Educating Patients about CKD: The Path to Self-Management and Patient-Centered Care

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Abstract
Patient education is associated with better patient outcomes and supported by international guidelines and organizations, but a range of barriers prevent widespread implementation of comprehensive education for people with progressive kidney disease, especially in the United States. Among United States patients, obstacles to education include the complex nature of kidney disease information, low baseline awareness, limited health literacy and numeracy, limited availability of CKD information, and lack of readiness to learn. For providers, lack of time and clinical confidence combine with competing education priorities and confusion about diagnosing CKD to limit educational efforts. At the system level, lack of provider incentives, limited availability of practical decision support tools, and lack of established interdisciplinary care models inhibit patient education. Despite these barriers, innovative education approaches for people with CKD exist, including self-management support, shared decision making, use of digital media, and engaging families and communities. Education efficiency may be increased by focusing on people with progressive disease, establishing interdisciplinary care management including community health workers, and providing education in group settings. New educational approaches are being developed through research and quality improvement efforts, but challenges to evaluating public awareness and patient education programs inhibit identification of successful strategies for broader implementation. However, growing interest in improving patient-centered outcomes may provide new approaches to effective education of people with CKD.

Benefits of Patient Education
In the United States, patient-centered care and patient self-management are increasingly advocated. Patient education is not only a critical mechanism through which patients can have their questions, concerns, and needs regarding kidney disease care addressed, but it is also a crucial pathway to ensuring that patients can be taught to engage in self-management of their CKD risks. Patients with CKD are charged with assimilating complex treatment regimens, including monitoring blood glucose and BP, maintaining physical activity, changing eating patterns, adhering to complicated medication regimens, and avoiding nephrotoxins. To implement these activities and participate in care decisions and planning, patients with CKD must have knowledge of their condition and self-management support (SMS). Research shows that patient understanding of CKD improves outcomes. For example, compared with those lacking knowledge, patients with CKD aware of BP goals had improved BP (1), and patients with dialysis knowledge were more likely to use permanent arteriovenous access at initiation of dialysis (2). Conversely, incident dialysis patients who were unaware of their chronic comorbid conditions had increased mortality risk compared with those who accurately identified their comorbid diagnoses (3).

CKD education may increase both objective and perceived kidney disease knowledge among patients (4). Although much CKD patient education research has focused on patients with end stage disease, education has improved outcomes across the CKD spectrum (Table 1). Nonsteroidal anti-inflammatory drug (NSAID) avoidance education in patients at risk for AKI increased knowledge of NSAID-associated risks and patient-reported intentions to limit NSAID use (5). CKD patient education programs may defer dialysis initiation (6), increase use of self-care–based dialysis modalities (7,8), lengthen survival on dialysis (9–11), and improve overall mood and feelings of good health (12). National programs and CKD care guidelines uniformly recommend patient education as a critical component of care (13–16). Additionally, many patients with CKD report that they desire CKD education (17–19).

Need for CKD Education in the United States
Evidence points to large deficiencies in awareness of CKD in the United States, highlighting the need for improved CKD education. The National Health and Nutrition Examination Survey (NHANES; 1999–2012) (20) reports the following information:

Overall awareness of CKD status among people with CKD was 6.4% (well under the Healthy People 2020 goal of 11.7% [21]).

Although awareness was higher among people with more severe disease, even among people with eGFR of 15–29 ml/min per 1.73 m², awareness was only 51.6%.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Patient Population</th>
<th>Participants (N)</th>
<th>Study Design</th>
<th>Education Topic(s)</th>
<th>Intervention</th>
<th>Outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Patients at risk for AKI on the basis of prescription for hypertension or diabetes medications</td>
<td>152</td>
<td>Prospective cohort study</td>
<td>NSAID avoidance</td>
<td>Pharmacist-led education intervention administered during prescription pickup or pharmacy purchase</td>
<td>Increased knowledge of risks associated with NSAIDs; patient-reported intentions to limit NSAID use</td>
</tr>
<tr>
<td>115</td>
<td>Adult patients with eGFR&lt;60 ml/min per 1.73 m² not on dialysis</td>
<td>89</td>
<td>Randomized, controlled clinical trial</td>
<td>Protein intake</td>
<td>Addition of nutrition education materials to a dietary counseling program</td>
<td>Reduced protein intake in the intervention compared with the control group; adherence rates did not differ between groups</td>
</tr>
<tr>
<td>6</td>
<td>Patients with progressive CKD expected to require RRT within 6–18 mo (sCr≤3.4 mg/dl)</td>
<td>297</td>
<td>Inception cohort, prospective, randomized, controlled trial</td>
<td>Healthy kidney function, kidney diseases, RRT modalities, diet/nutrition, medications, lifestyle changes</td>
<td>90-min one-on-one slide-based teaching sessions supported by a printed 60-page booklet and 10-min telephone support calls every 3 wk</td>
<td>Delayed dialysis initiation in the intervention group; knowledge acquisition was directly associated with time to dialysis</td>
</tr>
<tr>
<td>8</td>
<td>Patients with eGFR&lt;30 ml/min per 1.73 m²</td>
<td>70</td>
<td>Randomized, controlled trial</td>
<td>Self-care dialysis (i.e., peritoneal dialysis, home hemodialysis)</td>
<td>Two-phase education program, including educational booklets and a 15-min video (phase 1) as well as a 90-min interactive small group session (phase 2)</td>
<td>Increase in patient-reported intention to use self-care dialysis among intervention compared with usual care group</td>
</tr>
<tr>
<td>11</td>
<td>Patients with progressive CKD expected to require RRT (sCr≥3.96 mg/dl and increasing)</td>
<td>335</td>
<td>Randomized, controlled trial</td>
<td>Normal kidney function, kidney diseases, dietary management, RRT modalities</td>
<td>60- to 75-min one-on-one slide lecture presentation supplemented by a 22-page booklet summarizing the presentation content</td>
<td>The intervention group survived an average of 8 mo longer after dialysis initiation than the usual care group</td>
</tr>
<tr>
<td>116</td>
<td>Patients on hemodialysis</td>
<td>118</td>
<td>Randomized, controlled trial</td>
<td>BP control</td>
<td>Nurse–led education program incorporating monitoring, goal setting, and reinforcement</td>
<td>The intervention group had reduced systolic and diastolic BPs compared with the control group</td>
</tr>
</tbody>
</table>

sCr, serum creatinine; NSAID, nonsteroidal anti-inflammatory drug.
Among people with eGFR=15–59 ml/min per 1.73 m², awareness increased from 6.1% in 1999–2000 to 11.9% in 2011–2012.

Finkelstein et al. (22) found that, of 676 patients followed in nephrology practices, “about one-third reported limited or no understanding of their chronic kidney disease and no awareness regarding their treatment options.” Wright Nunes et al. (4) and Wright et al. (23) showed similar gaps in perceived and objective knowledge in another group of >400 patients followed in nephrology practices. CKD awareness is not uniform across patient groups. An analysis of NHANES data (24) suggests that awareness of CKD status is lower in women compared with men, non-Hispanic whites compared with non-Hispanic blacks and Mexican Americans, and those age ≥65 years old.

Barriers to Patient Education

Barriers to improving patient education in the United States are substantial and well documented, and they stem from patient, provider, and system factors.

Patient Barriers

Patient barriers include low baseline awareness of CKD, health literacy and numeracy, access to information on CKD, and readiness to learn.

Low Baseline Understanding of CKD Health Risks. The general public may have poor understanding of the role that kidneys play in health relative to their understanding of the roles of other solid organs, such as the heart, brain, and lungs (25). Even among individuals at high risk for CKD, understanding of kidney disease may be low. In patients with hypertension, concern about CKD was low compared with concern about cancer or cardiovascular disease, suggesting that patients may have less knowledge of the serious health consequences of CKD compared with their knowledge of other health risks (26). Similarly, a study of 2017 blacks found that <3% reported CKD as a top health concern, despite nearly one half having additional CKD risk factors (27).

Limited Health Literacy and Numeracy. The US Health Resources and Services Administration defines health literacy as “the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness” (28). Among patients with CKD, limited health literacy is common: a systematic review suggests between 9% and 32% of patients with CKD may have limited health literacy (29). Low health literacy may contribute to inferior CKD knowledge (23) and poor dialysis patient self-management (30).

Sometimes considered a component of overall health literacy, health numeracy is defined as “the degree that individuals can apply numerical, graphical, and statistical skills to understand and act on health information needed to make effective health decisions” (31). Similar to health literacy, low health numeracy seems to be common among patients with CKD. One study found that more than one half of patients with kidney failure answered one or fewer numeracy assessment questions correctly (32). In qualitative interviews, patients on dialysis identified health numeracy as critical to self-care but expressed concerns about understanding numeric concepts as they relate to individual health needs (33).

Literacy- and numeracy-sensitive education efforts improve diabetes outcomes (34,35), suggesting that similar consideration of health literacy in CKD may help overcome these barriers.

Limited Access to CKD Information. Existing patient education resources do not seem to adequately convey CKD information, especially for non–English-speaking patients. Even for English-speaking patients, reliable, easy to read CKD information is limited. A review of 69 CKD patient education materials (PEMs) found that nearly one half were above the sixth grade reading level, and only 20% were superior in terms of suitability and readability; however, nearly 80% were at least adequate (36). A recent review of 80 PEMs found that the average reading level was ninth grade and noted particularly low availability of CKD information for patients at early stages of the disease (37); however, as noted by Tuot and Cavanaugh (38), the study excluded fact sheets and assessed only reading level, which is just one component of suitable PEMs. Additionally, clinicians do not seem to effectively provide CKD information to patients, which was evidenced by the lack of effect that health care access has on CKD awareness or knowledge (24,39), the low CKD awareness seen even among patients under nephrology care (22), and the extremely low use of the US Centers for Medicare and Medicaid Services (CMS) kidney disease education benefit (40,41).

Readiness to Learn. Many people at risk for CKD have low perceived susceptibility to the disease (26,27), which may limit motivation to seek CKD knowledge. Notably, lack of perceived susceptibility to and concern about CKD are associated with low health literacy (42), suggesting that lack of understandable health information may contribute to patients’ poor awareness and knowledge of CKD risks. The asymptomatic nature of CKD may also contribute to patients’ readiness to learn, because patients may not perceive an urgent need to understand CKD when they do not feel ill. Individuals facing a CKD diagnosis may also feel emotionally overwhelmed (43,44). As a result of this emotional turmoil, these patients may avoid education and care (45). Family members of patients with CKD have reported that patients with CKD can feel so overwhelmed about their illness that they avoid dialysis education (46). Porter et al. (47) posit that traditional education efforts by providers may backfire when patients with CKD are not ready to receive information.

Provider Barriers

Provider barriers include poor prioritization of CKD, time constraints, lack of confidence, challenges communicating the complexity of CKD, competing demands, and lack of consensus regarding the timing and appropriateness for initiating CKD education.

Poor Prioritization of CKD. Providers may not routinely recognize CKD as a priority health condition. Documentation from the Veterans Administration (VA) showed that, for patients cared for by the VA with evidence of CKD stages 3–5, the percentage who also had an ICD-9-CM diagnosis code for CKD was 27% in 2005 and increased to 39% in 2011 (20).
Time Constraints. Clinicians, especially those working in primary care, often have very limited time to address a wide range of patient issues (48). In qualitative discussions with primary care providers (49), limited time availability within routine clinic visits was the most commonly cited barrier to CKD education.

Lack of Confidence. Many providers express lack of confidence or feel that they have inadequate training in managing or explaining kidney disease (50,51). Lengthy, prescriptive, and evolving kidney disease guidelines as well as lack of clear guidance on timing and content of education may confuse and intimidate nonkidney specialists, leaving them uncertain about management and causing them to delay education until referral to a nephrologist. The absence of consensus on collaborative management and communication between primary care clinicians and nephrologists may leave patients in an educational gap, because primary care providers and specialists each assume that the other has provided education.

Challenges Communicating the Complexity of CKD. In qualitative focus groups (49), primary care clinicians cited their difficulty explaining CKD to patients in simple terms as a major barrier to patient education. Poor public understanding of the role of kidneys in health (25–27) may contribute to this often-cited difficulty. Additionally, providers may have limited tools to help them explain CKD and CKD risks during short clinic visits.

Competing Management and Education Demands. The challenge of managing multiple chronic conditions may also be a barrier to appropriately prioritizing education. Not only are there conflicting recommendations (e.g., whole grain intake in diabetes versus CKD), but there are many concurrent issues requiring focus. For example, providers may prioritize cardiovascular disease risk modification over CKD prevention or not recognize CKD as a distinct chronic condition (49), reducing provider emphasis on CKD when educating patients about common risk-reducing behaviors.

Confusion about When to Diagnose and Educate Patients. The nephrology community continues to debate whether individuals of advanced age who meet eGFR criteria for CKD should be diagnosed with CKD (52,53). Lack of consensus on this issue has generated confusion about whether providers should diagnose and educate all patients who meet CKD criteria. Providers may fear that heightening awareness of CKD too early in the disease could induce unnecessary concern about CKD progression, particularly for patients in whom the disease has not progressed rapidly or kidney function is preserved. Reluctance to induce emotional distress may inhibit engaging patients in CKD education as early as possible (50).

System Barriers

System-level barriers to patient education are multifaceted in nature and may stem from limited incentives for education, lack of decision support, and inadequate interdisciplinary care models.

Limited Incentives for Education. Existing United States quality improvement initiatives and efforts to revamp reimbursement structures have failed to incentivize CKD education. Current United States national clinical quality measures omit patient education-specific goals. Accordingly, most United States health systems do not prioritize patient education initiatives. Furthermore, recent United States policy efforts to boost CKD education rates through revised reimbursement policies have been initiated but have had limited effect. In January of 2010, the CMS launched a first of its kind mechanism (54) as part of the Medicare Improvements for Patients and Providers Act to reimburse eligible clinicians for providing CKD education to Medicare beneficiaries with eGFR < 30 ml/min per 1.73 m². However, this kidney disease education benefit is underused. According to the US Renal Data System 2013 Annual Data Report (40), 2% of eligible Medicare beneficiaries received the kidney disease education benefit in the 2010–2011 year, and the number of recipients seems to be decreasing. In 2013, only 3600 beneficiaries received the benefit compared with 4200 in 2012 and 2011 (41). The US Government Accountability Office is exploring barriers to use of this benefit and may identify opportunities to facilitate its use (55). Many nongovernment health insurance providers offer limited or no reimbursement for educating patients with CKD, or they restrict reimbursement to a subset of patients at risk of CKD progression.

Limited Decision Support Tools. Although automated eGFR reporting has improved clinician awareness of CKD, the extent to which eGFR reporting has increased patients’ understanding of CKD is unclear. Primary care providers who are prompted to recognize the presence of CKD by automated mechanisms may be more likely to refer patients for nephrology care (56–58) but may be no more likely to educate patients about CKD. Providers may lack access to decision tools (e.g., risk prediction models) (59) that could identify patients at high risk of CKD progression who most need education. When it is apparent that patients do need education, information guiding patients to the most comprehensive education resources may be limited. Although electronic health records have gained substantial penetration in care, use of patient portals to guide CKD education remains limited.

Lack of Interdisciplinary Care Models. Where interdisciplinary chronic disease care models have been implemented (e.g., diabetes), educational responsibilities are shared by a range of professionals. Despite their success internationally (60,61), such models are not widely implemented for CKD in the United States. Diverse patient self-care needs require coordinated strategies for consultation with multidisciplinary teams, including dieticians, pharmacists, and other clinicians. To accomplish self-care goals, patients at risk of CKD progression often benefit from behavioral education and training in self-care (62), but few systems provide these resources to patients. Patients also need substantial education and facilitated shared decision making regarding treatment choices as CKD progresses, but most frequently, they feel undereducated and undersupported in this arena (63,64).

Overcoming Barriers to Patient Education

Ensuring that patients receive the educational support that they need as their disease progresses requires innovative approaches that target patient, provider, and system barriers. Effective education strategies exist but are not yet incorporated into routine care. Incorporating such strategies
will require innovative approaches to CKD education, increased efficiency of education approaches, and policies and research to expand our capacity to provide effective patient education.

**Innovative Approaches to CKD Education**

**SMS.** The Institute of Medicine defines SMS as “the systematic provision of education and supportive interventions to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support” (65). SMS is widely recognized as effective across numerous chronic conditions, including diabetes, which requires similar patient participation as CKD. On the basis of rigorous evidence of the benefits of SMS in diabetes (66,67), the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics released a joint statement identifying SMS as essential for all individuals with diabetes (68). Evidence showing the benefits of SMS in CKD is growing. In patients with diabetic kidney disease, a multidimensional SMS program enhanced understanding of diabetic kidney disease and its treatment regimens, reduced A1C and albuminuria, increased physical activity, and improved BP control (69). SMS programs have been associated with decreased hospitalization and slowed progression of CKD.

**Shared Decision Making.** Shared decision making (SDM)—“a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences” (70)—is recognized as a central component of patient-centered care and SMS (68). SDM may increase patient knowledge, lower uncertainty, and result in more realistic expectations about treatment outcomes (71). Although patients with CKD face decisions throughout the disease course (72), much SDM research has focused on treatment of kidney failure. SDM has been shown to reduce uncertainty about treatment of kidney failure and improve patient satisfaction (73). As early as 2000, the Renal Physicians Association and the American Society of Nephrology released a guideline recommending SDM as critical to decisions around initiation and withdrawal from dialysis (74,75). However, studies suggest that SDM has not been widely implemented in treatment decisions (76), and the need for development and evaluation of decision aid tools for CKD remains (77,78). In response, Boulware and colleagues (79) developed Providing Resources to Enhance Patients’ Readiness to Make Decisions about Kidney Disease, a decision aid program addressing key patient concerns—morbidity/mortality, autonomy, treatment delivery, symptoms, relationships, psychologic wellbeing, and finances—to help patients and their providers work together to choose a kidney failure treatment that best meets the patients’ needs. The effect of this program on increasing use of transplant among blacks is currently being evaluated (80).

**Use of Digital Media.** Patients increasingly rely on digital resources—including websites, social media, and mobile phones—for medical information. In 2012, 59% of United States adults and 72% of Internet users sought health information online (81). Over the past year, 62% of smartphone users researched a health condition using their phone (82). These trends seem to hold for individuals with and at risk for CKD. An evaluation of a website providing safety information to patients with CKD suggests that patients are interested in accessing CKD information online (83). Among patients with transplants, interest in receiving CKD education and SMS through mobile health has been confirmed through focus groups (84) and surveys (85), and a mobile health intervention improved medication adherence and BP control (86). An analysis of online discussions revealed that patients are actively discussing CKD on social media (87). However, providers are not using social media to provide CKD education (87). Use of digital channels for health information is expected to continue to grow in coming years, making digital media an increasingly important channel for raising awareness of CKD among individuals at risk and educating patients with CKD about how to manage their disease. However, it is important to acknowledge that digital access is not uniform across race, age, and socioeconomic status, factors that may be particularly relevant in CKD populations. Although a growing percentage of older adults—60% of those age >65 years old in 2013—is accessing information online, online access decreases with education and income among older adults (88). Additionally, the racial digital divide persists, with 80% of blacks accessing the Internet compared with 87% of whites and greater reliance on mobile devices for Internet access among blacks (89).

**Inclusion of Family, Caregivers, and Community.** Family members and other caregivers provide important support to patients with chronic conditions. In CKD, support from family and other social groups has been cited as a key factor in changing diet patterns (e.g., sodium reduction) (90) and increasing physical activity (91). However, research shows that caregivers report feeling unprepared, having insufficient knowledge, and receiving inadequate support from clinicians (92). Including family and other caregivers in CKD patient education may better equip them to support the patients who they care for and ultimately yield improved patient outcomes. A randomized, controlled trial to assess the effects of inclusion of individuals from patients’ community networks during education sessions on treatment of kidney failure is underway in The Netherlands (93). Another study is exploring the effectiveness of peer support to improve education about CKD treatments in the United States (94).

As trusted sources of information, family and community members have the potential to help overcome sociocultural barriers and institutional/medical mistrust, which is prevalent among hard to reach groups who carry the highest burden of CKD (95). Advice from within informal, interpersonal networks (e.g., community members) can significantly affect health decision making (96–98). The National Kidney Disease Education Program (NKDEP) supports such networks through its Kidney Sundays (99) and Family Reunion (100) initiatives, which provide resources to promote kidney health conversations and education sessions during faith community and family reunion events, respectively.

**Increasing Education Efficiency**

**Focus on People with Progressive Disease.** Not every individual who develops reduced kidney function or low-grade albuminuria will progress to kidney failure. Individuals with high levels of albuminuria, progressive GFR
decreases, and poorly controlled BP may be most likely to progress (13). Although education may be beneficial to all individuals with CKD, focusing interventions on these high-risk patients may yield the greatest overall benefits to patient outcomes. Efforts to better identify such high-risk patients are ongoing through the Chronic Renal Insufficiency Cohort Study and other studies (59) and may yield validated prediction models for disease progression, which could be incorporated into patient management.

Promote Interdisciplinary Care Models. Interdisciplinary care models that emphasize shared responsibility for CKD education among multiple professionals may improve patient outcomes and create efficiencies in education delivery. A systematic review suggests that multidisciplinary CKD care models effectively delay disease progression and cite educational interventions as central to this approach (101). Recipients of a multidisciplinary education program, including nephrologists, dialysis nurses, pharmacists, dieticians, and social workers experienced reduced unplanned urgent dialysis, hospital stays, cardiovascular events, and infections as well as improved metabolic status on dialysis initiation compared with nonrecipients (102).

Community health workers (CHWs) and other lay health education providers may be an effective and untapped resource for providing patient education. As discussed above, individuals from within a patient’s community have the opportunity to influence health decision making (96–98). Research shows that CHWs are effective in supporting health behavior change, particularly among the Hispanic community (103). A CHW intervention with patients with diabetes improved knowledge, blood glucose levels, and BP control (104). Lay health worker interventions are currently being explored in CKD. Researchers at the Cleveland Clinic hypothesize that engaging lay patient navigators to coordinate care, eliminate system barriers, and educate patients will increase patient adherence to evidence-based CKD care and improve patient outcomes (105). Additionally, evaluation of a pilot program designed to incorporate CKD information into CHW–led diabetes education classes found that CHWs are capable of and interested in providing CKD information to patients (E. Newman, unpublished data) (106).

Group Education. Research shows that group–based educational interventions are effective in CKD and related conditions. A group–based education program with patients with CKD approaching kidney failure resulted in improved knowledge perceptions compared with a control group as well as knowledge gains compared with preintervention assessments (12). Among patients with diabetes and albuminuria, a group–based education intervention improved self-management behaviors, increased physical activity, and reduced A1C relative to a nonintervention group (107). Group education may maximize provider investment in education. A survey of education programs across nephrology practices found that group education was associated with more hours of patient education and increased use of home-based dialysis (108). Additionally, patients with CKD have expressed interest in group education (109).

Policies and Research to Further CKD Education

Kidney Disease Education Benefit. Because CMS education benefits are severely underused, it is crucially important to reduce barriers to this benefit. An analysis of 2010 and 2011 CMS data by Zuber and Davis (110) found that physician assistants and nurse practitioners are underused in providing the kidney disease education benefit, despite being qualified to do so. Expanded guidelines on which providers are able to provide the education benefit and the models of education that are supported by the benefit may encourage greater use among advanced practitioners. Efforts to understand whether the benefit is perceived as sustainable and supportive of existing practice models could identify strategies for improved uptake. Additionally, expanding the benefit to include nurses may increase kidney disease education.

Quality Improvement Efforts. Demonstrations of patient engagement and patient safety are increasingly important in quality improvement and physician recertification efforts (111). These institutional efforts supported by health care payers, including the CMS, may facilitate innovative efforts to educate and prepare patients with progressive kidney disease.

Research Opportunities. Patient-centered outcomes are the focus of many type 2 translational (from clinical evidence to the community) research efforts and central to work supported by the Patient-Centered Outcomes Research Institute (PCORI). Most of seven funded PCORI CKD–related grants have a significant educational component, including peer counseling, multidisciplinary care, and formal training in SDM (112). The National Institutes of Health has an initiative in type 2 translation in CKD, which has funded a number of innovative approaches to patient education (113). These include the use of patient navigators, mhealth (e.g., smart phone reminders), multidisciplinary care, and SDM (114). The NKDEP helps disseminate innovative tools developed by National Institute of Diabetes and Digestive and Kidney Diseases–funded investigators to patients, families, and providers, especially those serving high-risk populations as primary care clinicians.

Future Directions

Despite promising efforts to overcome barriers, substantial opportunity to improve CKD education remains. First, efforts to monitor public awareness of CKD are needed to assess patient education programs. Currently, evaluation of public awareness and patient education programs is quite difficult. Evaluation by federal agencies (e.g., NKDEP and the Centers for Disease Control and Prevention) is limited by clearance requirements from the Office of Management and Budget for any survey involving more than nine respondents. Even with clearance, surveys of public awareness are expensive, and it may be impossible to attribute changes to specific efforts. The NHANES survey question, “Have you ever been told you have weak or failing kidneys?” is an imperfect assessment tool, but it is the only tool that has been used in a representative population over a prolonged period of time. Most researchers have focused on the quality and effectiveness of educational materials or activities in a discrete study population (37). There is opportunity for investigators to develop pragmatic tools for assessing CKD educational materials and the efficacy of their implementation.
Second, the CKD patient population is diverse with varied needs. Efforts to tailor education strategies to persons with various literacy, cultural backgrounds, and resources are needed to ensure that all patients receive adequate support. Third, successful public and patient education will require collaborative efforts between public agencies, voluntary organizations, health care systems, and payers. Limited public and private resources emphasize the importance of reducing redundant efforts and directing more effort toward reaching patients from high-risk populations with materials that are understandable, relevant, and useful. These efforts will be informed by new knowledge from a growing community of researchers working to identify strategies to improve education among patients with CKD.

Finally, as new models of patient education are developed, collaboration between professional organizations, public agencies, and other key stakeholders will be essential to implement and sustain effective education of people with CKD.

Disclosures
None.

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