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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, not receiving kidney replacement therapy), 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 this can also impact treatment satisfaction and clinical outcomes [1]. Despite this, the past several decades have seen limited improvement in the quality of life of people with CKD [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 regional and global kidney health projects have addressed these important questions, including the Standardised Outcomes in Nephrology (SONG) trial with >9000 patients, family members and health professionals from >70 countries [2, 3]. Across all treatment stages, including CKD, dialysis and transplantation, children and adults with CKD participating in SONG consistently gave higher priority to symptoms and life impacts than did health professionals [2, 3]. In comparison, health professionals gave higher priority to

mortality and hospitalization than did patients and family members. The patient-prioritized outcomes are shown in Figure 1. Irrespective of the 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 do meaningful activities of life including, but not limited to work, study, family responsibilities, travel, sports and social and recreational activities, was established as a critically important outcome across all treatment stages of CKD [1, 2]. The quotations from patients with kidney disease provided in Table 1 demonstrate how life participation reflects the ability to live well with CKD [4]. According to the World Health Organization (WHO), participation refers to ‘involvement in a life situation’ [5]. 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 Steering Committee calls for the inclusion of life participation, a key focus in the care of patients with CKD, to achieve the ultimate

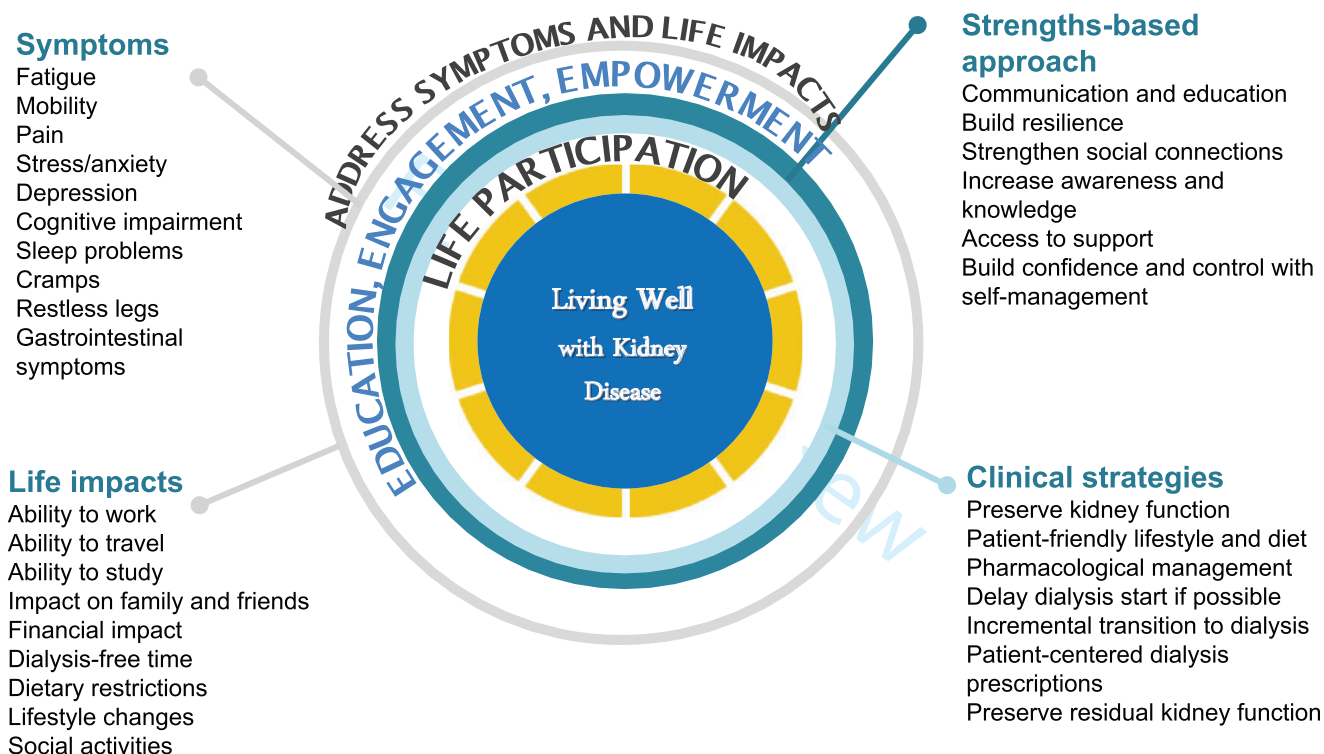


FIGURE 1: Conceptual framework of ‘Living Well with Kidney Disease’, based on patient-centeredness and empowering patients with focus on effective symptom management and life participation.

Table 1. Quotations related to priorities for living well from patients with CKD

<p>‘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</p> <p>‘Life participation is most important because without it, you can’t do anything’. —Child with CKD</p> <p>‘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</p> <p>‘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</p> <p>‘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</p> <p>‘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</p> <p>‘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</p> <p>‘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</p> <p>‘I prefer to be above ground, then below ground. So why not enjoy life whilst being above ground’. —Adam Martin</p> <p>‘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</p> <p>‘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</p>

Note: Quotations are identified by name with permission.

goal of living well with kidney disease. This calls for the development and implementation of validated patient-reported outcome measures, which 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’ [6], which requires patients to understand

their role, to have knowledge to be able to engage with clinicians in shared decision making and to have the skills and support for self-management. For patients receiving dialysis, understanding the rationale for a lifestyle change, having access to practical assistance and family support promoted patient empowerment while feeling limited in life participation undermined their sense of empowerment [7].

The World Kidney Day Steering Committee advocates for strengthened partnerships with patients in the development, implementation and evaluation of interventions for practice and policy settings that enable patients to live well with kidney diseases. 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 of studies through dissemination and implementation, is now widely advocated [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 2, 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 is in contrast to the medical model where chronic disease is traditionally focussed on pathology, problems and failures [10]. Instead, the strengths-based approach acknowledges that each individual has strengths and abilities 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 healthcare system are identified, so all patients are given the opportunity to have a voice.

THE ROLE OF THE CARE PARTNER

A care partner is often an informal caregiver who is also a family member of the patient with CKD [11]. They may take on a

wide range of responsibilities, including coordinating care (e.g. transportation to appointments) and administration of treatment, including medications, home dialysis assistance and supporting dietary management. Caregivers of patients with CKD have reported depression, fatigue, isolation and also burnout. The role of the care partner has increasingly become more important in CKD care, given the heightened complexity in communication and therapeutic options, including the expansion of telemedicine under the coronavirus disease 2019 (COVID-19) pandemic, and given the goal of achieving longer life expectancy with CKD [12]. The experience of caring for a partially incapacitated family member with progressive CKD can represent a substantial burden on the care partner and may impact family dynamics. Not infrequently, the career goals and other occupational and leisure aspects of the life of the care partner are affected because of the CKD care partnership, leading to care partner overload and burnout. Hence the above-mentioned principles of life participation need to apply equally to care partners as well as all family members and friends involved in CKD care.

Living with kidney disease in low-income regions

In low- and low- and middle-income countries (LICs and LMICs), including in sub-Saharan Africa, Southeast Asia and Latin America, patients' ability to self-manage or cope with chronic disease varies but may often be influenced by internal factors including spirituality, belief systems and religiosity and external factors including appropriate knowledge of the disease, poverty, family support system and one's social relations network. The support system comprising healthcare providers and caregivers plays a crucial role, as most patients rely on them in making decisions and for the necessary adjustments in their health behavior [13]. In LIC regions, where there are often a relatively small number of physicians and even fewer kidney care providers per population, especially in rural areas, a stepwise approach can involve local and national stakeholders, including both non-governmental organizations and government agencies, by extending kidney patient education in rural areas,

Table 2. 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"> Identify or provide strategies and resources to manage stress and functioning when encountering challenges, adversity and trauma (e.g. commencement of dialysis)
Harness social connections	<ul style="list-style-type: none"> Facilitate connections with other patients to learn coping strategies and for support Support family members/caregivers
Build awareness and knowledge	<ul style="list-style-type: none"> Provide education (including practical advice) on diet and lifestyle modifications Understand, identify and address the potential impacts of CKD (e.g. cognitive function) Encourage patients to ask questions Encourage the use of knowledge to empower and prepare for the future
Facilitate access to support	<ul style="list-style-type: none"> Refer to allied healthcare professionals (e.g. dietitian, social worker, mental health professionals, occupation therapists) Provide support that enables the patient to participate in important life activities, e.g. work
Establish confidence and control in self-management	<ul style="list-style-type: none"> Support informed and shared decision making (including dialysis, kidney transplantation, conservative or nondialytic care) 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 Provide strategies to prevent or manage complications (e.g. infection) Support open communication regarding goals, concerns and priorities

adapting telehealth technologies if feasible to educate patients and train local community kidney care providers and implementing effective retention strategies for rural kidney health providers, including adapting career plans and competitive incentives.

Many patients in low-resource settings present in a very late stage needing to commence emergency dialysis [14]. The very few fortunate ones to receive kidney transplantation may acquire an indescribable chance at 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 and religiosity may engender hope; when ill, they are energized by the anticipation of restored health and spiritual well-being. For many patients, being informed of a diagnosis of kidney disease is a harrowing experience both for the patient (and caregivers) and the healthcare professional. Most patients present to kidney physicians (usually known as ‘renal physicians’ in many of these countries) with trepidation and apprehension. It is rewarding therefore to see the patient’s anxiety dissipate after reassuring him/her of a diagnosis of simple kidney cysts, urinary tract infection, simple kidney stones, solitary kidneys etc., which do not require extreme measures like kidney replacement therapy. Patients diagnosed with glomerulonephritis who have an appropriate characterization of their disease from kidney biopsies and histology, who receive appropriate therapies and then achieve remission are relieved and very grateful. Patients are glad to discontinue dialysis following resolution of acute kidney injury or CKD.

Many CKD patients 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 promptly corrected using erythropoiesis-stimulating agents. They are happy when their peripheral edema resolves with treatment. For those on maintenance hemodialysis who had woeful stories about emergency femoral cannulations, they appreciate the construction of good temporary or permanent vascular accesses. Patients remain grateful for waking from a uremic coma or recovering from recurrent seizures when they commence dialysis.

WORLD KIDNEY DAY 2021 ADVOCACY

The World Kidney Day 2021 theme ‘Living Well with Kidney Disease’ was deliberately chosen to redirect focus on plans and actions towards achieving patient-centered wellness. ‘Kidney Health for Everyone, Everywhere’, with emphasis on patient-centered wellness, should be a policy imperative that can be successfully achieved if policymakers, nephrologists, healthcare professionals, patients and care partners place this within the context of comprehensive care. The requirement of patient engagement is needed. The WHO in 2016 put out an important document on patient empowerment: ‘Patient engagement is increasingly recognized as an integral part of health care and a critical component of safe patient-centred services [15]. 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 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’. In the International Society of Nephrology (ISN) Community Film Event at the World Congress of Nephrology 2020, it was good to see a quote in the film from patients: ‘Tell me. I will forget; Show me. I will remember; Involve me. I will understand [16].’ The ISN Global Kidney Policy Forum 2019 included a patient speaker, Nicki Scholes-Robertson, from New Zealand: ‘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.’

World Kidney Day 2021 would like to promote to policymakers increasing the focus and resources of both drug and nondrug programs in improving patient wellness. Examples include funding for erythropoiesis-stimulating agents and antipruritic agents for managing anemia and itchiness, respectively, just to name a few [17, 18]. Home dialysis therapies have been consistently found to improve patient autonomy and flexibility, as well as 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. Also, self-management programs, cognitive behavioral therapy and group therapies for managing depression, anxiety and insomnia should be promoted before resorting to medications [19]. 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. The involvement of primary care and general physicians, especially in LICs and LMICs, would be useful in improving the affordability and access to services through the public sector, helping with symptom management of CKD patients and improving their wellness. In the overall wellness program for kidney disease patients, the need for prevention should be reiterated. Early detection with a prolonged course of wellness despite kidney disease and an effective secondary prevention program should be promoted [20]. Prevention of CKD progression can be attempted through 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 [21]. World Kidney Day 2021 continues the call for increased awareness of the importance of preventive measures that are applicable to both developed and developing countries [20].

CONCLUSIONS

Effective strategies to empower patients and their care partners strive to pursue 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. The World Kidney Day 2021 theme of ‘Living Well with Kidney Disease’ was deliberately chosen to redirect focus on plans and actions towards achieving patient-centered wellness. Notwithstanding the COVID-19 pandemic that has overshadowed many activities in 2020, the World Kidney Day Steering Committee has declared 2021 the year of ‘Living Well with Kidney Disease’ in an effort to increase education and awareness on the important goal of effective symptom management and patient empowerment. While the World Kidney Day continues to emphasize the importance of effective measures to prevent kidney disease and its progression [20], 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 [22]. Living well with kidney disease is an uncompromisable goal of all kidney foundations, patient groups and professional societies alike, to which the ISN and the International Federation of Kidney Foundations–World Kidney Alliance are committed at all times.

CONFLICT OF INTEREST STATEMENT

K.K.-Z. reports 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. P.K.-T.L. reports personal fees from Fibrogen and AstraZeneca. G.S. reports personal fees from Multicare, Novartis, Sandoz and AstraZeneca. V.L. reports nonfinancial support from Genesis Pharma.

DATA AVAILABILITY STATEMENT

There is no new data in this manuscript.

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