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What patients don't know may hurt them: knowledge and the perception of knowledge among patients with CKD

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It is generally accepted that informed patients have better health outcomes. Wright Nunes *et al.* report low levels of perceived chronic kidney disease (CKD) knowledge among patients treated in a nephrology clinic and describe a low-to-moderate association between perceived and objective CKD knowledge. Association of these two types of knowledge with health behaviors and clinical outcomes should be further explored to inform the development and evaluation of CKD educational interventions as well as communication between nephrologists and patients.

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A central tenet of contemporary medicine is that informed patients have better health outcomes.¹ However, in the case of chronic kidney disease (CKD), recent studies have demonstrated that knowledge of CKD in the general population^{2,3} and awareness of disease status among those with laboratory markers of CKD^{4–6} are both quite low relative to other common chronic diseases. Wright Nunes *et al.*⁷ (this issue) augment these previous findings by reporting low levels of perceived knowledge of CKD among patients treated in a nephrology clinic for kidney dysfunction. Disturbingly, approximately two-thirds of their clinic patients reported that they had little or no knowledge of medications that help or harm the kidney, foods

to avoid with CKD, or symptoms of CKD. Additionally, nearly one-quarter of subjects reported having little or no knowledge of blood pressure treatment goals. Patients who were female, had a high school degree, knew someone with CKD, or had attended kidney education classes had higher—but still unacceptably low—perceived knowledge of CKD relative to their counterparts.⁷

Further, Wright Nunes *et al.*⁷ distinguish between perceived knowledge and objective knowledge of CKD and report that the two entities are only moderately correlated. This corroborates results of other studies that showed no significant relationship between the perception of being well informed and factual knowledge with regard to common medications, cancer screenings, and common surgeries.⁸ The distinction and lack of concordance between perceived and objective knowledge of CKD suggests that perceived knowledge of CKD is not a reliable assessment of actual CKD knowledge. As Figure 1 shows, individual CKD patients can have low perceived knowledge accompanied by low or high objective knowledge, or high perceived knowledge

accompanied by low or high objective knowledge. Among those with low perceived knowledge, those who also have low objective knowledge are less likely to self-manage effectively, leading to higher risk of poor outcomes. However, self-awareness of their lack of essential knowledge could increase communication with providers and mitigate the overall risk of poor outcomes. Patients with low perceived and high objective knowledge have the factual knowledge necessary to make informed decisions regarding their health and health behaviors. However, without provider reassurance and guidance, their capacity to self-manage may be decreased by their lack of confidence, and their risk for poor outcomes may thus be increased. Patients with high levels of perceived and objective knowledge are fully capable of self-management and probably represent individuals who report high self-efficacy (belief in their own competence to attain goals). High self-efficacy has been associated with optimal self-care behaviors among individuals requiring dialysis.⁹ In contrast, patients with high levels of perceived knowledge and low levels of objective knowledge may feel sufficiently confident to self-manage their disease but are likely to make poor health decisions based on inadequate knowledge. Additionally, they may not seek provider guidance when necessary. The two groups of patients with high perceived knowledge may thus represent the lowest- and highest-risk groups, respectively (Figure 1); despite the disparity in possible risks, these groups appear identical to the provider who does not assess objective knowledge.

The study by Wright Nunes *et al.*⁷ is somewhat limited by its lack of patient diversity with regard to race/ethnicity and language; its inclusion of only patients from a single center who have recognized and treated CKD; and its lack of outcome assessment by levels of perceived and objective knowledge. Despite these limitations, this work has important implications, particularly for CKD patient education. Widespread existing kidney education efforts, such as the National Kidney Disease Education Project in the United States (<http://www.nkdep.nih.gov/>) and the International Society of Nephrology's Program for Detection and

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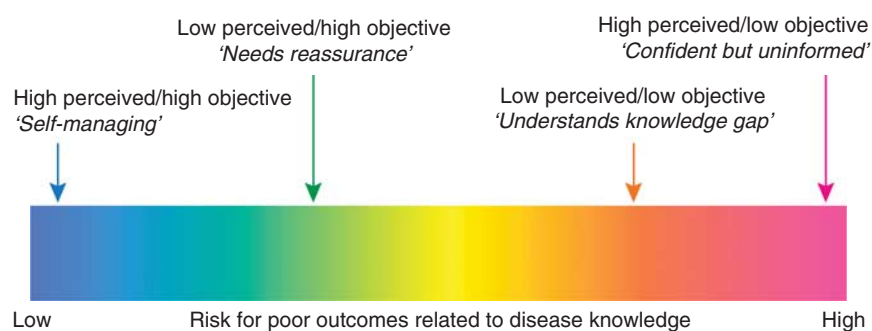


Figure 1 | Proposed risk for poor outcomes conferred by different levels of perceived and objective disease knowledge.

Management of Chronic Kidney Disease, Hypertension, Diabetes, and Cardiovascular Disease in Developing Countries (<http://www.theisn.org/>), should consider targeting both domains of CKD knowledge. Perceived and objective CKD knowledge are likely to impact risk-modifying behavior in different ways and merit equal attention. Professional educators or health-care professionals may be best suited to disseminate objective knowledge, but it is possible that perceived knowledge may be best imparted through peer educators and health coaches. Indeed, Wright Nunes *et al.*⁷ found a positive association between greater perceived knowledge and knowing someone with CKD.

The survey tools used in this study—or modified versions thereof—could also be used to evaluate the effectiveness of CKD educational programs. As the nephrology and primary-care communities seek to increase the availability of CKD education (for example, mandated free educational opportunities for US CKD stage 4 patients through the Medicare Improvement for Patients and Providers Act (H.R. 6331, 110th Congress, §152)), they must be diligent in evaluating those educational efforts via both domains of knowledge, ensuring widespread dissemination of only high-quality, effective programs. Improvements in perceived and objective knowledge scores could serve as metrics, among others, for such program evaluations.

The study by Wright Nunes *et al.*⁷ also has possible implications for patient care. Pre-visit assessment of perceived and objective knowledge could help focus clinicians on providing, during the patient visit, individualized self-efficacy

tools, including reassurance, targeted objective education, or both. This model has been used with some success in the breast cancer clinic at Dartmouth-Hitchcock Medical Center, where patient answers to a short objective knowledge survey are immediately available to physicians, who can correct any mistakes in understanding during the visit.¹⁰ Not only could this model allow for dissemination of individually tailored educational concepts about CKD, but it could also be used to identify individuals with CKD who are at greatest risk for adverse outcomes based on their lack of knowledge and provide them with needed additional resources (for example, care management, home nursing visits, pharmacy interventions). Furthermore, direct use of patient survey data during the visit could lead to greater rapport between provider and patients, which, in turn, could improve patient satisfaction with provider communication. Wright Nunes *et al.*⁷ report that patient satisfaction with provider communication was weakly correlated with knowledge of CKD (positively with perceived knowledge, but negatively with objective knowledge). Directly addressing patient knowledge and knowledge gaps during provider visits, as suggested by Sepucha *et al.*,⁸ could change these associations, perhaps by equipping patients with targeted self-management tools and greater information about local resources. Such actions could lead to increased levels of knowledge and self-efficacy, conceivably leading to increased patient participation and shared decision making.

Wright Nunes *et al.*⁷ present a well-conducted first examination of two distinct

domains of knowledge—perceived and objective—among CKD patients that has possible implications for both patient education and patient care. Future studies could focus on confirming their findings in more ethnically, culturally, and geographically diverse patient populations. Most importantly, the associations of these two types of knowledge with outcomes, including not only patient satisfaction but also health behaviors and clinical outcomes (for example, progression or complications of CKD), must be examined. Confirmation of a differential effect of perceived and objective knowledge on outcomes will further justify efforts to evaluate and target both domains of knowledge.

DISCLOSURE

The authors declared no competing interests.

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