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World Kidney Day 2021: Living Well With Kidney Disease by Patient and Care Partner Empowerment—Kidney Health for Everyone Everywhere



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Patient Priorities for Living Well: A Focus on Life Participation

Chronic kidney disease (CKD) and its associated symptoms and treatment, including kidney replacement therapy, can disrupt daily living and impair the quality of life of patients and their family members. Consequently, this can impact treatment satisfaction and clinical outcomes.¹ To advance research, practice, and policy, there is increasing recognition of the need to identify and address patient priorities, values, and goals.¹

Several efforts have addressed these important questions, including the Standardised Outcomes in Nephrology (SONG) initiative, which includes more than 9,000 patients, family members, and health professionals from over 70 countries.^{2,3} Children and adults with CKD have consistently given higher priority to symptoms and life impacts than health professionals.^{2,3} In comparison, health professionals have given higher priority to mortality and hospitalization than patients and family members. The patient-prioritized outcomes are shown in [Fig 1](#).

Life participation, defined as the ability to do meaningful activities of life including, but not limited to, work, study, family responsibilities, travel, sport, social, and recreational activities, was established as a critically important outcome across all treatment stages of CKD.^{1,2} Patients wanted to be able to live well, maintain their role and social functioning, protect some semblance of normality, and have a sense of control over their health and well-being. The quotations from patients with kidney disease provided in [Box S1](#) demonstrate how life participation reflects the ability to live well with CKD.⁴ The World Health Organization (WHO) specifically defines participation as “involvement in a life situation.”⁵ Life participation places the life priorities and values of those affected by CKD and their families at the center of decision making. The World Kidney Day (WKD) Steering Committee calls for the inclusion of life participation as a key focus in the care of patients with CKD to achieve the ultimate goal of living well with kidney disease. This necessitates the development and implementation of validated patient-reported outcome measures that could be used to assess and address areas of life participation in routine care. Monitoring of life participation could be supported by

regulatory agencies as a metric for quality care or to support labeling claims for medicines and devices. Funding agencies could establish targeted calls for research that addresses the priorities of patients, including life participation.

Patient Empowerment, Partnership, and a Paradigm Shift Towards a Strengths-Based Approach to Care

Patients with CKD and their family members, including care partners, should be empowered to achieve life goals and the best-possible health outcomes. The WHO defines patient empowerment as “a process through which people gain greater control over decisions or actions affecting their health.”⁶ For patients receiving dialysis, understanding the rationale for a lifestyle change and having access to practical assistance and family support has been reported to promote patient empowerment, whereas feeling limited in life participation undermines their sense of empowerment.⁷

The 2021 WKD Steering Committee advocates for strengthened partnership with patients in the development, implementation, and evaluation of interventions for practice and policy settings. This needs to be supported by meaningful communication and patient and family involvement across the entire research process.⁸ There have also been efforts, such as the Kidney Health Initiative, to involve patients in the development of drugs and devices to foster innovation.⁹

We urge greater emphasis on a strengths-based approach as outlined in [Table S1](#), which encompasses strategies to support patient resilience, harness social connections, build patient awareness and knowledge, facilitate access to support, and establish confidence and control in self-management. Different from the medical model where chronic disease is traditionally focused on pathology, problems, and failures,¹⁰ the strengths-based approach acknowledges that each individual has strengths and abilities to overcome problems and challenges, and requires collaboration and cultivation of the patient’s hopes, aspirations, interests, and values. Efforts are needed to ensure that structural biases, discrimination, and disparities in the health care system also are identified.

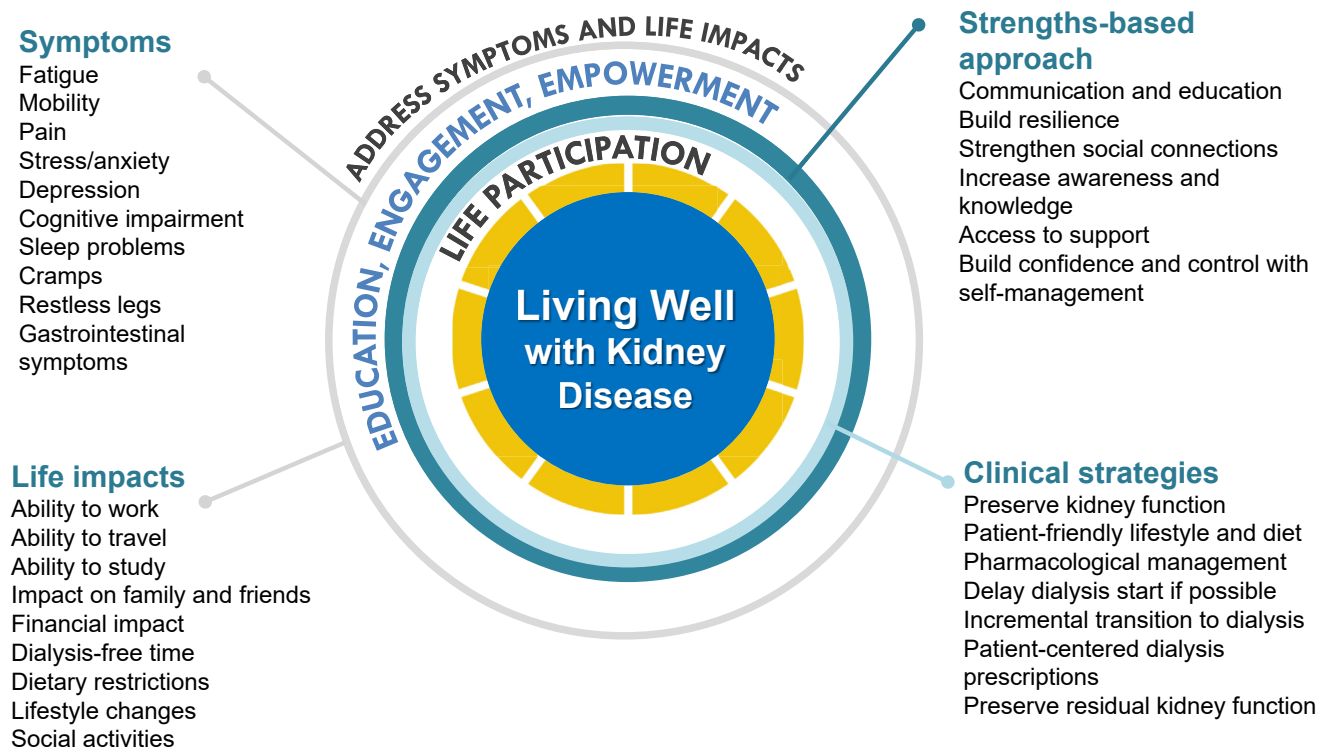


Figure 1. Conceptual framework of “Living Well With Kidney Disease” based on patient centeredness and empowering patient, with focus on effective symptom management and life participation.

The Role of Care Partner

A care partner is often an informal caregiver who is also a family member of a CKD patient.¹¹ Care partners may take on a wide range of responsibilities and may become more important in CKD care, given the heightened complexity in communication and therapeutic options, including the expansion of telemedicine during the coronavirus 2019 (COVID-19) pandemic, and given the goal to achieve higher life expectancy with CKD.¹² They may experience a substantial burden, which may impact family dynamics. Hence, the above-mentioned principles of life participation need to equally apply to care partners involved in CKD care.

Living With Kidney Disease in Low-Income Regions

In low- and lower-middle-income countries, patient care may often be influenced by internal factors including belief systems and personal attributes and external factors including knowledge of the disease, income, support system, and social network. Many patients in low-resource settings present in a very late stage and need to commence emergency dialysis.¹³ The very few who are fortunate to receive a kidney transplant may encounter highly unaffordable immunosuppressive medication costs. Thus, the support system—comprising health care providers and caregivers—plays a crucial role, as most patients rely on them in making decisions, and for adjustments in their health behavior.¹⁴ However, in low-income country

regions, there are often a low number of kidney care providers per capita, especially in rural areas. A stepwise approach that can involve local and national stakeholders including both nongovernmental organizations and government agencies can address this shortage by (1) extending kidney patient education in rural areas; (2) adopting telehealth technologies, if feasible, to educate patients and train local community kidney care providers; and (3) implementing effective retention strategies for rural kidney health providers.

World Kidney Day 2021 Advocacy

The 2021 WKD theme, “Living Well With Kidney Disease,” is deliberately chosen to redirect more focus on achieving patient-centered wellness, which is a policy imperative that can be successfully achieved if policy makers, health care professionals, patients, and care partners place this within the context of comprehensive care.

The 2021 WKD Steering Committee encourages policy makers to increase resources to enable patients to live well with kidney disease. Home dialysis therapies have been consistently found to improve patient quality of life in a cost-effective manner and enhance life participation, and should be promoted in conjunction with appropriate “assisted dialysis” programs to reduce patient and care partner fatigue and burnout. Achieving equitable health outcomes relies upon recognizing that different approaches and resources are needed for different people with different levels of

disadvantage. The involvement of primary care and general physicians, especially in low- and lower-middle-income countries, would be useful in improving the affordability and access to services through the public sector and in improving symptom management of CKD patients. However, primary prevention should remain a priority. Early detection, with an effective secondary prevention program to enable a prolonged course of wellness despite kidney disease, should be promoted.¹⁵ Prevention of CKD progression can be attempted by lifestyle and diet modifications such as a plant-dominant low protein diet and by effective pharmacotherapy, including administration of sodium/glucose transport protein 2 (SGLT2) inhibitors.¹⁶ The 2021 WKD campaign continues to call for increased awareness of the importance of preventive measures, applicable to both developed and developing countries.¹⁵

Conclusion

Effective strategies to empower patients and their care partners help in achieving the overarching goal of minimizing the burden of CKD-related symptoms in order to enhance patient satisfaction, health-related quality of life, and life participation. In declaring 2021 the year of “Living Well With Kidney Disease” despite the COVID-19 pandemic overshadowing many activities, the WKD Steering Committee seeks to increase education and awareness regarding effective symptom management and patient empowerment. Even as WKD continues to emphasize the importance of effective measures to prevent kidney disease and its progression,¹⁵ patients with preexisting kidney disease and their care partners should feel supported to live well through concerted efforts by kidney care communities and other stakeholders throughout the world.¹⁷ As a joint initiative of the International Society of Nephrology and the International Federation of Kidney Foundation World Kidney Alliance, and in alliance with kidney foundations, patient groups, and professional societies, WKD affirms living well with kidney disease as an uncompromisable goal.

Supplementary Material

Supplementary File (PDF)

Box S1: Quotations from patients with CKD related to priorities for living well.

Table S1: Suggested strategies for “living well with CKD” using a strengths-based approach.

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