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## Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere



OPEN

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**Living with chronic kidney disease (CKD) is associated with hardships for patients and their care partners. Empowering patients and their care partners, including family members and friends involved in their care, may help minimize the burden and consequences of CKD-related symptoms to enable increased life participation. There is a need to broaden the focus on living well with kidney disease and reengagement in life, including emphasis on the patient being in control. The World Kidney Day (WKD) Joint Steering Committee has declared 2021 the year of “Living Well with Kidney Disease” in an effort to increase education about and awareness of the important goal of patient empowerment and life participation. This calls for the development and implementation of validated patient-reported outcome measures to assess and address areas of life participation in routine care. It 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 address the priorities of patients. Patients with kidney disease and their care partners should feel supported to live well through concerted efforts by kidney care communities, including during pandemics. In the overall wellness program for patients with kidney disease, the need for prevention should be reiterated. Early detection with prolonged course of wellness despite kidney disease, after effective secondary and tertiary prevention programs, should be promoted. WKD 2021 continues to call for increased awareness of the importance of preventive measures across populations, professionals, and policy makers, applicable to both developed and developing countries.**

**KEYWORDS:** care partner; health policy; low- to middle-income countries; patient empowerment

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**C**hronic kidney disease (CKD), its associated symptoms, and its treatment, including medications, dietary and fluid restrictions, and kidney replacement therapy, can disrupt and constrain daily living and impair the overall quality of life of patients and their family members. Consequently, it can also affect treatment satisfaction and clinical outcomes.<sup>1</sup> Despite this, the past several decades have seen limited improvement in the quality of life of individuals living with CKD.<sup>1</sup> To advance research, practice, and policy, there is

increasing recognition of the need to identify and address patient priorities, values and goals.<sup>1</sup>

Several regional and global kidney health projects have addressed these important questions, including the Standardised Outcomes in Nephrology (SONG), with more than 9000 patients, family members, and health professionals from more than 70 countries.<sup>2,3</sup> Across all treatment stages, including CKD, dialysis, and transplantation, SONG- participating children and adults with CKD consistently gave higher

priority to symptoms and life impacts than health professionals.<sup>2,3</sup> In comparison, health professionals gave higher priority to mortality and hospitalization than patients and family members. The patient-prioritized outcomes are shown in Figure 1. Irrespective of type of kidney disease or treatment stage, 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.

*Life participation*, defined as the ability to engage in meaningful activities of life, including but not limited to work, study, family responsibilities, travel, sport, social, and recreational activities, was established a critically important outcome across all treatment stages of CKD.<sup>1,2</sup> The quotations from patients with kidney disease provided in Box 1 demonstrate how life participation reflects the ability to live well with CKD.<sup>4</sup> According to the World Health Organization (WHO), participation refers to “involvement in a life situation.”<sup>5</sup> This concept is more specific than the broader construct of quality of life. Life participation places the life priorities and values of those affected by CKD and their family at the center of decision-making. The World Kidney Day (WKD) Steering Committee calls for the inclusion of life participation, a key focus in the care of patients with CKD, to achieve the ultimate goal of living well with kidney disease. This calls for 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 address the priorities of patients, including life participation.

### **Patient empowerment, partnership, and a paradigm shift toward a strengths-based approach to care**

Patients with CKD and their family members, including care partners, should be empowered to achieve the health outcomes and life goals that are meaningful and important to them. The WHO defines patient empowerment as “a process through which people gain greater control over decisions or actions affecting their health,”<sup>6</sup> which requires that patients understand their role and have the ability to engage

with clinicians in shared decision-making, skills, and support for self-management. For patients receiving dialysis, understanding the rationale for lifestyle change, and having access to practical assistance and family support promoted patient empowerment, whereas feeling limited in life participation undermined their sense of empowerment.<sup>7</sup>

The WKD Steering Committee is advocating for strengthened partnership with patients in the development, implementation, and evaluation of interventions for practice and policy settings, that enable patients to live well with kidney disease. This needs to be supported by consistent, accessible, and meaningful communication. Meaningful involvement of patients and family members across the entire research process, from priority setting and planning the study through to dissemination and implementation, is now widely advocated.<sup>8</sup> There also have been efforts, such as the Kidney Health Initiative, to involve patients in the development of drugs and devices to foster innovation.<sup>9</sup>

We urge greater emphasis on a strengths-based approach as outlined in Table 1, 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. The strengths-based approach contrasts with the medical model, in which chronic disease is traditionally focused on pathology, problems, and failures.<sup>10</sup> Instead, the strengths-based approach acknowledges that each individual has strengths and capabilities to overcome the problems and challenges faced 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 are identified and addressed, so that all patients are given the opportunity to have a voice.

### **Role of the care partner**

A care partner is often an informal caregiver who is also a family member of the patient with CKD.<sup>11</sup> Care partners may take on a wide range of responsibilities, including coordinating care (including transportation to appointments), administering treatment including medications, assisting with home dialysis, and supporting dietary management. Caregivers of patients with CKD have reported depression, fatigue, isolation, and

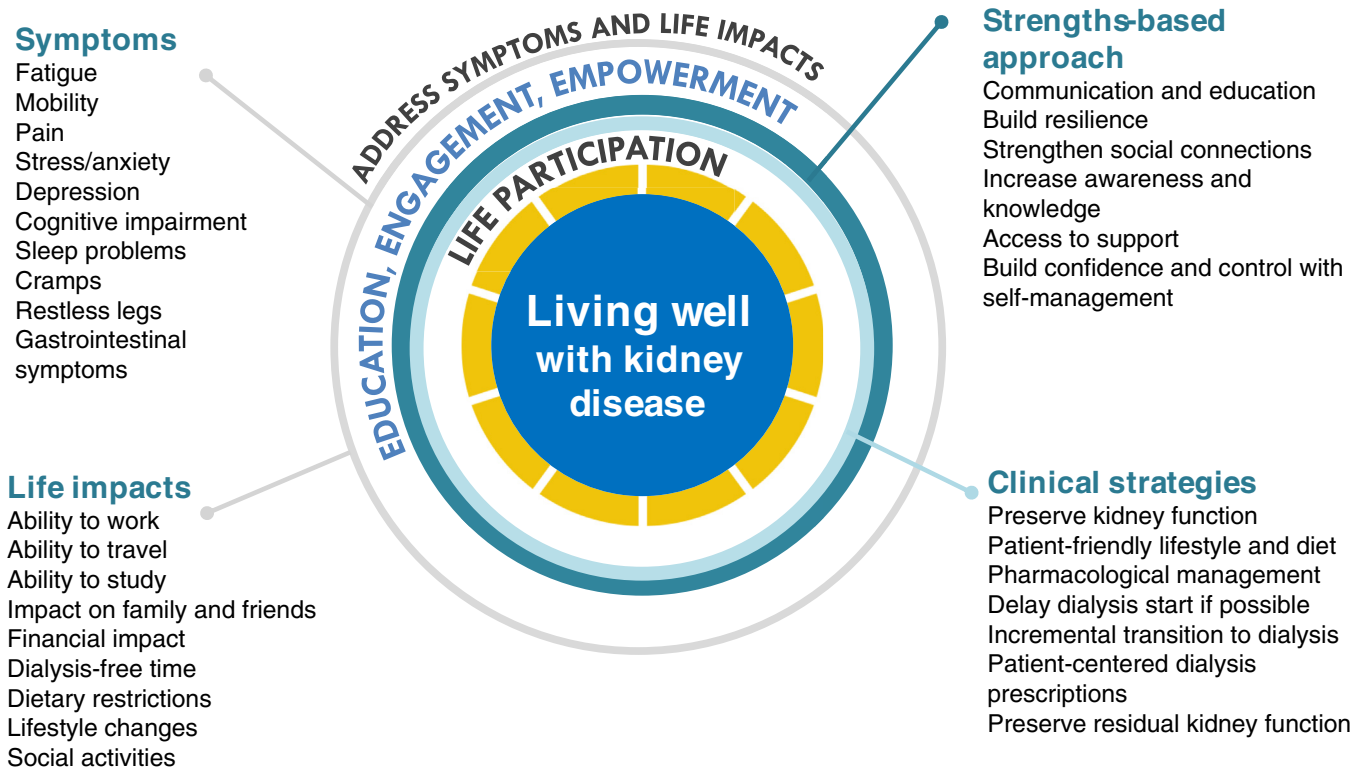
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**Figure 1 | Conceptual framework of “Living Well with Kidney Disease” based on patient centeredness and empowering patient, with a focus on effective symptom management and life participation.**

burnout. The role of the care partner has become increasingly important in CKD care, given the heightened complexity of communicative and therapeutic options, including expansion of telemedicine during the coronavirus disease 2019 (COVID-19) pandemic, and given the goal of achieving a longer life expectancy with CKD.<sup>12</sup> Caring for a partially incapacitated family member with progressive CKD can impose a substantial burden on the care partner and may impact family dynamics. Not infrequently, career goals and other occupational and leisure aspects of the life of the care partner are affected because of CKD care partnership, leading to care partner overload and burnout. Thus, the aforementioned principles of life participation for patients need to apply equally to care partners as well as all family members and friends involved in care of a patient with CKD.

**Living with kidney disease in low-income regions**

In low-income countries (LICs) and lower-middle income countries (LMICs), including in sub-Saharan Africa, Southeast Asia, and Latin America, a patient’s ability to self-manage or

cope with chronic disease may be influenced by internal factors, including spirituality, belief system, and religiosity, and external factors, including appropriate knowledge of the disease, poverty, family support system, grit, and social network. The support system comprising healthcare providers and caregivers plays a crucial role as most patients rely on them when making decisions and necessary adjustments in health behaviors.<sup>13</sup> In LIC regions, where there are often relatively low numbers of physicians and even fewer kidney care providers, especially in rural areas, a stepwise approach can involve local and national stakeholders, including both nongovernmental organizations and government agencies, by (i) extending kidney patient education in rural areas, (ii) adapting telehealth technologies if feasible to educate patients and train local community kidney care providers, and (iii) implementing effective retention strategies for rural kidney health providers, including adapting career plans and competitive incentives.

Many patients in low-resource settings present in very late stages with the need for emergency dialysis.<sup>14</sup> The very few fortunate patients to undergo kidney transplantation may

**Box 1 | Quotations from patients with CKD related to priorities for living well**

*"I don't want to think about dying from my disease. I want to be able to live well with my disease."* – Patient with CKD

*"Life participation is most important because without it, you can't do anything."* – Child with CKD

*"Maybe it's as simple as asking patients whether, how well they are able to participate in the life that they want to lead because it's going to be different for different people."* – Kidney transplant recipient

*"Everyone has to face death, what I would like to have is a good quality of life rather than to face death."* – Kidney transplant recipient

*"So, it doesn't actually really matter what the numbers say, and some of my numbers should have suggested that I should be feeling a lot worse than what I actually was; it's about how much I feel I can do and participate in my life and feel normal."* – Patient with CKD

*"I'm still living. I get out of bed, and I'm still living and still breathing. As long as I can do that, I'm going to carry on and be positive because life is short."* Patient with CKD<sup>a</sup>

*"I put life participation because I know that looking from the outside, I know [his kidney disease] stops [him] from thinking bigger.... Although that's really big, there's this life that has to happen at the same time."* – Family member

*"Amazed at comments from professional(sic) about travel, free time, etc., they seem to think the mechanics of dialysis far more important. Dialysis is a treatment which keeps us alive to live a life, not just to wait for death."* – Patient receiving dialysis

*"I prefer to be above ground, then below ground. So why not enjoy life whilst being above ground."* Adam Martin

*"Over the years, I have learned to worry less, control my emotions and not fear death. I keep my mind active. I follow the advice of the philosopher-emperor Marcus Aurelius to 'love the hand that fate [has dealt me] and play it as [my] own'. Living well with CKD means to live the best life I can in the time I have available.... Living well with CKD is the same as living well."* – Tess Harris

*"While CKD brings me some limitations, I can maximize the possibility to live well. I kept working when I was doing hemodialysis. After transplant, I could live: study, work, travel, marry, have children, and service the community."* – Maggie Ng

CKD, chronic kidney disease.

<sup>a</sup>Personal communication; quotations are identified by name with permission.

have a chance to live a normal life again, notwithstanding the high costs of immunosuppressive medications in some countries. For some patients and care partners in low-income regions, spirituality/religion may engender

hope when ill, energized by the anticipation of restored health and spiritual well-being. In many cases, informing a patient of a diagnosis of kidney disease is a harrowing experience for both the patient (and caregivers) and the

**Table 1 | Suggested strategies for "living well with CKD" using a strengths-based approach**

Strengths-based approach	Suggested strategies
Build resilience	<ul style="list-style-type: none"> <li>Identify or provide strategies and resources to manage stress and functioning when encountering challenges, adversity and trauma (e.g., commencement of dialysis)</li> </ul>
Harness social connections	<ul style="list-style-type: none"> <li>Facilitate connections with other patients to learn coping strategies and for support</li> <li>Support family members/caregivers</li> </ul>
Build awareness and knowledge	<ul style="list-style-type: none"> <li>Provide education (including practical advice) on diet and lifestyle modifications</li> <li>Understand, identify, and address the potential impacts of CKD (e.g., cognitive function)</li> <li>Encourage patients to ask questions.</li> <li>Encourage the use of knowledge to empower and prepare for the future.</li> </ul>
Facilitate access to support	<ul style="list-style-type: none"> <li>Refer to allied health care professionals (e.g., dietitian, social worker, mental health professionals, occupation therapists)</li> <li>Provide support that enables patient to participate in important life activities (e.g., work)</li> </ul>
Establish confidence and control in self-management	<ul style="list-style-type: none"> <li>Support informed and shared decision-making (including dialysis, kidney transplantation, conservative or nondialysis care)</li> <li>Encourage patients to learn to "get in tune" with what works well for them and to voice any concerns, and work together to develop better management strategies to enable patients to feel better.</li> <li>Provide strategies to prevent or manage complications (e.g., infection)</li> <li>Support open communication regarding goals, concerns, and priorities</li> </ul>

CKD, chronic kidney disease (not receiving kidney replacement therapy).

healthcare professional. Most patients present to kidney physicians (usually known as “renal physicians” in many of these countries) with trepidation and apprehension. Thus, it is rewarding to see a patient’s anxiety dissipate after receiving a diagnosis of simple kidney cyst, urinary tract infection, kidney stones, solitary kidneys, or another disorder that does not require extreme measures like kidney replacement therapy. Patients diagnosed with glomerulonephritis who have appropriate characterization of their disease from kidney biopsy and histology and who receive appropriate therapy and achieve remission are relieved and are very grateful. Patients are happy to discontinue dialysis following resolution of acute kidney injury, acute kidney disease, or CKD.

Many patients with CKD who have residual kidney function appreciate being maintained in a relatively healthy state with conservative measures, without dialysis. They experience renewed energy when their anemia is corrected using erythropoiesis-stimulating agents. They are happy when their peripheral edema resolves with treatment. Those on maintenance hemodialysis with woeful stories of emergency femoral cannulations appreciate the provision of good temporary or permanent vascular access. Many patients in low-resource settings present in very late stages in need of emergency dialysis. Patients remain grateful on waking from uremic coma or recovering from recurrent seizures when they commence dialysis.

#### **WKD 2021 advocacy**

The WKD 2021 theme “Living Well with Kidney Disease” was deliberately chosen to focus on plans and actions toward achieving patient-centered wellness. “Kidney health for everyone, everywhere,” with an emphasis on patient-centered wellness, should be a policy imperative that can be successfully achieved if policy makers, nephrologists, health care professionals, patients, and care partners address it within the context of comprehensive care. Patient engagement is needed. In 2016, the WHO addressed patient empowerment: “Patient engagement is increasingly recognized as an integral part of health care and a critical component of safe people-centered services. Engaged patients are better able to make informed decisions about their care options. In addition, resources may be better used if they are aligned with

patients’ priorities, and this is critical for the sustainability of health systems worldwide. Patient engagement may also promote mutual accountability and understanding between the patients and health care providers. Informed patients are more likely to feel confident to report both positive and negative experiences and have increased concordance with mutually agreed care management plans. This not only improves health outcomes, but also advances learning and improvement, while reducing adverse events.”

At the International Society of Nephrology’s Community Film Event at the 2020 World Congress of Nephrology, it was good to see a quote in the film from a patient: “Tell me, I will forget; show me, I will remember; involve me, I will understand.” The International Society of Nephrology’s Global Kidney Policy Forum 2019 featured a patient speaker, Nicki Scholes-Robertson, from New Zealand, who noted that culturally appropriate and sensitive patient information and care are being undertaken in New Zealand to fight inequities in kidney health, especially in Maori and other disadvantaged communities.

WKD 2021 aims to promote an increasing focus on and resources for both drug and nondrug programs for improving patient well-being. Examples include funding for erythropoiesis-stimulating agents and antipruritic agents for managing anemia and itchiness, respectively, to name but a few.<sup>15,16</sup> Home dialysis therapies have been consistently found to improve patient autonomy, flexibility, and quality of life in a cost-effective manner, enhancing life participation. Promoting home dialysis therapies should tie in with appropriate “assisted dialysis” programs to reduce patient and care partner fatigue and burnout. Other services, such as self-management programs and cognitive behavioral therapy and group therapy for managing depression, anxiety, and insomnia, should be promoted before resorting to medications.<sup>17</sup> The principle of equity recognizes that different people with different levels of disadvantage require different approaches and resources to achieve equitable health outcomes. The kidney community should push for adapted care guidelines for vulnerable and disadvantaged populations. Involvement of primary care and general physicians, especially in LICs and LMICs, would be useful in improving the affordability of and access to services through the public sector in helping

the symptom management of CKD patients and improve their wellness. In the overall wellness program for patients with kidney disease, the need for prevention should be reiterated. Early detection with a prolonged course of wellness despite kidney disease, after a effective secondary prevention program, should be promoted.<sup>18</sup> Prevention of CKD progression can be attempted by lifestyle and diet modifications, such as a plant-dominant low-protein diet, and by means of effective pharmacotherapy, including administration of sodium-glucose transport protein 2 inhibitors.<sup>19</sup> WKD 2021 continues to call for increased awareness of the importance of preventive measures across populations, professionals, and policy makers, applicable to both developed and developing countries.<sup>18</sup>

### Conclusions

Effective strategies to empower patients and their care partners aim to achieve the overarching goal of minimizing the burden of CKD-related symptoms to enhance patient satisfaction, health-related quality of life, and life participation. The WKD 2021 theme of “Living Well with Kidney Disease” was chosen to focus on plans and actions toward achieving patient-centered wellness. Notwithstanding the COVID-19 pandemic that had overshadowed many activities in 2020 and beyond, the WKD Steering Committee has declared 2021 the year of “Living Well with Kidney Disease” in an effort to increase education on and awareness of the important goals of effective symptom management and patient empowerment. Whereas WKD continues to emphasize the importance of effective measures to prevent kidney disease and its progression,<sup>18</sup> 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 even during a world-shattering pandemic such as COVID-19 that may drain many resources.<sup>20</sup> Living well with kidney disease is an uncompromisable goal of kidney foundations, patient groups, and professional societies alike, to which the International Society of Nephrology and the International Federation of Kidney Foundation World Kidney Alliance are committed at all times.

### DISCLOSURE

KK-Z reports receiving honoraria from Abbott, Abbvie, ACI Clinical, Akebia, Alexion, Amgen, Ardelyx, AstraZeneca, Aveo, BBraun, Cara Therapeutics,

Chugai, Cytokinetics, Daiichi, DaVita, Fresenius, Genentech, Haymarket Media, Hospira, Kabi, Keryx, Kissei, Novartis, Pfizer, Regulus, Relypsa, Resverlogix, Dr Schaer, Sandoz, Sanofi, Shire, Vifor, UpToDate, and ZS-Pharma. PK-TL reports receiving personal fees from Fibrogen and AstraZeneca. GS reports receiving personal fees from Multicare, Novartis, Sandoz, and AstraZeneca. VL reports receiving nonfinancial support from Genesis Pharma. All the other authors declared no competing interests.

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