be possible to make a more accurate assessment after peritoneal dialysis specific modules are added to the registry. This would be modality of choice as more patients are starting to agree to initiate dialysis while having some residual renal function or awaiting a transplant.

Attention is being given in the NKR to a special subset of HD patients: those who came into dialysis after a failed *kidney transplant* (N=91, 4.8% of patients analyzed – Table 5.6). Demographic and clinical profile of these patients provides an indirect look into kidney transplant patients in Lebanon. This opens a window to inform planning of a transplant component of the NKR to be introduced in the coming years.

Also, the registry has offered an accurate demographic and clinical profile for patients who are incident to HD. Such knowledge can be used to inform a number of research, screening, community-based patient education and public awareness programs aiming for earlier diagnosis of CKD and better management of patients with moderate or severe CKD (stages 3 & 4). These programs are of critical importance since based on a crude estimate of RRT prevalence (dialysis + transplant) in Lebanon, there are between 41,000 and 82,000 stage 3 & 4 CKD patients, and most of them are unaware of their condition.

Some information recording issues were uncovered in the conduct of the registry during its first two years of operation such as:

- 1. Differences in units, methods and assays used in some laboratory measurements (ex. iPTH and P)
- 2. Inconsistent recordings of complications and outcomes, and
- 3. Unsatisfactory attention to nutritional and anthropometric parameters.

On the other hand, the congruence between most of the generated information and expected measurements and distributions based on international literature reports provided high confidence in the

quality of the collected data. Finally, two important venues will be opened, building on the success of the NKR:

- 1. Potential for research activity to include hospitals throughout Lebanon with involvement of all seven medical schools and their faculty and trainees. Schools of nursing, pharmacy and nutrition also have an opportunity for research in this patient population.
- 2. The possibility to assist in establishing guidelines, recommendations and standardized forms to be adopted universally among practicing nephrologists under auspices of the MOPH and LSNH. Performance measures can be monitored annually and plans refined accordingly.

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The research program (see appendix III) associated with the NKR has the potential to contribute to the refinement of patient management and practice patterns, enhance standardization efforts and assess cost effectiveness of present practice and proposed changes. The two studies that are currently in progress were funded by the Lebanese National Council for Scientific Research and provide a clear example:

 <u>The Vascular Access (VA) study (PI: Salim Kabalan, MD / Sponsor University: Lebanese)</u>: Evaluates changes in outcomes of VA construction in the context of recommended international guidelines and the utilization of standard forms to capture VA insertion parameters. These include pre-insertion assessments, construction parameters and maintenance care and repair procedures. This standard practice in the prospective cohort will be compared to historical practices in documentation, nephrologist-surgeon coordination and access care and repair. Corresponding outcomes will be evaluated in the retrospective cohort.

**Practical Value**: Emphasize adherence to international guidelines in VA construction, promotes the usage of standardized forms for process documentation of AVF creation, and obtains an assessment of parameters impacting success or failure of VA insertion.

 The Nutritional Education for Management of Osteodystrophy (NEMO) study (PI: Saade <u>Abboud, MD / Sponsor University: USEK</u>): Evaluates the impact of medical nutritional therapy (MNT) on objective outcomes of mineral balance, assessed in three study groups: 1) Full intervention using a dedicated dietitian trained on MNT practices, 2) Partial intervention using hospital dietitian equally trained on MNT practices, and 3) Control group using existing practices by hospital dietitian.

**Practical Value**: The clinical justification and cost effectiveness for having a dedicated dietitian trained in MNT for dialysis patients are evaluated. This intervention is compared to the alternative of providing similar training to the hospital dietitian who is also involved in a number of other responsibilities in the hospital.

These two research projects are being conducted at 19 dialysis centers throughout Lebanon with participation by 26 Nephrologists, 14 vascular surgeons and 12 hospital dietitians. Junior researchers are involved including one PhD candidate, two medical residents and 28 Masters Students in Nutrition at the Lebanese University, University of St. Joseph and USEK.

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The MOPH covers the cost of therapy for over 55% of dialysis patients in Lebanon and regulates the operation of the 66 centers where patients are treated. The cost of dialysis accounts for about 8% of the Ministry's budget. Incidence rates of dialysis are expected to progressively increase over the next few years to account for diagnosis shortfalls before eventually stabilizing. The NKR provides a key entry for prevention programs, refinement in practices and processes and improved efficiencies and cost effectiveness. It also offers a system that enhances continuous quality improvement in patient outcomes through ongoing monitoring of key performance measures.