



EDITORIAL COMMENT

Advocacy for renal replacement therapy: the role of renal registries

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ABSTRACT

The paper by Jardine *et al.* reporting results from the South African Renal Registry describes a 2-fold success. First, even in a limited-resource environment, survival of patients on renal replacement therapy (RRT) is favourable. Secondly, this information is available because a few years ago, South African nephrologists started a renal registry. These successes cannot conceal, however, that numerous patients are not offered RRT. Robust health information systems make it possible to define chronic kidney disease and end-stage kidney disease (ESKD) burdens, guide resource allocation, inform service planning and enable policy. Registries can highlight inequitable RRT access and help support advocacy in favour of additional resources for ESKD care.

Keywords: advocacy, epidemiology, ESKD, inequity, registry

INTRODUCTION

The paper by Jardine *et al.* [1] reporting results from the South African Renal Registry describes a 2-fold success. First, they show that the 1-year survival of South African patients on renal replacement therapy (RRT) is favourable and similar in the public and private healthcare sectors, in a limited-resource environment (especially the public sector). Secondly, this information is available because a few years ago, South African nephrologists embarked on the adventure of a renal registry. These successes cannot conceal, however, that numerous patients are not offered RRT.

ACCESS TO END-STAGE KIDNEY DISEASE CARE

Jardine *et al.* show that RRT benefits the patients that are lucky or rich enough to receive it. Given the massive gap between the private sector, which covers ~16% of South

Africans with medical insurance, and the public sector in terms of RRT incidence [139 per million population (pmp) versus 4.4 pmp] and prevalence (855 pmp versus 66 pmp), the renal healthcare supply is clearly inadequate to meet the population's needs.

The Global Kidney Health Atlas Project, part of the Closing the Gaps initiative led by the International Society of Nephrology, indicates that the health systems of many countries face substantial challenges in closing the large gaps reported to exist today in meeting the health needs of the people with acute kidney injury (AKI) and chronic kidney disease (CKD) around the world [2, 3].

More than 850 million individuals worldwide have kidney diseases [4]. A systematic review has estimated the number of patients needing RRT as between 4902 million [95% confidence interval (CI) 4438–5431 million] in a conservative model and 9701 million (8544–11 021 million) in a high-estimate model, and suggested that at least 2284 million people may have died prematurely due to lack of access to RRT [5].

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Many patients remain undiagnosed or unreported, and others untreated. This unequal access to care is a significant ethical concern.

DATA-DRIVEN ADVOCACY FOR RENAL HEALTH EQUITY

RRTs have largely been proven to be effective. As a specialty and profession, nephrology has deep roots in the arenas of advocacy and public policy, with nephrologists playing a significant role in attracting legislative attention to the needs of patients with end-stage kidney disease (ESKD) [6].

At the same time, providing maintenance dialysis and kidney transplantation are an economic burden that challenges the healthcare resources in many countries and makes this disease a public health issue. Public health professionals thus have a role in data production and in the dissemination of information to partners, especially for needs analysis, issue framing, problem-solving and evaluation. The data generated facilitate evidence-informed policy-making based on the best and most contextually relevant available evidence.

These data may also be used to advocate for renal health equity. As defined by Farrer *et al.*, advocacy for health equity is 'a deliberate attempt to influence decision-makers and other stakeholders to support or implement policies that contribute to improving health equity using evidence' [7]. By 'evidence', they mean knowledge derived from qualitative and quantitative research intended for use in support of a conclusion.

Because health is a public good and global resource, and high levels of population health are a measure of a society's soundness, it is the duty of the states to enable the progressive improvement of its citizens' health by providing a framework for organizing the equitable delivery of services. Advancing health equity involves recognizing and replacing standard practices that maintain unfair distributions of power and resources in a given society. The scientific literature suggests that critical consideration of dominant discourses and assumptions and the mobilization of political will from a more informed and transparent democratic process can use knowledge to take action to achieve health equity [8].

ROLES OF RENAL REGISTRIES

An essential prerequisite in improving access to care is by estimating needs in order to define a sustainable strategy. Transparency and reliable statistics are key preconditions [9]. Robust health information systems make it possible to define CKD and ESKD burdens, guide resource allocation, inform service planning and enable policy development [10]. By collecting data on patients in a given territory, RRT registries have the opportunity to inform policymakers, professionals and the population about the provision and accessibility of RRT [11, 12]. CKD registries, on the contrary, are better able to provide information about the burden of the disease, insofar as they would identify all patients.

Registries also allow comparison between regions and countries and highlight diversity in practice but also potential inequity in access to renal care [13]. For example, the ERA-EDTA registry, which describes the epidemiology of RRT in 36 countries, shows that the transplantation rates vary from 3 pmp to >70 pmp across Europe [14]. Participating in the EDITH project (Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health

Expenditure and Patient Outcomes), European registries generate information that can be used for concrete action to improve the availability, quality and safety of kidney transplantation in the European Union [15].

The majority of countries have at least a dialysis registry, less often a renal transplant registry. However, the Global Kidney Health Atlas Project has reported the limited availability of reliable surveillance systems for both AKI and CKD across countries and regions. This lack is a major impediment to the design and implementation of effective interventions to close recognized gaps in infrastructures and services [2, 3, 16].

CONCLUSION

It is the duty of professionals to provide and demand the best quality for their patients, it is the duty of health administrations to guarantee equity of access to care and it is the duty of societies to find solutions to financial barriers.

Effective advocacy should include persistent efforts to raise awareness and understanding of the social determinants of health [7]. As the paper by Jardine *et al.* demonstrates, registries can highlight inequitable RRT access and help support advocacy in favour of additional resources for ESKD care.

CONFLICT OF INTEREST STATEMENT

None declared.

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