



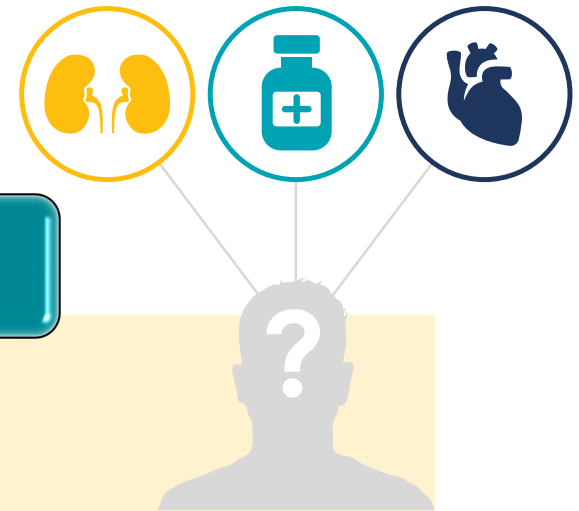
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Improving Awareness & Patient Outcomes

Empowering Patients Through Health Literacy

What Is Health Literacy?

- **Health literacy is defined as the capacity of an individual to understand information related to a disease in order to make an informed decision**
 - Health literacy goes beyond being able to read; it involves oral understanding, numeracy, and cultural and conceptual knowledge
- The prevalence health literacy is higher amongst the elderly, minorities, and those with lower socioeconomic status



Health literacy is particularly important in CKD, as patients with kidney disease must:

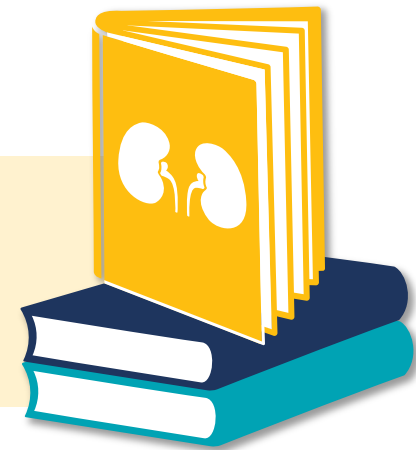
- Follow appropriate dietary restrictions
- Adhere to complex medication regimens
- Make decisions about dialysis
- Keep up with multiple appointments in the healthcare system

CKD. Chronic kidney disease.
Jain D and Green JA. *World J Nephrol.* 2016;5:147-51.

Importance of Health Literacy

- Clinical practice guidelines by RPA and ASN recommend engaging patients using shared decision-making for initiation or withdrawal of dialysis¹
 - Results from several studies support the effectiveness of incorporating these guidelines in managing patient care²
- However, health literacy can be necessary for patients to make informed decisions and to be involved in their dialysis care³

**Evidence suggests that
limited health literacy is common in
patients with CKD³**

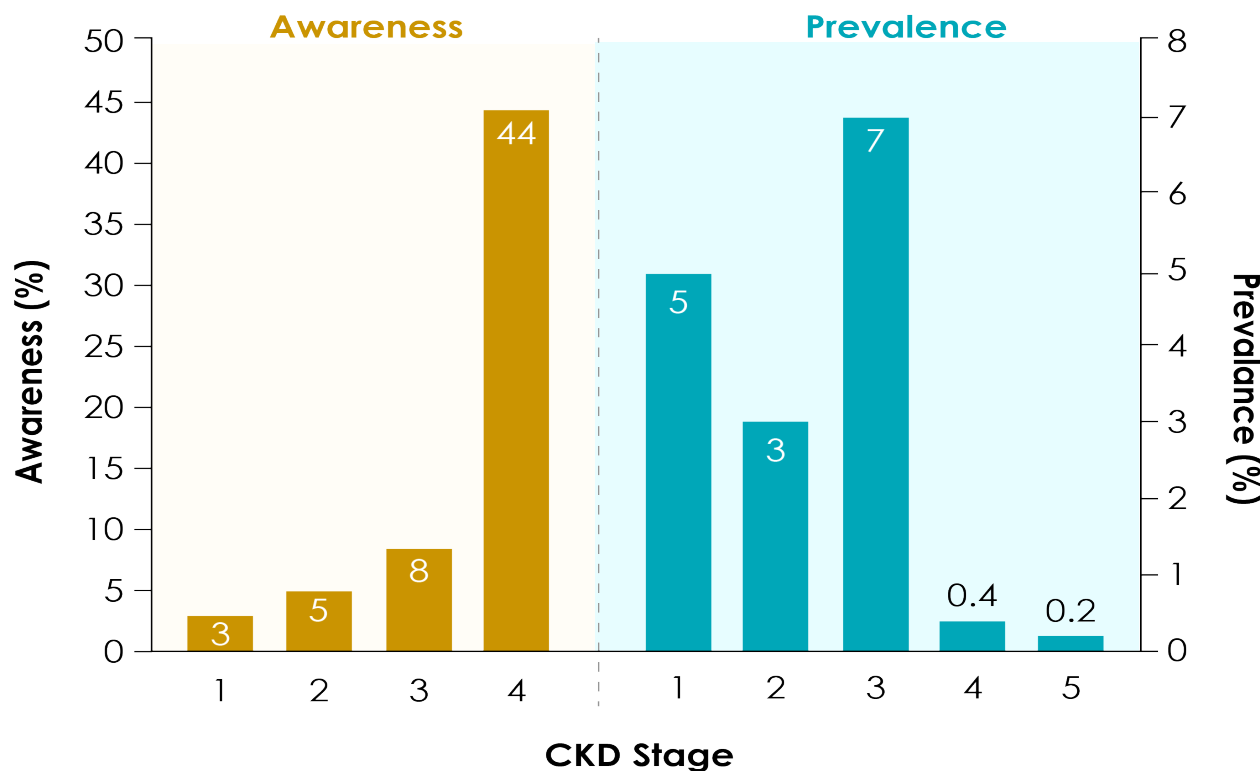


ASN, American Society of Nephrology; CKD, chronic kidney disease; RPA, Renal Physician's Association.

1. Galla JH. *J Am Soc Nephrol* 2000;11:1340-2.
2. Holley JL et al. *Clin J Am Soc Nephrol*. 2007;2:107-11.
3. Jain D and Green JA. *World J Nephrol*. 2016;5:147-51.

Awareness of CKD

- A key feature of CKD is a lack of awareness of the disease among patients and HCPs
- Among patients in the US with CKD, < 50% were aware of their kidney damage, even if the damage was severe*







Awareness and **prevalence** of CKD by CKD stage in the NHANES population†

Patient awareness of CKD can increase with improved health literacy

*CKD at stage 4; †Awareness was estimated from 2009 to 2012. Prevalence was estimated from 2011 to 2014. CKD staging by GFR (mL/min/1.73 m²): stage 1, > 90; stage 2, 60–89; stage 3, 30–59; stage 4, 15–29; stage 5, < 15.
 CKD, chronic kidney disease; GFR, glomerular filtration rate; HCP, healthcare provider; NHANES, National Health and Nutrition Examination Survey; US, United States.
 Duru OK et al. *Curr Diab Rep.* 2018;18:14.

Health Literacy and Medical Care

- Patients with low health literacy tend to have worse outcomes in the setting of chronic medical conditions including hypertension, diabetes, and end-stage renal disease

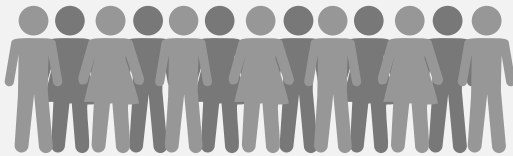
Patients' level of health literacy	Can identify BP cutoff for hypertension	Can identify symptoms of hypoglycemia
Adequate	92% 	94% 
Low	55% 	50% 

BP, blood pressure.
 Luckenbaugh AN and Moses KA. *Urol Oncol*. 2019. doi: 10.1016/j.urolonc.2019.06.016.

Health Literacy and Access to Kidney Transplantation

- A prospective cohort study in the UK evaluated the relationship between health literacy and clinical outcomes

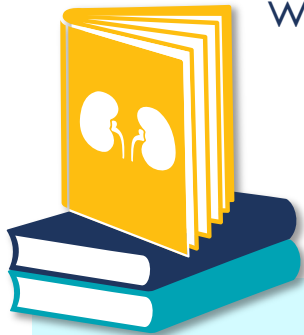
Study participant characteristics



N = 2,274

- Incident dialysis patients
- Aged 18–75 years
- Fluent in English

Limited Health literacy* was independently associated with a reduced chance of†:



- **Transplantation listing**
– HR: 0.68; 95% CI: 0.51–0.91
- **Living donor transplantation**
– HR: 0.68; 95% CI: 0.51–0.91
- **Transplantation from any donor type**
– HR: 0.68; 95% CI: 0.51–0.91



Conclusions

- Limited health literacy was associated with decreased access to transplantation
- Interventions related to health literacy may improve access to transplantation

*Defined by a validated Single Item Literacy Screener.

†Adjusted for demographics, primary renal diagnosis, comorbidity and socioeconomic status.

CI, confidence interval; HR, hazard ratio; UK, United Kingdom.

Taylor DM et al. *Kidney Int.* 2019;95:1244-52.

Opportunities to Improve Awareness, Management, and Outcomes in Patients with Diabetic Kidney Disease

- Poor health literacy can be a barrier to optimal care in patients with CKD
 - Improving patient health literacy is a recommended strategy to improve awareness, management, and outcomes in CKD

Barriers

Low awareness of CKD

Proportion of individuals aware of their disease was only 3%-10%

Education/socioeconomic status

Higher economic/education status was associated with lower CKD incidence and mortality rate

Healthcare literacy

Limited knowledge of medications that help/hurt the kidneys, and foods to avoid with CKD

Health Insurance

Individuals without health insurance are at higher risk of progression

Access to healthcare

Only 6%-30% of individuals with CKD stage 3 and CKD stages 4 to 5 saw a nephrologist

Inadequate screening

Screening to detect albuminuria in patients at risk for DKD may be underused in primary care

Delayed nephrology referral

Late referral associated with increase in mortality

Fragmented care

Poor coordination/communication among healthcare providers

Opportunities

Patient or HCP education may improve clinical outcomes

New community-level education paradigms can promote self-management

Enhanced communication can improve awareness, self-management, and outcomes

Applying a risk-prediction model can help with early identification of people at risk for DKD or CKD

Optimal screening can provide for early detection of DKD or CKD

Early nephrology referral can improve patient outcomes

Multidisciplinary care can improve DKD or CKD outcomes

CKD, chronic kidney disease; DKD, diabetic kidney disease; HCP, healthcare provider.
Duru OK et al. *Curr Diab Rep.* 2018;18:14.

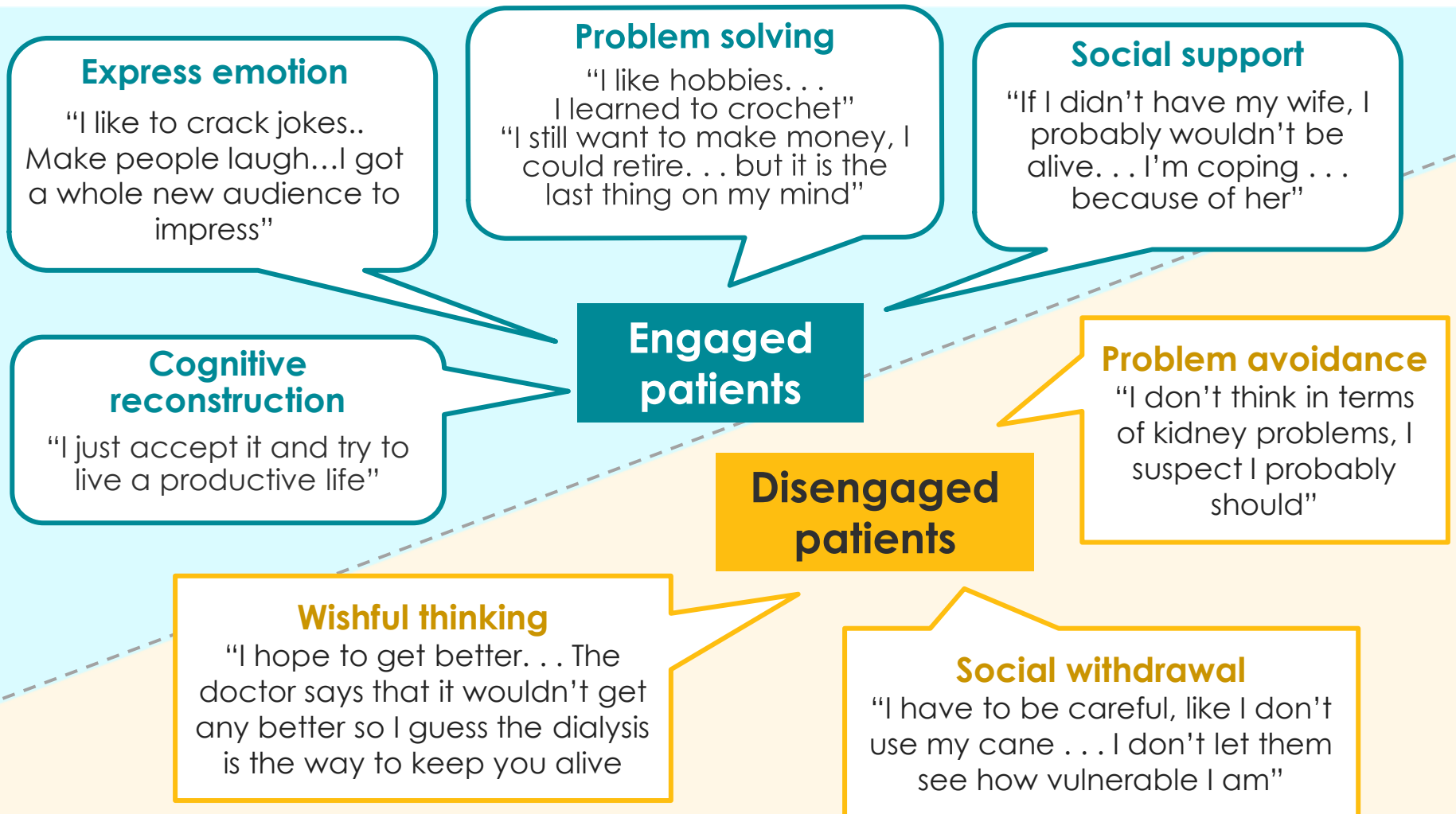
Recognizing Patients at Risk for Limited Health Literacy

Clinical “red flags” can be used to predict those patients who may have limited health literacy

Examples of signs for limited health literacy include:

- Patient registration forms that are incomplete or inaccurately completed
- Nonadherence with medications or treatments
- Frequently missed attendance at appointments
- Lack of follow-through with laboratory/imaging tests or referrals
- Unable to name medications, explain what medications are for, or explain timing of medication administration
- May offer excuses to deflect reading tasks, such as
 - "I forgot my glasses"
 - "Let me bring this home so I can discuss it with my children"
- Seldom have questions
- Seeking help only when illness is advanced
- Having difficulty explaining medical concerns

Engaged vs Disengaged Patients

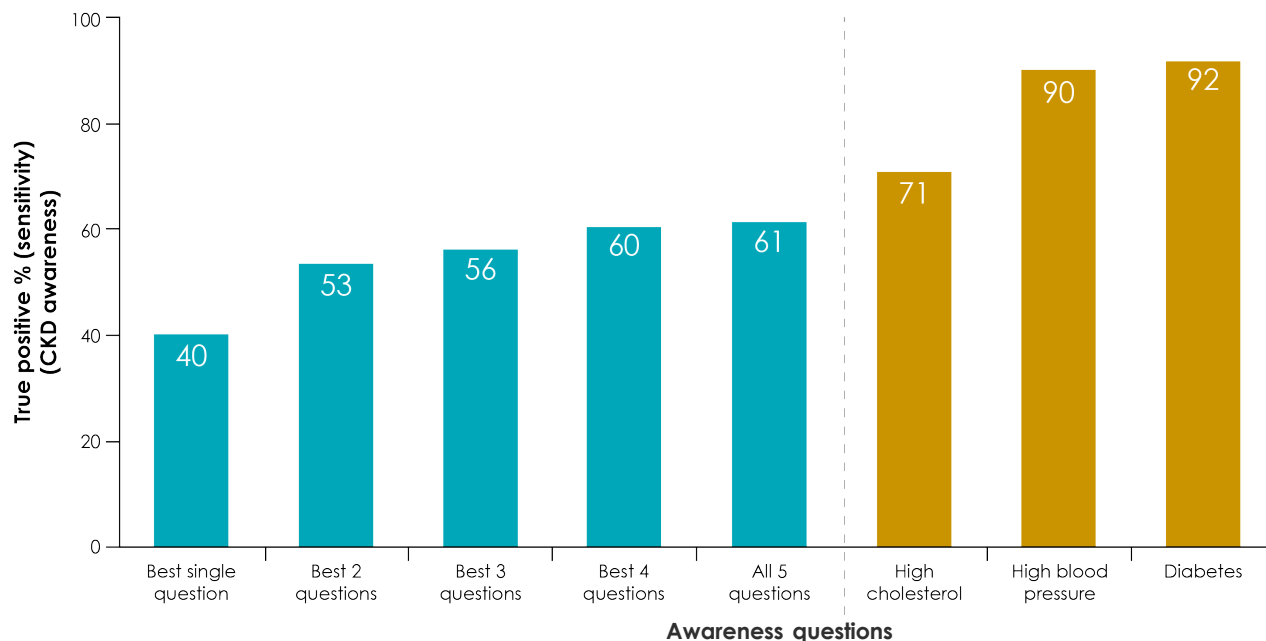


Subramanian L et al. *BMC Nephrol.* 2017;18:119.

CKD Awareness Using Effective Communication

- Awareness of CKD is necessary for patient engagement and adherence to medical regimens; however, awareness of CKD is low vs other chronic diseases
- Recognizing phrases related to CKD that can be easily understood by patients can be an important first step in improving awareness of CKD

True-positive responses among patients with chronic health conditions answering whether a provider had ever told them that they had kidney disease, high cholesterol, high blood pressure, or diabetes



Awareness Questions:

Best single question: “kidney problem”

Best 2 questions: “kidney problem + protein in urine”

Best 3 questions: “kidney problem + protein in urine + kidney disease”

Best 4 questions: “kidney problem + protein in urine + kidney disease + weak or failing kidneys”

All 5 questions: “kidney problem + protein in urine + kidney disease + weak or failing kidneys + kidney damage”

CKD, chronic kidney disease.
Tuot DS et al. *Clin J Am Soc Nephrol*. 2016;11:1566-73.

Effective Health Communication Strategies

Ask open-ended questions and listen reflectively¹

- Ask what, why, and how?¹
- Restate what patient means¹

Affirm and summarize¹

- Validate the patients' experiences and feelings¹
- Communicate back what patients express¹

Elicit self-motivational statements¹

- Help patients recognize how life might be better¹
 - Ask patients to identify extremes of the problem and what they want for their future¹
- Use importance and confidence rulers²

Promote health literacy

- Strategies include encouraging using clear health communication principles, such as³:
 - Using analogies or educational materials
 - Explaining ideas clearly in plain language
 - Writing down important instructions
 - Slowing down

1. Center for Substance Abuse Treatment. Enhancing Motivation for Change in Substance Abuse Treatment. Chapter 3. Substance Abuse and Mental Health Services Administration;1999.
2. Sanders KA et al. *Semin Dial.* 2013;26:175-9.
3. Jain D and Green JA. *World J Nephrol.* 2016;5:147-51.

Benefits of Patient-Centered CKD Research

- Engaging patients and stakeholders in clinical studies can have multiple benefits, including:
 - Generating reliable and actionable evidence specific to the patient's unique circumstances
 - Allowing investigators to implement research studies using input from the patients and stakeholders who have a direct experience of living with kidney disease
 - Creating more meaning for patients to feel as though their experience positively impacts others
 - Offering the research team a new perspective on the importance of their work
 - Providing the research team an opportunity to share in co-learning, empathy, trust, and values with patient populations

CKD, chronic kidney disease.
Cukor D et al. *Clin J Am Soc Nephrol*. 2016;11:1703-712.

Improving Health Literacy by Research Dissemination

- The Patient-Centered Outcomes Research Institute (PCORI) aims to make research findings accessible and usable

Strategies include:

Translation



- Ensure released research findings are useful and understandable by patients and HCPs

Evidence for decisions



- Present findings from systematic reviews and research studies in concise, accessible formats
- Conduct activities that assist HCPs to apply research to practice

Promote access to publications



- Require PCORI-funded research papers to be deposited in PubMed Central
- Pay journals to provide free public access to articles reporting key PCORI research findings

HCP, healthcare provider.

PCORI. Dissemination and Implementation. <https://www.pcori.org/sites/default/files/PCORI-Dissemination-Implementation.pdf>. August 2019. Accessed March 4, 2019

Tools to Promote Health Literacy

Association of Clinicians for the Underserved¹

Creates patient-education materials and handouts for patients with low and very low literacy, in both English and Spanish languages

Readability Formulas²

Contains an automatic readability checker to enable users to find the literacy- and grade-level that people need to read and comprehend text

Health Literacy Universal Precaution Toolkit³

Contains evidence-based guidance for clinicians to reduce the complexity of healthcare, increase patient understanding of health information, and enhance support for patients of all health-literacy levels

Health Literacy Data Map⁴

An interactive, searchable, national map of health-literacy estimates for neighborhoods throughout the US

US, United States.

1. Association of Clinicians for the Underserved. Patient Education Materials. <http://clinicians.org/our-issues/acu-diabetes-patient-education-series/>. Accessed March 4, 2020.
2. Readability Formulas. <http://www.readabilityformulas.com/>. Accessed March 4, 2020.
3. University of North Carolina; Health Sciences Library. Health Literacy Universal Precautions Toolkit. <https://hsl.lib.unc.edu/health-literacy/toolkit/>. September 13, 2019. Accessed March 4, 2020.
4. University of North Carolina; Health Sciences Library. Health Literacy Map. <https://hsl.lib.unc.edu/health-literacy>. November 19, 2019. Accessed March 4, 2020.

Summary

- Health literacy is defined as the capacity of an individual to understand information related to a disease in order to make an informed decision¹
- Health literacy can be necessary for patients to make informed decisions about their care¹
- A strategy to promote health literacy can be to encourage the use of clear health communication principles¹
- Patients, researchers, and other stakeholders can collaborate to develop a culture of patient-centered kidney disease research²
- Engaged patients can better deal with the many challenges faced in living with kidney disease³



1. Jain D and Green JA. *World J Nephrol.* 2016;5:147-51.
2. Cukor D et al. *Clin J Am Soc Nephrol.* 2016;11:1703-12.
3. Subramanian L et. al. *BMC Nephrol.* 2017;18:119.



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