



Chronic Kidney Disease Management Programs and Patient Education

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Before You Start: Facts You Need to Know

- Chronic kidney disease (CKD) prevalence is increasing with one in ten adults affected worldwide. Due to the asymptomatic nature of the early disease, many individuals are unaware of their disease and present late for care.
- Beyond the increased morbidity and mortality for those with CKD, there are financial, social, and societal impacts related to the diagnosis.
- Multidisciplinary team approaches including involvement by community health workers, pharmacists, nursing, primary care providers, healthcare institutions, and payers are necessary to change the progression of kidney disease.
- Patient engagement is developed through education programs, self-management strategies, and peer support. This engagement is essential for successful long-term management.

35.1 Chronic Kidney Disease Management Programs

With the increasing prevalence of CKD worldwide and the implications in terms of financial burden on healthcare systems for care and the increased cardiovascular morbidity and mortality, the need for early identification and management is important. Beyond the health effects, there are the additional impacts on the ability to work, remain in school, or change in family roles when needing to start renal replacement therapy that make kidney disease a potentially life-changing event. These other changes necessitate that management strategies extend beyond diagnosis, slowing progression of kidney disease, and treatment of complications of kidney disease. The healthcare burden and financial burden have led to development of CKD management programs. Disease management refers to multiple approaches to identify patients with health conditions and encourage adherence to treatment plans with the goals of reducing healthcare costs [1, 2]. Such programs have been used successfully with other health conditions such as diabetes and congestive heart failure. There has not been as much ease in implementation of CKD management programs.

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35.2 Barriers to Development of CKD Management Programs

Understanding the unique challenges of CKD are key prior to building a management program. The asymptomatic nature of kidney disease and the unfamiliarity with how the kidneys work contribute to the late diagnosis and presentation to care for many patients [3, 4]. For many individuals the extent of knowledge of kidney disease is that some people have received a kidney transplant and some are on dialysis. This is in combination with primary care providers not prioritizing CKD due to the number of competing health issues to be addressed during visits, the challenges in providing the education and counseling to patients, absence of the appropriate testing for diagnosis of kidney disease, and the lack of an established co-management strategy with nephrologists. Compounding these issues are the gaps in assessment of at-risk populations. Social determinants of health such as access to care, access to healthy food choices, ability to get to appointments, and lack of support symptoms result in less opportunities for medical care and less opportunity for early diagnosis. These factors are often not addressed or accommodated during program development. Addressing the needs of a CKD population would require significant resources: financial, personnel, engagement of community programs, and healthcare institutions. Additionally, the nature of CKD being progressive and potentially requiring several years of management, it is harder to see benefits in terms of healthcare costs and changes in morbidity and mortality. The arguments advocating for healthcare institutions and payers to commit to the costs of CKD management programs are made difficult by the lack of immediate results or cost savings.

35.3 Can CKD Programs Be Successful and Improve Outcomes?

Gauging outcomes start with defining the goals of CKD management programs. The overall goals include identifying those at risk, early diagnosis, delay of progression of kidney disease,

management of complications, reduced hospitalizations, and overall cost savings. There are many variations in programs depending on if it is a practice-based program, a healthcare plan, or a public health initiative. This coupled with the need for long-term follow-up or large numbers of individuals studies has limited the amount of data on the benefit of CKD programs. One area that lends itself to analysis is the impact of CKD programs on the amount of money spent on care, rates of hospitalization, rate of pursuing home dialysis, and rates of transplantation. Lower rates of “crash starts” of dialysis (those without previous preparation), reduced number of days in the hospital when starting dialysis, and decreased expenditures when starting dialysis have been demonstrated with use of multidisciplinary clinics for those with advanced CKD [5]. There has also been success for healthcare programs to incorporate CKD programs that involved primary care providers through treatment guidelines/protocols and engaged nurse case managers who serve to guide those patients identified with CKD through education, reinforcing treatment plans and self-management strategies [6]. With this multidisciplinary approach, there were reductions in hospitalization and significant cost savings in annual cost of care across all the stages of CKD in a population of 7420 patients. Savings of \$276.80 for those patients with stage G3 and \$480.79 for stage G5 CKD can add up to significant healthcare costs per year and the initial cost of implementing the program, the primary care provider education, and the maintenance of a team of nurse clinical managers. More impactful is that the interventions involved low cost strategies of education to primary care providers and nurses that could be duplicated at other locations and were achievable with voluntary participation by primary care providers.

35.4 Development of a CKD Management Program

Considering the barriers in CKD care and what strategies have been successful, a framework of a CKD management program can be defined. A meaningful CKD program will require a multi-

Table 35.1 Elements of a successful CKD management program

| Component | Details |
|--|---|
| Provider education (primary care) | <ul style="list-style-type: none"> – Co-management strategies – Education on screening and diagnosis of CKD – Information on when to refer |
| Provider education (nephrology) | <ul style="list-style-type: none"> – Co-management strategies – Education on counseling regarding early CKD diagnosis/management – Education on counseling regarding renal replacement therapy – Guideline/protocols for CKD management |
| Insurers/payer/healthcare administration | <ul style="list-style-type: none"> – Commitment of resources for CKD screening – Commitment of resources for CKD management |
| Multidisciplinary team | <ul style="list-style-type: none"> – Addressing risk factors and management of CKD |
| Patient | <ul style="list-style-type: none"> – Understanding of kidney disease – Incorporation of self-management behaviors – Active role in healthcare decisions |

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disciplinary team (MDT) and have features to address the roles by the different team members (Table 35.1). The structure of a CKD management program will target the goals of timely identification of those with CKD, patient education, patient engagement, slowing progression of kidney disease, renal replacement therapy planning, and provider education.

The patient is the central member of the CKD management team. Without initiatives to provide patient education in a useful manner and encouragement of self-management behaviors, other aspects of programming will not be meaningful. Primary care providers, nephrologists, nursing, pharmacist, community health care workers, public health advocates, healthcare administrators and insurers all have roles in CKD management.

The lack of awareness of being at risk for CKD and late identification of those with CKD are two obstacles to providing meaningful care. One component of CKD management programs will incorporate protocols for screening of high-risk populations and utilization of electronic medical records to risk stratify individuals. Provider education on patients to screen, developing protocols for timely referral to nephrology, laboratory testing for different stages of CKD, and establishing co-management framework for nephrology and primary care providers to work together is an important step in CKD management programs. Use of community health work-

ers, public health campaigns, and nursing managers will help reinforce education efforts and potentially reach those that do not have routine access to care.

Protocol/guidelines are necessary for CKD management programs. These allow for primary care providers to readily adopt management in their routine practice without an excess burden of time. Protocols to standardize frequency of labs, frequency of visits, and timing of nephrology referral will allow for ability to study the impact of interventions and ensure quality standards for care of this patient population. Primary care provider education will supply the tools necessary to counsel and manage patients with early CKD. A structured co-management plan between primary care providers and nephrologists will avoid duplication of work, will allow healthcare providers to know their responsibilities and optimize their areas of expertise. Nephrologists would take lead on management of the risk factors of progression of kidney disease, diagnostic workup of proteinuria, acute kidney injury, and glomerular disease, and management of those with advanced CKD (stage G4 and up). Nephrology practices would utilize workflows for patient education topics dependent on level of kidney function, renal replacement counseling and preparation, management of complications of CKD including anemia, bone mineral metabolism, and electrolyte changes, and best practices for immunizations, nutrition, and cardiovascular risk factor manage-

ment. An approach with delineation of responsibilities will allay concerns of patients regarding continuity of care and how the different team members play a role in their care.

CKD management programs will seek input from dietitians, pharmacists, social workers, and case managers. The dietary challenges of having CKD can be overwhelming in an effort to reconcile the different restrictions for different comorbidities. Pharmacist input can help address the medication changes and potential safety events with the potential risk of accelerating CKD progression. The potential for depression, disability, interruption in work or schooling need to be acknowledged. The diagnosis of kidney disease or the development of end-stage kidney disease are life-changing events. Case managers and social workers can help with screening for depression or difficulty coping and help identify resources for patients.

35.5 Health Literacy Within Chronic Kidney Disease

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” [7]. It requires a complex group of reading, listening, analytical, decision-making skills, and the ability to apply these skills to health situations [8]. Health literacy has a direct impact on vulnerable groups such as the elderly, racial or ethnic minority group, polymedicated patients, immigrants, low socioeconomic status, and the chronically ill [9]. It is very likely that patients with CKD or end-stage kidney disease will fall within one of these vulnerable groups.

A low level of health literacy can lead to a lack of understanding of information about treatments, poor knowledge about chronicity, late detection of diseases, medication errors, misuse of healthcare services, and higher rate of morbidity and hospital admissions [9–12]. For moderate to severe CKD (considered CKD stage G3 or higher), the prevalence of poor health literacy ranges from 5% to 60% [9]. In advanced CKD (considered CKD

stage G4 or higher) prevalence of inadequate health literacy is estimated at 23% [10, 11]. Poor health literacy in CKD has been associated with higher reported cardiovascular disease, poor blood pressure control, poor self-management skills, missed dialysis sessions, more emergency department visits, more kidney disease-related hospitalizations, higher morbidity/mortality, and fewer transplant referrals [10, 13–16].

Many studies have shown that health literacy can be improved through educational interventions. Patient education involves increasing a patient’s knowledge about a disease in order to change behavior. For CKD, there are opportunities for patient education at all stages from time of diagnosis with CKD to end-stage kidney disease. The largest effects of patient education have been observed on increases in CKD-specific knowledge. There was some evidence that programs may have a positive impact on health-related outcomes. It has been linked to higher rates of pre-dialysis nephrology care; better proteinuria and blood pressure control; higher rates of peritoneal dialysis, preemptive kidney transplant wait listing, and kidney transplantation; and increased time to commencement of renal replacement therapy [15, 17–22].

35.6 Patient Education in Chronic Kidney Disease

Most patient education that is provided, including learning about dialysis options, comes from their treating nephrologist during a 20–30 min routine clinic visit. In these situations, the education must fit alongside the rest of the visit requirements. The opportunity to ask questions is limited by time. Some nephrology practices offer dialysis educational sessions led by dialysis-experienced nurse educators and may include a tour of in-center dialysis facilities or home dialysis equipment. Patients might receive written handouts regarding education for CKD including different dialysis options. Some patients will seek advice from “expert” patients who are already receiving dialysis or a kidney transplant [23].

Recent studies show dissatisfaction with current practices for CKD and dialysis education. Individuals feel that education is provided too late, the information is too complex or hard to understand, or feel that choices are limited. There are reports of unequal and insufficient presentation of all available dialysis modalities and insufficient facilitated communication with “expert” patients [23–29].

35.7 Guidance on Patient Education in Chronic Kidney Disease

There is a wide variation in patient education interventions from the educators (i.e. nurse educator vs. multidisciplinary panel), structure (i.e. one-on-one, group, in-person, virtual, etc.), intensity (i.e. one class vs. multiple classes), and topics covered. Studies are also variable in these characteristics and in study design such as outcome measures, sample sizes, and relatively short follow-up [18]. These differences make it difficult to compare the efficacy in the educational interventions.

Best practices in chronic disease education are individually tailored, understandable for patients with low health literacy, and culturally competent [30]. For there to be benefit, patient education must be high in quality, which includes that it is sufficient and useful [31, 32]. Sufficient patient education means that an adequate degree of essential knowledge is delivered to support patients’ empowerment [22, 33]. Useful patient education refers to education that patients need for their use and can implement in their lives and care [22, 34]. Overall, we see that patient education in CKD is desirable when it supports self-management of day-to-day aspects of a patient’s health [35].

There are several guideline organizations within CKD that address patient education on CKD. In general, they all recommend educating patients with CKD and their family/caregiver using an MDT. The Kidney Disease: Improving Global Outcomes (KDIGO) 2012 Clinical Practice Guideline for the Evaluation and

Management of Chronic Kidney Disease recommends focusing on dietary counseling, education and counseling about different renal replacement therapy modalities, transplant options, vascular access surgery, and ethical, psychological, and social care [36]. The Kidney Disease Outcomes Quality Initiative (KDOQI) Clinical Practice Guideline for Hemodialysis Adequacy: 2015 Update recommends beginning education with CKD patients with stage G4 or higher focusing on kidney failure and options for its treatment [37]. The National Institute for Health and Care Excellence (NICE) guidelines recommends shared decision-making over the course of CKD offering education on CKD and information tailored to the severity and cause of CKD, the associated complications, and the risk of progression [38, 39]. There are no specifics on how to offer patient education. Table 35.2 offers suggestions to developing patient education on CKD.

35.7.1 Multidisciplinary Team

At a minimum, there should be a nephrologist and CKD nurse. Optimally, there should be additional members involved in education with expertise in different areas to comprise an MDT. Usually the MDT consists of a healthcare provider, certified nurse specialist, social worker, and dietician. Some literature will include a physical therapist, mental health professional, and “expert” patient as well [44]. Physical therapist can help with daily functioning and improve quality of life. The mental health professional can help with coping and stress with living with a chronic illness. The “expert” patient can provide peer-to-peer support and add to aspects of daily life while dealing with CKD. It is helpful for the MDT to have a close relationship with the patient to reduce the stress of encounters [40, 41, 45].

35.7.2 Structure

A lot of thought should be focused on the structure of the patient education on CKD. There are different formats to providing information. If we

Table 35.2 Approach to developing patient education on CKD [30, 36–43]

| Core aspect | Details |
|---------------------|--|
| Target audience | Patients with CKD and family/caregivers |
| Educators | Involvement of a multidisciplinary team <ul style="list-style-type: none"> • Healthcare provider: Physician, NP, PA • Certified nurse specialist • Social worker • Dietician Optional members: Physical therapist, mental health professional, “expert” patient |
| Structure | Determine format: <ul style="list-style-type: none"> • One-on-one • Group class • Written material • Technology-based (websites, videos, webinars, etc.) |
| Content/topics | Examples of suggested topics: <ul style="list-style-type: none"> • General information on CKD • Treatment options for CKD • CKD complications and management • Managing the effects of CKD on daily life <ul style="list-style-type: none"> – Diet and exercise – Self-monitoring of blood glucose and blood pressure – Avoidance of nephrotoxins – Adherence to complex medication regimens • Ways for delaying CKD progression • Renal replacement therapy (including hemodialysis (in-center/home), peritoneal dialysis, kidney transplant, and conservative management) and necessary preparation • Coping with CKD and resources available • Nutrition and CKD |
| Community Resources | Written material “Expert” patient Incorporate models (example: dialysis equipment, vascular access model, food portions diagram, etc.) Tour of dialysis facility |

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focus on in-person education, then we need to consider whether it should be one-on-one sessions vs. group classes. One-on-one might be appropriate if the individual patient lacks sufficient knowledge [41]. Group classes have advantages of providing peer support. Group classes provide a more efficient use of resources in that you can reach more people at once if done effectively.

At least one session of patient education on CKD should be provided as part of CKD management. Optimally, the number of sessions should be driven by the number needed to reach an informed and balanced decision [41]. The number of sessions will also vary by the mode of

education such as in-person vs. technology-based. For example, it may be easier for someone to watch six videos on an e-learning website than to attend six in-person sessions.

35.7.3 Topics Covered

At a minimum, topics should include general of CKD, CKD treatment of associated conditions, renal replacement therapies including transplantation and conservative management, how to delay the progression of disease, and additional manage CKD (such as diet). Topics can be expanded to cover coping with CKD, blood pres-

sure control, medication compliance, advance directives, etc. The topics that can be covered are not limited to these areas [41]. The specific needs of your CKD patient population can further tailor the program.

35.7.4 Resources

Written materials are helpful for some patients. They provide a reference that can be reviewed multiple times and at the pace of the patients learning. Materials should be written at about a seventh to ninth grade reading level [46]. Ideally, written education is best understood when written at a reading level that is 3–5 grades lower than their last grade of school completed [47]. In this technological age, there are many high-quality multimedia resources available such as websites, blogs, videos, webinars, etc. that can aid in educating patients on CKD. Having a list of suggested online resources will guarantee the accuracy and quality of information provided to patients [41, 48].

In the long-term the ability to visit a dialysis unit or see models of home dialysis equipment help to relieve anxiety. There are some reports that in the short term it might create anxiety as well. An “expert” patient can help provide support, understanding, and insight into living with CKD that healthcare professionals might not be able to provide. There is some bias toward their own experience by the “expert” patient that will need to be taken into account [41].

35.7.5 Learning Style/Teaching Method

The literature supports that patients want a wider range of teaching methods and particularly active learning methods [49–51]. Along the lines with the principles of adult learning theory, patients want more time spent on helping apply information to their own lives [52]. As people age, they move from a dependent learning toward self-

directing learning. This would imply that adult patients are more apt to seek out information like finding classes or from online resources. As individuals mature they move from using information for future application to immediate use in their daily life [53]. As the population ages, there should be accommodations for visual impairment, decreased attention span and short-term memory, and slower processing of new information [54].

35.7.6 Timing of Education

Education regarding CKD is usually undertaken in the pre-dialysis period and thus called “pre-dialysis education,” but there is more than dialysis options that should be covered. Additionally “pre-dialysis education” might need to be extended beyond the pre-dialysis period. Examples of patients that might benefit from this are those that are highly distressed in the pre-dialysis period or become open to other treatments only once they have started treatment [52].

A good example of patient education that extends beyond dialysis is transitional care units (TCU). TCUs (also sometimes called transitional start units) designed to provide a more gentle start to dialysis therapy with more frequent dialysis, increased provider interaction, acknowledgment of emotional and mental needs particular to new patients and their families, and an in-depth patient-centered education curriculum [55]. TCUs are usually utilized for patients that have not received much pre-dialysis care. They provide detailed patient-centered education on all modalities of renal replacement therapy including kidney transplantation. Initially started as a platform to bridge the gap between an unplanned, acute, or new start with the hope to transition more patients to home therapies [56]. TCUs have been proven to improve mortality and other quality parameters such as permanent vascular access [55–59]. Table 35.3 is an example of how a 4-week TCU is organized with regard to education.

Table 35.3 Example of 4-week TCU education [55, 56]

| |
|---|
| Week 1: Introduction to TCU and MDT; Get to know the patient |
| Week 2: In-depth discussion of in-center hemodialysis, home hemodialysis, peritoneal dialysis, kidney transplant, and conservative care; Discuss vascular access |
| Week 3: Continue education; Facilitate interaction with other patients on home dialysis modalities; Possible use of home hemodialysis equipment; Confirm desired dialysis modality; Initiate referral for creation of access (as applicable) |
| Week 4: Transition to appropriate dialysis setting; Confirm access plan and appointments (as applicable); Confirm transplant evaluation appointments; If conservative management, then arrange palliative care or hospice referrals/consultations; Discuss advanced care planning |

This education occurs while the patient is receiving hemodialysis. Education is provided by multidisciplinary team (healthcare provider, dialysis nurse educator, dietician, social worker). *TCU* transitional care unit, *MDT* multidisciplinary team

35.8 Use of Technology for Patient Education on Chronic Kidney Disease

There are various formats for providing education including individual meetings, group classes, written handouts, videos, etc. that provide useful information for patients. Technology has been used to enhance healthcare delivery for years. The Internet is now an essential source of health information: 80% of Internet users look online for health information and 25% of Internet users watch health-related videos [60]. In the USA, about 90% of adults own a mobile device and nearly 60% of them access the Internet with their phones [61]. Many patients make health decisions based on the information they find online. More than 50% of patients who use the Internet say they were influenced by online health information and tools when choosing healthcare providers, treatments, and services [48, 62].

The availability of Internet-based technology can increase the reach of telehealth education to the CKD population with limited mobility due to physical disability or frailty and to those patients who live in rural areas. Telehealth educational

Table 35.4 Internet-based education examples[63]

| |
|--|
| • Tailored e-learning |
| • Comprehensive informational websites |
| • CKD patient advocacy websites |
| • Blogs |
| • Webinars |
| • Email listservs |
| • Social media |

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opportunities are also more flexible and adaptable to learner preferences. They can reach more learning styles; for example, by using both visual and auditory modalities of content delivery. Additionally, all of these educational opportunities occur outside the traditional office visit, which allow healthcare professionals the opportunity to reinforce key ideas and answer questions during an office visit [23, 30, 48, 63]. Examples of Internet-based education are listed in Table 35.4.

In summary, it is important to understand that no matter how patient education is organized not all patients will benefit. You are more likely to benefit more patients by having a varied approach to education and teaching methods. Patient education on CKD should cover multiple topics, using different formats for educating, offering education at varying points within a CKD spectrum, applying principles to daily life for the patients, and using multiple members of the team for education.

Before You Finish: Practice Pearls for the Clinician

- CKD management programs should be designed to address the needs of the patient and not just limited to medical care.
- Patient education and encouragement of self-management is the core of successful CKD management.
- Unlike other diseases, the benefits of CKD management are seen after long-term management.
- CKD management programs require a multidisciplinary approach including nephrologists, primary care providers, social work, pharmacist, dieticians, nursing, health care administration, and payers.

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