Patient Education and Support During CKD Transitions: When the Possible Becomes Probable

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Patients transitioning from kidney disease to kidney failure require comprehensive patient-centered education and support. Efforts to prepare patients for this transition often fail to meet patients' needs due to uncertainty about which patients will progress to kidney failure, nonindividualized patient education programs, inadequate psychosocial support, or lack of assistance to guide patients through complex treatment plans. Resources are available to help overcome barriers to providing optimal care during this time, including prognostic tools, educational lesson plans, decision aids, communication skills training, peer support, and patient navigation programs. New models are being studied to comprehensively address patients' needs and improve the lives of kidney patients during this high-risk time.

Key Words: CKD, Patient education, Decision aid, Psychosocial support, Patient navigator

INTRODUCTION

It is widely acknowledged that patients with advanced CKD require tailored care that is focused on chronic disease self-management and discussions that help them consider potential kidney failure treatment options.[1] Despite this, most patients who develop kidney failure report being completely unprepared for this transition, even when they have received routine nephrology care for years.[2] Efforts to prepare patients for the transition from kidney disease to kidney failure often fall short of meeting patients' needs because: (1) disease trajectories are often unpredictable; (2) the optimal approach to patient education is unknown; (3) providers are often unprepared to have these discussions; (4) patient psychosocial factors may influence their coping and decision-making capacity; and (5) there is lack of support to help patients follow-through with recommendations. In this review, we provide guidance on emerging approaches to providing comprehensive patient-centered kidney failure education and support that address these barriers.

ESTIMATING PROGNOSIS

Uncertainty exists about which patients will progress to kidney failure and how well a patient will tolerate various renal replacement therapy options. Disease trajectories are often variable, with some patients having nonprogressive or slowly progressive disease and others experiencing rapid and unpredictable loss of kidney function.[3-5] In some cases, estimated glomerular filtration rate (eGFR) may actually improve.[6] This uncertainty may serve as a barrier to timely discussions about prognosis and treatment options.[7] In a survey of almost 600 patients with Stage 4 to 5 CKD, more than 90% reported having had no discussion about prognosis with a doctor.[8]

Validated risk prediction tools are available to help nephrology providers predict which patients will progress to ESRD or estimate prognosis on dialysis.[9,10] Risk prediction models can be used to guide discussions about treatment options, initiate planning for renal replacement therapy, or refer for palliative care. In a Canadian study, Tangri and colleagues[11] developed ($n = 3449$) and externally validated ($n = 4942$) a predictive model for progression of CKD to kidney failure using routinely obtained laboratory tests including age, gender, eGFR, albuminuria, serum calcium, serum phosphate, serum bicarbonate, and serum albumin (C statistic 0.841, 95% confidence interval [CI] 0.825-0.857 in the validation cohort). The kidney failure risk equation provides the 2- and 5-year probability of kidney failure for patients with CKD Stage 3 to 5. Different risk thresholds can be used to guide clinical decision-making rather than using eGFR alone, which may prevent unnecessary referrals and/or procedures in patients least likely to benefit.[12] For example, providers could use a risk threshold of greater than 20% over 2 years for dialysis planning,[10] which is consistent with current guidelines.[1] This risk equation has recently been validated in 31 multinational cohorts including more than 700,000 individuals,[13] but, further studies are needed to test the utility in clinical practice. An online calculator and smart phone application are available at https://qxmd.com/calculate/kidney-failure-risk-equation-8-variable.

In certain patients with kidney failure, dialysis may not offer a survival or quality of life advantage over conservative care.[14,15] In a study of 3702 nursing home residents initiating treatment with dialysis, 58% of the sample died within the first year. Moreover, the initiation of dialysis was associated with a sharp and sustained decline in functional status even when adjusting for patient demographics and predialysis functional status trajectory.[16] Murtagh and colleagues compared the survival of patients aged older than 75 years treated with dialysis ($n = 52$) vs conservative care

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($n = 77$). Although the cumulative survival was lower in the conservative group compared with the dialysis group at 1 and 2 years ($P < .001$), the survival advantage was lost in patients with high comorbidity, especially those with ischemic heart disease.[17] In addition, both the presence and degree of frailty have been independently associated with mortality.[18-20]

Tools are available to help nephrology care providers identify patients who may have a poor prognosis on dialysis and may benefit from early palliative care interventions. Use of the "surprise" question, "Would I be surprised if this patient died in the next year?" has been shown to be a strong predictor of early mortality.[21] Moss and colleagues performed a prospective cohort study of 147 dialysis patients classified into "yes" and "no" groups based on the "surprise" question response. The odds of dying within 12 months for the patients in the "no" group were 3.5 times higher than for patients in the "yes" group (odds ratio 3.5, 95% CI 1.4-9.1, $P = .01$). An integrated 6-month prognostic tool has also been developed, which includes the "surprise" question, age, serum albumin, dementia, and peripheral vascular disease.[22] This tool has good accuracy in identifying patients with increased risk of short-term mortality (area under the curve 0.80, 95% CI 0.73-0.88 in the validation cohort) and is available online at https://qxmd.com/calculate/6-month-mortality-on-hd. In addition, 2 new risk scores have recently been published to predict early mortality in incident elderly dialysis patients.[23,24] A subjective frailty scale is also available for use in clinical practice, which grades frailty on a scale from 1 to 7 (1, very fit; 2, well without active disease; 3, well with treated comorbid disease; 4, apparently vulnerable; 5, mildly frail; 6, moderately frail; and 7, severely frail).[25] These tools can help nephrology providers identify patients who may do poorly on dialysis and support informed discussions of renal replacement therapy options.

CLINICAL SUMMARY

- Patients progressing from advanced kidney disease to kidney failure are often unprepared for this transition.
- Validated risk prediction tools can help nephrology providers identify patients in need of kidney transitions support.
- Although structured lesson plans are available for predialysis education, programs should be individualized and tailored to patients' readiness to change. In addition, few have been formally tested, which represents an opportunity for further research endeavors.
- Kidney failure–specific decision aids are available to facilitate shared decision-making along with guided discussion by nephrology providers.
- Comprehensive care for patients experiencing kidney transitions must also include psychosocial support and navigation assistance.

PREDIALYSIS EDUCATION

There is increasing recognition of the benefits of predialysis education on patient outcomes. Predialysis education has been shown to prolong the time to dialysis by a median of 3 to 6 months[26,27] and extend survival in CKD patients by approximately 2 years.[28] Patients who receive predialysis education are more likely to receive pre-ESRD nephrology care (76% of participants in the Kidney Early Evaluation Program compared with 69% of matched nonparticipants, $P < .01$),[29] choose self-care modalities (82% of patients randomized to a patient-centered educational intervention vs 50% in the standard care group, $P = .015$),[30] and remain employed after starting dialysis (47% of blue-collar workers who received a predialysis educational intervention vs 24% of blue-collar worker controls, $P < .05$).[31] They are also less likely to have an urgent start (13% of patients exposed to a multidisciplinary clinic-based education program vs 35% unexposed, $P < .05$) and spend half as many days in the hospital during the first month of dialysis.[32]

The Medicare Improvement for Patients and Providers Act of 2008 established coverage for 6 kidney disease educational sessions for all Stage 4 Medicare beneficiaries.[33] The law includes provisions on the content of the sessions, allowable teachers, and required evaluation measures. Under Medicare Improvement for Patients and Providers Act, education services must provide comprehensive education regarding management of comorbidities, prevention of uremic complications, and options for renal replacement therapy including dialysis access options. Several organizations offer lesson plans that follow these guidelines, including the National Kidney Disease Education Program Lesson Builder (http://nkdep.nih.gov/identify-manage/education/lesson-builder.shtml) and Medical Education Institute's tool kit "How to Have a Good Future with Kidney Disease" (http://lifeoptions.org/goodfuture), which can be used by institutions to structure their own kidney education sessions.

Despite these available resources, uptake has been poor,[34] and predialysis education remains suboptimal.[35] This suggests that comprehensive CKD education requires more than just the imparting of medical information and facts. A more patient-centered approach is needed that focuses on individual patient needs and readiness to change. The Transtheoretical or Stages of Change Model can be used to determine the psychological readiness of patients to accept education or engage in treatment decisions.[36] This model includes 5 stages: precontemplation, contemplation, preparation, action, and maintenance. A recent survey-based study of 55 patients with CKD found that patients' behavioral stage of change was associated with dialysis decision-making (odds ratio 5.8, 95% CI 1.0-32.6, $P = .05$).[37] Depending on what stage patients are in, additional techniques such as motivational interviewing can be used to guide behavioral changes.[38-40] In a predialysis educational program, the use of motivational interviewing using the stages of change model improved patient self-reported adherence, depression and anxiety levels, and health-related quality of life.[41]

DECISION SUPPORT

Patients with advanced kidney disease approaching kidney failure face complex treatment decisions regarding the type