

A patient perspective on kidney disease in the public health agenda

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Chronic kidney disease is a life-changing diagnosis for millions of people worldwide, as the risk of disease progression and kidney failure creates unbearable uncertainty and limits lifestyle. The devastating impact of advanced kidney disease must be acknowledged in the public health agenda to pave way for improved outcomes for patients at all stages of disease.

Chronic kidney disease (CKD) has emerged as one of the most prominent causes of death and suffering in the twenty-first century. Owing in part to the rise in the prevalence of risk factors such as hypertension, obesity and type 2 diabetes mellitus, the number of patients affected by CKD has also been increasing, affecting an estimated 843.6 million individuals worldwide¹ in 2017. Although mortality has declined in patients with kidney failure, the Global Burden of Disease studies highlight CKD as an emerging leading cause of worldwide mortality¹. Importantly, such numbers likely underestimate the prevalence of kidney disease, as comprehensive registries and real-life data are notoriously lacking, especially in low-resource regions.

In 2020, the World Health Organization reported CKD as the tenth leading cause of death² – Global Burden of Disease data³ show that CKD mortality increased by 41.5% from 1990 to 2017 – and it is expected to become the fifth leading cause of years of life lost⁴ by 2040. Incomprehensibly, CKD is not listed by the World Health Organization as a priority and non-communicable disease driver of early mortality, like cancer or cardiovascular disease.

For patients with kidney disease with first-hand knowledge of its far-reaching impact – CKD deeply affects relationships with care partners, work prospects, leisure, sexual and mental health, life participation and the daily life activities of patients and their families – the need to prioritize kidney disease as a major public health issue is abundantly clear. Thus far, the discussion of kidney disease in the public health arena has mainly focused on advanced CKD and kidney replacement therapies (KRT), such as dialysis and kidney transplantation, with the narrow goal of improving kidney failure mortality. Do not misunderstand: as someone who has received dialysis since 1995, I am grateful for this life-saving KRT; however, this goal is not enough. It is time to go further. International and national strategic health plans must tackle the burden of CKD through initiatives that focus on disease prevention and early detection, especially among groups at high risk of kidney disease, to spare as many people as possible the burden and pain of kidney failure.

Patients with kidney disease ask policy makers and health authorities to urgently take a different approach and prioritize CKD in the public health agenda through collaboration with all stakeholders, including

patients, governments, policy makers, the pharmaceutical industry and health professionals. Nobody should face the need to receive dialysis or transplantation in the last part of twenty-first century. To achieve this goal, the awareness by the general population of CKD and its risk factors must increase, as has been achieved for cancer or cardiovascular diseases. For example, national awareness campaigns and widespread availability of educational materials can be effective tools to highlight CKD as a major public health issue, although such efforts require the support of global health authorities. Effective strategies for disease prevention must also be deployed among individuals at high risk of developing CKD – for example, people with diabetes, hypertension, obesity or genetic diseases affecting the kidneys – including better education for patients and primary care physicians, in combination with initiatives that enable early disease diagnosis. Furthermore, new therapeutic options that can manage and delay CKD progression or even restore kidney function must be developed and widely integrated into primary care.

“Effective strategies for disease prevention must ... be deployed among individuals at high risk of developing CKD”

Preventing CKD and delaying its progression are essential, given the high morbidity and mortality burden of kidney disease, especially for patients with kidney failure. All currently available forms of KRT are far from adequate, including in-centre and home dialysis. Kidney transplantation is cost-effective and is associated with better outcomes than dialysis, but <15% of patients with advanced kidney disease are eligible for transplantation, owing to comorbidities or other counter-indications⁵. Consequently, >85% of patients receiving dialysis remain dependent on these treatments indefinitely. Moreover, even for those awaiting transplantation, organ shortages mean that only a minority of patients benefit from this KRT. Importantly, the cost of kidney transplantation makes it inaccessible to many, especially in low- and middle-income countries⁵. Moreover, considerable challenges related to surgical infrastructure, medication adherence, graft rejection and the medium- and long-term side effects of the necessary immunosuppressant therapy (for example, osteoporosis, skin cancer and diabetes)⁶ remain broadly relevant.

The model of dialysis worldwide is obsolete, with 78% of patients receiving in-centre dialysis, three times a week⁷. This has a huge psychosocial impact, with ramifications for patient quality of life including barriers in the access to work, the need for unbearable diet and fluid restrictions, and the sequelae of retaining fluids and toxins in their bodies, especially during the weekends. Notably, haemodialysis is only

able to replicate a small fraction of kidney functions, which include not only glomerular filtration, but also hormonal and body volume balance. Despite its shortcomings, dialysis remains a life-saving therapy, but in regions without universal health coverage, millions of patients with kidney failure die each year because they cannot afford the out-of-pocket costs of dialysis treatments⁷. The environmental impact of dialysis, including the use of vast amounts of water, electricity and medical supplies that create tons of plastic waste, adds to the overall financial and societal burden of kidney failure⁸.

“All currently available forms of KRT are far from adequate”

In the current landscape, patients with kidney failure must adapt their lives to their treatments (timetables, transportation, medication, restrictions), and not the treatments to their lives. The recurrent need for vascular access is particularly problematic, and patients must get used to the pain of repeated cannulation and the complications associated with long-term vascular access, including the high risk of infection. Each vascular access type comes with own restrictions – for example, avoiding swimming pools – and interferes with daily life activities and life participation, including personal hygiene, directly affecting self-esteem, physical appearance, and sexual and mental health. Patients with kidney disease are advocating for vascular access that is permanent, painless and with low infection risk. Moreover, the treatment of chronic kidney failure must be re-evaluated to give patients more options, including facilitated disease management at home. Patients need innovative approaches to improve home therapies; new artificial kidney devices that are truly portable (not merely movable); methods for regeneration of dialysate flow; and improvements in vascular access, which has not advanced for decades.

Thus far, strategies to tackle and reduce CKD have been insufficient to alleviate the burden placed on people living with kidney disease and their families. These inadequacies will only continue to increase, with health-care systems unable to deliver appropriate treatments and care for a growing population with CKD, including those

with kidney failure, unless health authorities decisively and directly target kidney disease.

No health policy is truly complete without strategies for disease prevention and early diagnosis. The direct consequence of delayed diagnosis of CKD is a reduced lifespan and compromised quality of life. Such efforts to tackle the early stages of CKD must be complemented with strategies that ensure equitable access to therapies that can reduce the incidence of kidney failure while improving the treatment and quality of life of patients who need KRT.

We are living a unique moment in which the uncertain landscape of a CKD diagnosis can be transformed to provide hope to patients with kidney disease, rather than the fatality of a CKD diagnosis for which there is no solution or cure.

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Competing interests

The author declares no competing interests.