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Authors

Kalantar-Zadeh, Kamyar

Li, Philip Kam-Tao

Tantisattamo, Ekamol

et al.

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

Viver bem com doença renal através da capacitação do paciente e do cuidador: saúde dos rins para todos em todos os lugares


Authors


Kamyar Kalantar-Zadeh^{1*} 


Philip Kam-Tao Li² 

Ekamol Tantissattamo¹ 


Latha Kumaraswami³

Vassilios Liakopoulos⁴ 


Siu-Fai Lui⁵ 

Ifeoma Ulas⁶ 

Sharon Andreoli⁷

Alessandro Balducci⁸ 

Sophie Dupuis⁹

Tess Harris¹⁰ 


Anne Hradsky⁹

Richard Knight¹¹

Sajay Kumar³

Maggie Ng¹²

Alice Poidevin⁹

Gamal Saadi¹³ 

Allison Tong¹⁴ 

¹University of California Irvine School of Medicine, Division of Nephrology, Hypertension and Kidney Transplantation, Department of Medicine, Orange, California, USA.

²Chinese University of Hong Kong, Department of Medicine and Therapeutics, Prince of Wales Hospital, Hong Kong.

³Tanker Foundation, Chennai, India.

⁴Aristotle University of Thessaloniki, 1st Department of Internal Medicine, AHEPA Hospital, Thessaloniki, Greece.

⁵Hong Kong Kidney Foundation, Hong Kong, China.

⁶University of Nigeria, Ituku-Ozalla, Department of Medicine, College of Medicine, Enugu, Nigeria.

⁷Indiana University School of Medicine, Riley Hospital for Children, Indianapolis, USA.

⁸Italian Kidney Foundation, Rome, Italy.

⁹World Kidney Day Office, Brussels, Belgium.

¹⁰Polycystic Kidney Disease Charity, London, UK.

¹¹American Association of Kidney Patients, Tampa, Florida, USA.

¹²Hong Kong Kidney Foundation, Hong Kong, China.

¹³Cairo University, Faculty of Medicine, Department of Internal Medicine, Giza, Egypt.

¹⁴The University of Sydney, Sydney School of Public Health, Sydney, NSW, Australia.

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Correspondence to:

Kamyar Kalantar-Zadeh.

E-mail: kkz@uci.edu

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ABSTRACT

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 or friends involved in their care, may help minimize burden and consequences of CKD-related symptoms to enable life participation. There is a need to broaden the focus on living well with kidney disease and re-engagement in life, including emphasis on patients 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 and awareness on 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 labelling 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 kidney disease patients, 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 throughout populations, professionals,

RESUMO

Viver com doença renal crônica (DRC) está associado a dificuldades para os pacientes e seus cuidadores. Capacitar os pacientes e seus cuidadores, incluindo familiares ou amigos envolvidos em seus cuidados, pode ajudar a minimizar a carga e as consequências dos sintomas relacionados à DRC para permitir uma participação efetiva na vida. Há uma necessidade de se ampliar o foco em viver bem com a doença renal e de um reengajamento na vida, com ênfase em pacientes assumindo o controle. O Comitê Diretor Conjunto do Dia Mundial do Rim (DMR) declarou 2021 como o ano de "Viver Bem com Doença Renal", em um esforço para aumentar a educação e a conscientização sobre o importante objetivo do fortalecimento do paciente e maior participação na vida. Isto exige o desenvolvimento e a implementação de medidas de desfechos relatados pelos pacientes que tenham como objetivo avaliar e abordar áreas como a participação na vida dentro dos cuidados de rotina. O assunto poderia ser apoiado por agências reguladoras como uma métrica para o atendimento de qualidade ou para apoiar as reivindicações de rotulagem para medicamentos e dispositivos. As agências de financiamento poderiam estabelecer chamadas direcionadas para pesquisas que abordem as prioridades dos pacientes. Os pacientes com doença renal e seus cuidadores devem se sentir apoiados para viver bem através de esforços conjuntos por parte das comunidades de cuidados renais, inclusive durante a pandemia. No programa de bem-estar geral para pacientes com doenças renais, a necessidade de prevenção deve ser reiterada. Ações de detecção precoce com curso prolongado de bem-estar, apesar da doença renal, após programas eficazes de prevenção secundária e terciária, devem ser promovidas. O DMR 2021 continua a exigir uma maior conscientização da importância de medidas preventivas em todas as populações,

and policy makers, applicable to both developed and developing countries.

Keywords: Patient Participation; Caregivers; Developing Countries; Health Policy.

profissionais e legisladores, aplicáveis tanto aos países desenvolvidos quanto aos em desenvolvimento.

Descritores: Participação do Paciente; Cuidadores; Países em Desenvolvimento; Política de Saúde.

PATIENT PRIORITIES FOR LIVING WELL: A FOCUS ON LIFE PARTICIPATION

Chronic 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, this can also impact on treatment satisfaction and clinical outcomes¹. Despite this, the past several decades have seen limited improvement in the quality of life of people with CKD¹. To advance research, practice, and policy, there is an increasing recognition of the need to identify and address patient priorities, values, and goals¹.

Several regional and global kidney health projects have addressed on these important questions including the *Standardised Outcomes in Nephrology* (SONG) with more than 9,000 patients, family members, and health professionals from over 70 countries^{2,3}. 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^{2,3}. 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 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 wellbeing.

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}. The quotations from patients with kidney disease provided in Box 1 demonstrates how life participation reflects the ability to live well with CKD⁴. According 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 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 labelling 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 TOWARDS 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, 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, while feeling limited in life participation undermined their sense of empowerment⁷.

The World Kidney Day Steering Committee advocates 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 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 the study through to dissemination and implementation, is now widely advocated⁸. There have also been efforts, such as the *Kidney Health*

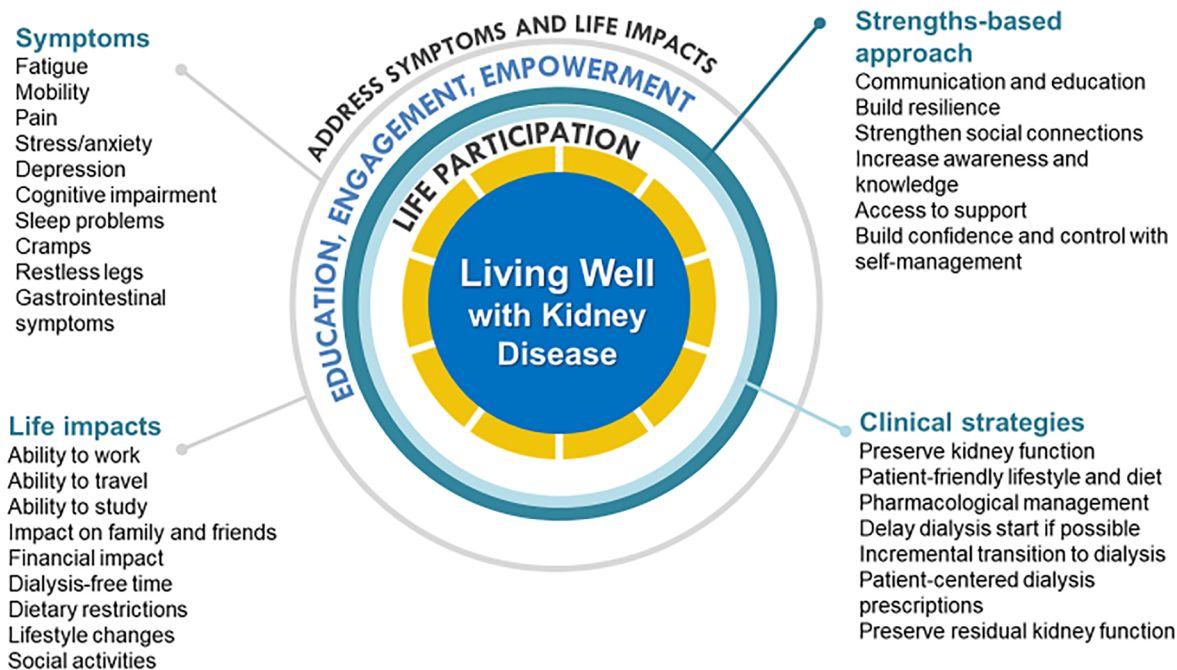


Figure 1. Conceptual framework of “Living Well with Kidney Disease” based on patient centeredness and empowering patient with focus on effective symptom management and life participation.

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 CKD4

“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

*Personal communication; quotations are identified by name with permission. This page is left blank.

Initiative, to involve patients in the development of drugs and devices to foster innovation⁹.

We urge for 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 is in contrast to the medical model where chronic disease is traditionally focused on pathology, problems, and failures¹⁰. 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 health care system are identified, so all patients are given the opportunity to have a voice.

THE ROLE OF CARE-PARTNER

A care-partner is often an informal caregiver who is also a family member of the patient with CKD¹¹. They

may take on a wide range of responsibilities including coordinating care (including transportation to appointments), administration of treatment including medications, home dialysis assistance, and supporting dietary management. Caregivers of patients with CKD have reported depression, fatigue, isolation, and burnout. The role of the care-partner has increasingly become more important in CKD care given the heightened complexity in communicative and therapeutic options including expansion of telemedicine under COVID-19 pandemic and given the goal to achieve higher life expectancy with CKD¹². 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 CKD care partnership, leading to care-partner overload and burnout. Hence, the above-mentioned principles of life participation need to equally apply to care-partners as well as all family members and friends involved in the CKD care.

TABLE 1 SUGGESTED STRATEGIES FOR "LIVING WELL WITH CKD" USING A STRENGTHS-BASED APPROACH

Abordagem baseada em Estratégias sugeridas pontos fortes	
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. Provide education (including practical advice) on diet and lifestyle modifications.
Build awareness and knowledge	<ul style="list-style-type: none"> 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 health care professionals (e.g. dietitian, social worker, mental health professionals, occupation therapists). Provide support that enables patient to participate in important life activities, e.g. work. Support informed and shared decision-making (including dialysis, kidney transplantation, conservative or non-dialytic care).
Establish confidence and control in self-management	<ul style="list-style-type: none"> 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.

Abbreviations: CKD: chronic kidney disease (not receiving kidney replacement therapy).

LIVING WITH KIDNEY DISEASE IN LOW INCOME REGIONS

In low and lower middle income countries (LICs and LMICs) including in sub-Saharan Africa, South East Asia, and Latin America, patient's ability to self-manage or cope with chronic disease vary but may often be influenced by internal factors including spirituality, belief system, and religiosity, and external factors including appropriate knowledge of the disease, poverty, family support system, and one's grit and 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 behavior¹³. In LIC regions, where there are often a relatively low number of physicians and even lower number of 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: 1) extending kidney patient education in rural areas, 2) adapting 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 including adapting career plans and competitive incentives.

Many patients in low resource settings present in very late stage needing to commence emergency dialysis¹⁴. The very few fortunate ones to receive kidney transplantation may acquire an indescribable chance to 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, as they are energized by the anticipation of restored health and spiritual wellbeing. For many patients, informing them 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 trepidations and apprehension. It is rewarding therefore to see the patient's anxiety dissipate after reassuring him or her of a diagnosis of simple kidney cysts, urinary tract infection, simple kidney stones, solitary kidneys, etc., that would not require extreme measures like kidney replacement therapy. Patients diagnosed with glomerulonephritis

who have appropriate characterization of their disease from kidney biopsies and histology and who receive appropriate therapies and achieve remission are relieved and are very grateful. Patients are glad to discontinue dialysis following resolution of AKI or acute on CKD.

Many CKD patients who have residual kidney function appreciate being maintained in 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 from emergency femoral cannulations, they appreciate construction of good temporary or permanent vascular accesses. Many patients in low-resource settings present in very late stage needing to commence emergency dialysis. Patients remain grateful on waking from uremic coma or recovering from recurrent seizures when they commence dialysis.

WORLD KIDNEY DAY 2021 ADVOCACY

World Kidney Day 2021 theme on 'Living Well with Kidney Disease' is deliberately chosen to have the goals to redirect more 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 policy makers, nephrologists, health care professionals, patients, and care partners place this within the context of comprehensive care. Patient engagement is a requirement. The World Health Organization (WHO) in 2016 put out an important document on patient empowerment (WHO 2016): '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.’ In the ISN Community Film Event at World Congress of Nephrology (WCN) 20 (ISN Community Film Event 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”. ISN Global Kidney Policy Forum 2019 included a patient speaker Nicki Scholes-Robertson from New Zealand who said: ‘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 support policy makers on increasing focus and resources on both drug and non-drug programs in improving patient wellness. Examples include funding for erythropoiesis stimulating agents and anti-pruritic agents for managing anemia and itchiness respectively, to name but a few^{15,16}. 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. Additionally, examples like self-management programs, cognitive behavioral therapy, and group therapies for managing depression, anxiety, and insomnia should be promoted before resorting to medications¹⁷. 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 and access to services through the public sector in helping the symptom management of CKD patients and improve patient wellness. In the overall wellness program for kidney disease patients, the need for prevention should be reiterated. Early detection with prolonged course of wellness despite kidney disease, after effective secondary prevention program, should be promoted¹⁸. Prevention of CKD progression can be attempted with 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 (SGLT2) inhibitors¹⁹. WKD 2021 continues to call for increased awareness of the importance of preventive measures throughout populations, professionals, and policy makers, applicable to both developed and developing countries¹⁸.

CONCLUSIONS

Effective strategies to empower patients and their care-partners strive to pursue the overarching goal of minimizing burden of CKD-related symptoms in order to enhance patient satisfaction, health-related quality of life, and life participation. World Kidney Day 2021 theme on ‘Living Well with Kidney Disease’ is deliberately chosen to have the goals to redirect more focus on plans and actions towards achieving patient-centered wellness. Notwithstanding the COVID-19 pandemic that had overshadowed many activities in 2020 and beyond, 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. Whereas the World Kidney Day continues to emphasize the importance of effective measures to prevent kidney disease and its progression¹⁸, 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 as COVID-19 that may drain many resources²⁰. Living well with kidney disease is an uncompromisable goal of all 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.

AUTHORS' CONTRIBUTION

Kamyar Kalantar-Zadeh, Philip Kam-Tao Li, Ekamol Tantisattamo, Latha Kumaraswami, Vassilios Liakopoulos, Siu-Fai Lui, Ifeoma Ulasi, Sharon Andreoli, Alessandro Balducci, Sophie Dupuis, Tess

Harris, Anne Hradsky, Richard Knight, Sajay Kumar, Maggie Ng, Alice Poidevin, Gamal Saadi, Allison Tong contributed substantially to the conception or design of the study; collection, analysis, or interpretation of data; writing or critical review of the manuscript; and final approval of the version to be published.

CONFLICT OF INTEREST

K.K.-Z. reports honoraria from Abbott, Abbvie, ACI Clinical, Akebia, Alexion, Amgen, Ardelyx, Astra-Zeneca, 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 Astra-Zeneca. G.S. reports personal fees from Multicare, Novartis, Sandoz, and Astra-Zeneca. V.L. reports nonfinancial support from Genesis Pharma.

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