

Need for a Jordanian National Registry of Chronic Renal Disease

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Abstract

Objective: There is sparse information on Chronic Kidney Disease (CKD) in developing countries which harbor the vast majority of the population with End Stage Renal Disease (ESRD). Data for children are inaccurate, with frequent underreporting of CKD.

Methods: With the escalating incidence of chronic kidney disease, it becomes obvious that there is a need for a Jordanian National Renal Registry (JNRR). This should be accomplished by the Ministry of Health, after establishing a national kidney foundation.

Conclusion: The Jordanian Society of Nephrology should be actively involved. The Registry should have representatives from the universities, government, armed forces, and private sectors. The registry should be considered as a national treasure.

Keywords: Jordanian National Renal Registry (JNRR), Chronic Kidney Disease, End Stage Renal Disease (ESRD).

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Introduction

Any systematic accumulation of data for the aim of planning, implementation, and evaluation of health care in a defined population is termed as a health care database. ¹ There are two types of health database. The first is patient registries such as the Australian/ New Zealand and Malaysian renal registries. ^{2, 3} These organized systems use observational study methods for data collection. The second type of health database is disease registries. These collected data are continuously and systematically applied in a defined population. The role of a disease registry is to evaluate and control a disease in the community. Examples are the National Cancer Registries. ⁴

Background

A World Kidney Day has been dedicated⁵ to the worldwide epidemic of Chronic Kidney Disease (CKD) especially in adults. ⁶ CKD is on the agenda for Healthy People 2010. ⁷ The increased incidence is mainly due to type 2 Diabetes Mellitus, and hypertension in adults. There is sparse information on CKD in developing countries which harbor the vast majority of the population with End Stage Renal Disease (ESRD). ^{8, 9} Data for children are inaccurate, with frequent underreporting of CKD. ¹⁰⁻¹⁶

In most developing countries, information on CKD patients comes from tertiary care hospitals and dialysis units. Data regarding the etiology, progression, and outcome of CKD is still sparse.

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Because of the dearth of National Registries, most of the statistics from developing countries do not reflect the true incidence or prevalence of CKD. The vast majority of studies are retrospective, and community hospitals are excluded.¹⁷ In addition to creating problems of international comparison, there is no emphasis on prevention.

In developing countries, data collection is mainly dependent on individual efforts of motivated and enthusiastic nephrologists. Proper National Registries for Renal Disease are virtually nonexistent, except in few countries. An excellent renal registry was established by the Turkish Society of Nephrology. The Turkish National Registry For Renal Disease, Dialysis, and Transplantation is highly successful, and is a good example to follow. In 2002, Turkey had around 2.5 nephrologists per million population.¹⁸ According to the 2008 Annual report of the Turkish National Registry, there is still a demand for nephrologists.¹⁹

In 2002, a working definition of CKD was provided by the Clinical practice guidelines developed by the Kidney Disease Outcomes Quality Initiative (KDOQI).²⁰ The new definition did not include the cause of the CKD. It focused on the presence of either a glomerular filtration rate < 60 ml/min/1.73 m² for more than three months, or kidney damage as reflected by proteinuria, hematuria, pathology findings, or imaging studies.²⁰ In 2004, K/DIGO modified the definition of CKD disease to include renal tubular syndrome, transplantation, and emphasized albuminuria.²¹ Based on estimated Glomerular Filtration Rate (eGFR) by the Modification of Diet in Renal Disease (MDRD) in adults,²² and the Schwartz formula in children,²³ CKD was divided into five stages, with stage I (the mildest), and stage V the most severe (ESRD). These stages formed a unifying nomenclature for CKD. Furthermore, the early stages (I-III) provided a ground for preventive measures to halt disease progression. Prevention is the current theme for CKD today.²⁴⁻²⁸ This is in sharp contrast to several decades of focusing only on treatment.

Many patients with stage III or IV CKD are labeled as such only on the basis of a low eGFR. However, that does not seem justified because the GFR is mostly < 60 ml/min/1.73 m² in people over 65 and in children < 2 years.

There are drawbacks in the estimated GFR, and some nephrologists call for modification of the equations.^{29,30}

Setting up a Jordanian National Registry for CKD

In line with other developing countries, CKD data in Jordan comes from tertiary care centers.^{10, 11, 31} The statistics are liable to bias. While some older ESRD pediatric patients attend hemodialysis sessions in one hospital, others (usually infants) are registered in another tertiary care center that provides only peritoneal dialysis. Unless a multicenter study is conducted, the data on the etiologies of ESRD will turn out to be completely different and deficient.^{11,33}

Furthermore, some patients with CKD are followed up in more than one tertiary care center, while others switch from one center to another depending on their medical insurance. This is liable to create duplication or deletion of data.

Likewise, many infants with CKD die in infancy. Most often, the cause of death is attributed to other etiologies such as sepsis. The renal disease is not even mentioned on the death certificate.

There is a need for a Jordanian National Registry of CKD including both adults and children. This will pave the way for proper statistics, avoids duplication or deletion of data.

Aim of the Registry

To establish a database of CKD in Jordan. It should include details of the various diseases including history, physical examination, pertinent laboratory findings, and imaging studies. The Jordanian National Registry (JNR) of Renal Disease will provide a national perspective of CKD and its treatment. It will foster prevention

and be able to make comparisons with international renal disease data from other registries, especially with the International Federation of Renal Registries (IFRR) which was founded in 1997.³² The registry will provide information needed for health care management, safety of therapeutic products, and data for clinical research. It will be involved in dialysis quality improvement.

Prelude to the Registry: The first vital step in paving the way for a JNR, should be the establishment of a National Kidney Foundation (NKF). This should be done by the Ministry of Health, that will be the patron of the registry.

Structure of the Registry

In collaboration with the Jordanian Society of Nephrology, the Registry should include members of the different health sectors (Universities, Government, Armed Forces, and private hospitals). There should be a Chairman with executive power.

In addition to a Secretary General and a general coordinator of the Registry, the committee should include a computer programmer, a statistics analyst, and a representative of the Registry from the various centers.

Besides motivation, funding of the Registry is also important.

At the start, it would be wise to include only patients with stage V CKD. This will cover those patients with Chronic Renal Failure (GFR < 60 ml/min/1.73 m²), and End Stage Renal Failure (GFR < 15 ml/min/1.73 m²).

There will be a need for a web site with a domain name such as www.CKD.Jo.com

To facilitate transfer of data, an electronic health system is fundamental. This includes developing electronic medical records, use of telemedicine, and evidence based practice. Germany has already started using the Smart Open Services employing an electronic card. This permits patients to access several dialysis centers, and hundreds of pharmacies.

However, for a developing country such as Jordan, it is essential to secure perpetual funding for the project to guarantee continuity.

Conclusions

The current methods of renal disease data collection in developing countries including Jordan are inadequate. There is a need for a National Renal Disease Registry after the establishment of a National Kidney Foundation.

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الحاجة الى سجل وطني لأمراض الكلى

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الملخص

مع ارتفاع حالات امراض الكلى المزمنة في الأردن، أصبحت هناك حاجة ماسة إلى تأسيس سجل وطني أردني لأمراض الكلى. ومن الممكن أن يتم ذلك عن طريق وزارة الصحة بحيث تكون الوزارة الراعي الرسمي للسجل، بالإضافة الى مشاركة فعالة من جمعية أمراض الكلى الأردنية. ومن الأهمية بمكان أن يكون هناك ممثلون لمختلف المشافي، سواء كانت جامعية، حكومية، تابعة للقوات المسلحة، أم متمركزة في القطاع الخاص. يجب أن نعتبر السجل الوطني الأردني لأمراض الكلى المزمن كنزاً وطنياً، من واجب كل مواطن الحفاظ عليه. فوجود هذا السجل يساعد الأطباء على إيجاد احصائيات دقيقة، بالإضافة إلى مقارنتها بالدول الأخرى.

الكلمات الدالة: السجل الوطني الأردني لأمراض الكلى، أمراض الكلى المزمنة، المرحلة النهائية من أمراض الكلى.