HEALTH POLICY

Older Adults and Chronic Kidney Disease Decision Making by Primary Care Physicians: A Scholarly Review and Research Agenda

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BACKGROUND: Chronic kidney disease (CKD) is a growing public health concern that overwhelmingly affects older adults. National guidelines have called for earlier referral of CKD patients, but it is unclear how these should apply to older adults.

OBJECTIVE: This scholarly review aims to explore the current literature about upstream referral decisions for CKD within the context of decisions about initiation of dialysis and general referral decisions. The authors propose a model for understanding the referral process and discuss future directions for research to guide decision making for older patients with CKD.

RESULTS: While age has been shown to be influential in decisions to refer patients for dialysis and other medical therapies, the role of other patient factors such as competing medical co-morbidities, functional loss, or cognitive impairment in the decision making of physicians has been less well elucidated, particularly for CKD.

CONCLUSIONS: More information is needed on the decision-making behavior of physicians for upstream referral decisions like those being advocated for CKD. Exploring the role of geriatric factors like cognitive and functional status may help facilitate more appropriate use of resources and improve patient outcomes.

KEY WORDS: chronic kidney disease; decision making; older adults.
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BACKGROUND

Chronic kidney disease (CKD), defined as the progressive loss of kidney function (glomerular filtration rate, GFR, <60 ml/min per 1.73 m^2 for greater than 3 months with or without kidney damage), will be increasingly important as the population ages. A majority of people over the age of 65 are currently estimated to have some degree of impaired renal function, and the prevalence of moderate to severe CKD (GFR<30) is 11%–38%.[1–4] Older persons are at increased susceptibility for developing chronic kidney disease because of both age-associated physiologic changes in kidney structure and function and higher incidences of hypertension and diabetes mellitus in this population. Because many persons with CKD may progress to end-stage renal disease (ESRD) requiring renal replacement therapy, it is not surprising that over half of the dialysis population is over age 65 and the cohort of persons age 75–84 is the fastest growing segment of the dialysis population.[1–3,5] In addition, decreased kidney function is associated with many other conditions including cardiovascular disease, anemia, bone disease, metabolic disturbances, and nutritional abnormalities.[6]

The high mortality and morbidity rate for persons requiring dialysis has prompted a new focus on prevention or slowing of renal failure by identifying and referring patients with CKD (pre-ESRD) to nephrologists well in advance of their needing dialysis. Early referral to nephrology results in improved survival for patients who ultimately start dialysis.[7–10] Expert panels have created practice guidelines that recommend earlier referral to a nephrologist and a focus on managing associated co-morbidities such as anemia, malnutrition, and heart disease.[6,11,12] These guidelines are intended to assist primary care physicians (PCPs) in making decisions for patients with CKD but do not account for the complexities of older adults including the effect of competing medical co-morbidities or the unpredictable rate of progression of renal disease to ESRD for an individual older adult. Because PCPs generally act as the decision-makers for initial patient access to specialty care, when and how these physicians make decisions about referrals has implications for health care service utilization, costs, clinical outcomes, and patient quality of life.

The contribution of the aging population to the increasing prevalence of CKD should not be underestimated. Understanding the referral decision process is important for PCPs and nephrologists alike in developing a rational and consistent means of determining when referrals for older persons with CKD are appropriate, particularly in the face of manpower shortages and limited resources.[13]

This paper will review the literature on referral decisions, specifically for early referral of moderate to severe CKD and late referral of ESRD, to identify important variables associated with the decision to refer and the implications of these studies for management of older persons. We will present a conceptual

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model describing the referral decision facing PCPs for older patients with CKD. Finally, we will outline a proposed research agenda for better understanding and, ultimately, improving the referral process and patient outcomes.

LITERATURE REVIEW

A literature search was performed using OVID search engine with Medline and PsychInfo databases for the years 1996–2007. The following search terms were used to identify appropriate articles: decision making, physician's role, physician's practice patterns, physicians, referral and consultation, kidney failure, chronic kidney diseases, and end-stage renal disease. Search terms were exploded and combined. A total of 142 articles were identified initially. Articles were further selected using the following criteria: (1) English language, (2) inclusion of adult patients as subjects or hypothetical cases, and (3) analysis of physician decision making either for initiation of dialysis or referral for specialty care. The citations of the articles identified were also reviewed and considered for inclusion using the same criteria. Abstracts and review articles were excluded. A total of 30 articles about referral for CKD or dialysis and general referral decisions were included in this review.

Referral Decisions for CKD

Despite the increasing awareness of the consequences of CKD and the call for earlier referral of CKD patients to nephrologists for specialty care, there is limited information available on how PCPs decide whether or not to refer their patients with moderate to severe CKD (GFR<30) who do not urgently need dialysis. There are 2 studies that evaluate the referral of patients with moderate to severe CKD. The first study by Boulware and colleagues used hypothetical clinical vignettes to assess primary care physician evaluation of the severity of CKD, recommendations for referral, and awareness of current guideline recommendations.[14] The participants were randomly selected from a nationally representative sample of PCPs (family medicine and internal medicine physicians) and nephrologists. Compared to the nephrologists, both PCP groups were worse at identifying patients with stage 3 (GFR 30 to 59 ml/min per 1.73 m^2) or stage 4 (GFR, 15 to 29 ml/min per 1.73 m^2) CKD. PCPs were less likely to recommend referral for the patient scenarios and requested input from the referring nephrologist at a less frequent rate than what nephrologists recommended. PCPs were less likely than nephrologists to be aware of existing practice guidelines, and awareness of the guidelines did increase the likelihood of referral by the PCP. These results are consistent with previous studies showing that physicians rarely use National Kidney Foundation guidelines in management of their patients.[15,16] Neither patient race nor the presence of diabetes as a co-morbid condition was significantly associated with either physician identification of the severity of CKD or the recommendation for referral.

The second study looking at CKD referral is by Montgomery and colleagues[17] from Ireland. This study also used hypothetical clinical scenarios to evaluate referral behavior of general practitioners. The study demonstrates that fewer than half of the patients were referred after the first encounter, whereas nearly all patients were referred as the renal function worsened and the patients became symptomatic. Patient age (40 versus 70) and presence of co-morbidity (rheumatoid arthritis or not) were not associated with the decision to refer the patient. As the scenarios increased in complexity, the likelihood of referral decreased. Physician characteristics including age, gender, specialty training, or location of practice was not associated with referral rates.

There are several limitations of the studies looking at referral for CKD. Both studies use creatinine rather than GFR to define renal disease. As current practice guidelines are based on GFR, this might lead to inaccurate assessments of the severity of renal disease. Both studies also used case scenarios to elicit referral behavior that may not reflect actual practice and may be subject to bias in reported behaviors. Another limitation of the Boulware et. al. study is the low response rate (28% for PCPs and 39% for nephrologists) that raises concerns about response bias.

One implication for older adults with CKD taken from these studies is that the complex chronic co-morbid conditions that many older patients experience may not be reflected in these studies, thereby, limiting the ability to extrapolate these findings to patients in clinical practice. Also, neither study included descriptions of cognitive nor functional status for the patient scenarios of that are conditions associated with age and are thought to be influential in decisions about the initiation of dialysis.[18–23]

Referral Decisions for Dialysis Initiation

Other studies in the nephrology literature have focused predominantly on the referral decision of patients with advanced CKD or ESRD (GFR<15) at the time of possible initiation or withholding of dialysis treatment (Table 1). In these studies, medical factors including creatinine, GFR, medical co-morbidities, life expectancy, and patient symptoms have been found to be associated with decisions to initiate dialysis.[18,24–26] Studies using case vignettes have identified physician-specific differences, such as experience with renal patients, geographic distance between nephrologists and PCPs, physician country of origin, culture, and health systems as important in determining which patients might be appropriate candidates for dialysis.[17–19] Patient variables including age, functional status, socioeconomic status, and preferences have been shown to be associated with physician decisions.[22,26] In several of these studies, patient age is a factor in decisions to withhold dialysis (i.e., increasing age associated with greater likelihood to withhold dialysis).[18–27] Retrospective studies of dialysis patients have also found patient variables to be important. For example, older patients were found to be less likely to receive dialysis or renal transplant compared to younger patients, women were less likely to receive dialysis than men, and blacks were more likely to receive dialysis compared to whites but less likely to receive a transplant.[28,29] Geographic location also has been significantly associated with variation in the rates of dialysis.[29] One prospective cohort study of ESRD patients presenting to a hemodialysis center demonstrated that dialysis was offered less often to patients with social isolation, functional impairments, late referrals, and diabetes, all of which may be directly applicable to older persons.[30]

The vignette-based studies suffer from the same problems described for the referral for CKD studies: unrepresentative of actual practice, response bias, and low response rates. The retrospective nature of other studies, using large databases, limits the analysis to the variables present in the database and does not allow for interpretation of other potentially important physician or patient characteristics that might affect the outcomes.

Table 1. Referral Decisions for Initiation of Dialysis

Reference	Population	Design	Outcomes	Results
Campbell et al.[19]	Physicians identified as having referred patients to the University of Missouri Health Sciences Center from 1982–1985 (n=86)	Structured interview, referring physicians	Coded responses compared to referral status of the patient—early versus urgent	Physician factors: no identifiable characteristics differentiated early versus late referrals Patient factors: patient understanding, insurance status, fear of dialysis, access to treatment center, desire to stay with local MD
Mendelssohn et al.[18]	General and family medicine (FP) physicians (n=489) and internal medicine (IM) physicians (n=239) in Ontario	Mailed survey	Pre-dialysis referral threshold; dialysis (non) referral decisions; dialysis rationing	Patient factors: increasing age, increasing number of co-morbidities
Parry et al.[20]	General and elderly care physicians (n = 138) and nephrologists (n=18) in England and Channel Islands	Mailed survey; brief case histories of older patients	Dialysis referral rates; dialysis acceptance rates	Patient factors: patient/family preferences, absence of liver metastases or dementia, age less than 80
McKenzie et al.[24]	Nephrologists in Canada (n=116), US (n=273), and UK (n=144)	Mailed survey; 5 clinical cases, seriously ill ESRD patients	Decision to initiate dialysis resource scarcity	Physician factors: country of practice Patient factors: patient/family preferences, perceived quality of life, mental illness System factors: cost of dialysis
Sekkarie et al.[21]	Nephrologists (n=22) and PCPs (n=76) in West Virginia	Prospective MD survey for every patient in whom a withhold/ withdraw decision was made	Decision to withdraw dialysis Decision to withhold dialysis	Patient factors: older age, poor prognosis, patient/family refusal, dementia
Sekkarie et al.[25]	Canadian (n=263) and US (n=176) PCPs; Canadian (n=166) and US (n=93) nephrologists	Mailed survey using brief descriptions of 10 potential patients with ESRD	Referral for dialysis Reasons for withholding	Patient factors: older age, patient/family refusal, end-stage organ disease, frail condition, dementia, terminal cancer
Wilson et al.[26]	Family physicians in New York State (n=889), Ontario (n=612), and the south of England (n=643)	Mailed survey; vignette-based case of age 55 woman with severe renal disease varying co-morbidities and SES	Referral rate for dialysis	Physician factors: no gender differences, in practice longer Patient factors: level of renal disease, older age, mental illness, ambulatory disability, cancer
Joly et al.[30]	Consecutive patients aged 80 or more with creatinine clearance<10 ml/min per 1.73 m^2 at university based hospital hemodialysis unit in France (n=146)	Prospective cohort	Offering of dialysis mortality	Patient factors: gender, social isolation, functional impairment, late referral, diabetic 1-year mortality predictors: nutritional status, late referral, functional status
Clement et al.[22]	Nephrologists in the Loire-Atlantique, Vendee, Iles et Vilaines, and Maine et Loire regions of France (n=17)	In-person interview using a semi-directive questionnaire	Decision to discontinue dialysis or withhold dialysis	Patient factors: patient refusal, quality of life, autonomy, suffering, cognitive disorder, prognosis
Montgomery et al.[17]	Members of the Irish College of General Practitioners in urban and rural settings (n=79)	Two-part interview using case scenarios with moderate/ severe kidney disease defined by creatinine	Referral rates for specialty care	Physician factors: increased training experience with renal patients Patient factors: no age difference, no difference in severity of renal disease
Lambie et al.[27]	Nephrologist medical director of hemodialysis units in France, Germany, Italy, Spain, UK and USA (n=242)	Survey questionnaire	Comparison: nephrologist opinion about dialysis initiation vs patient data from dialysis units	Physician factors: opinion about patient age, country of practice

Referral Decisions for Nonnephrology Specialty Care

The literature on primary care referrals for specialty care has focused on nonmedical factors, including patient factors, physician factors, and health care system factors, in an effort to explain variations in practice important because of the high economic costs associated with referrals (Table 2).[31–34] Some of these studies may have significance for understanding upstream referral decisions for CKD patients, especially given the diminished influence of medical factors like symptoms because of their general absence until the need for dialysis is imminent. Examples of physician-specific factors include knowledge and acceptance of proposed practice guidelines, perception of

Table 2. Referral Decisions for Nonnephrology Specialty Care

Reference	Population	Design	Outcomes	Results
Mort et al.[62]	Primary care physicians (*n*=1,182)	Telephone survey using 8 clinical vignettes	Evaluation of the role of insurance status in physician clinical recommendations	Physician factors: no differences in medical specialty Patient factors: presence of health insurance associated with more discretionary referrals
Langley et al.[41]	Family practice physicians in Nova Scotia (*n*=125 physicians)	In-person interview using 5 hypothetical cases	Evaluation of geographic differences in referral decisions	Physician factors: relationship to specialist, experience Patient factors: patient/family request, medicolegal issues System factors: access to hospital/ specialist, local style of practice
Ryynanen et al.[63]	Medical physicians in Finland (*n*=837)	Mailed self-administered questionnaire using vignettes	Decision to refer patient in vignette for elective surgical intervention, treat conservatively, or another alternative	Patient factors: age, multiple medical conditions, institutionalization, unhealthy lifestyle
Donahoe et al.[36]	Generalist attendings at academic sites in California (*n*=21)	Self administered post-referral questionnaire	Physician rating of the timeliness, complexity, and appropriateness of the referral	Physician factors: desire for diagnostic procedure, meet perceived standards of care Patient factors: patient request, patient self-education, reassurance, motivation System factors: insufficient time with patients
Watson et al.[35]	General practitioners identified as consecutive referrers to the Oxford Regional Genetics Service (*n*=50)	Self-administered post-referral questionnaire	Appropriateness of referral based on national guidelines	Physician factors: only 50% of respondents received referral guidelines, less than half of referrals met guideline criteria Patient factors: patient inquiry
Forrest et al.[48]	Family physicians in 80 office based practices across USA (*n*=136 physicians)	Self-administered post-referral questionnaire	Reasons for referral, expectations of referral	Physician factors: training, personal knowledge of specialist, quality of prior feedback, technical capability of specialist, availability Patient factors: preferences System factors: proximity to specialist
Starfield et al.[50]	Family physicians in 87 practices in 31 US states (*n*=2,535 patient visits)	Self-administered post-referral questionnaire	Rates of referral, reasons for referral	Physician factors: advice for treatment or diagnosis, direct management of condition Patient factors: no difference based on severity of medical condition
Ashworth et al.[37]	General practitioners in an inner city locality group (*n*=22)	Log diary of every surgery-based referral for 1 working week	Ranking of mental health consultation in terms of 'psychological content'	Physician factors: age, medical training
Clemence and Seamark[47]	General practitioners (*n*=6), physiotherapists (*n*=6), and patients (*n*=6) in the UK	In-depth in-person interview	Qualitative analysis using grounded theory to identify conceptual themes around referral to physiotherapist	Physician factors: perceived psychological benefit to patient, relief of stress without likely benefit to patient, variable level of communication with therapist, past experience
Kinchen et al.[43]	US primary care physicians (*n*=623)	Mailed self-administered questionnaire using clinical case vignettes	Decision about referral to which of 5 physician descriptions	Physician factors: foreign medical graduates received less referrals
Kinchen et al.[42]	Primary care physicians (*n*=740)	Mailed self-administered questionnaire	Rating of 17 items thought to be of importance to referral decision	Physician factors: race, gender, previous experience with specialist, specialist board certification Patient factors: convenience, insurance coverage
Ruston[49]	General practitioners in UK (*n*=85)	Semi-structured interviews	Factors which influence decision to refer Influence of patient and practice characteristics	Physician factors: subjective probability risk assessment, fear of litigation, past experience, clinical uncertainty
Sigel and Leiper[38]	General practitioners in UK (*n*=10)	In-person interview	Grounded theory analysis to model ways physicians explored psychological problems in context of patients' health problems	Physician factors: reached limits of capabilities, professional interactions with therapists Patient factors: preferences, insight, readiness to engage
Iverson et al.[45]	Family physicians DO (*n*=B450) and MD (*n*=419) in the USA	Mailed self-administered questionnaire	Physician and practice characteristics effects on referral rates	Physician factors: medical training (MD versus DO), size of town where practice located

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Table 2. (continued)

Reference	Population	Design	Outcomes	Results
O'Neill et al.[44]	National sample of non-federal office and hospital based physicians (n=12,528)	Telephone survey using clinical vignettes	Physician recommendation of test, treatment, or evaluation	Physician factors: board certification, foreign medical school graduate, age, years in practice
Forrest et al.[39]	PCPs in 30 US states (n=142)	Survey following referral	Occurrence of specialty referral	Physician factors: residency training, practice size, disclosure of uncertainty, gate-keeper arrangements, high levels of managed care Patient factors: age, gender, presenting problem, high burden of co-morbidities, insurance status
McKinlay et al.[46]	Internists and family medicine physicians in New England (n=128)	In-person interview using video-taped clinical vignettes	Most likely diagnosis Physician level of certainty Number of tests likely to be ordered	Physician factors: specialty, age, race Patient factors: no influence

psychological content of referral, relationship with specialists, and tolerance of uncertainty.[23,35–41] Physician demographic factors have been also found to be associated with referral decisions such as years of experience, foreign medical school graduate status, board certification, gender, and medical specialty training.[42–48] Patient traits such as litigiousness or neuroticism, preferences, convenience, and trust in their provider have been also evaluated and found to influence referral decisions.[36,49,50] System factors influential in the decision making of physicians include practice size, presence of managed care, and geographic location of practice.[31,39,41,48] Other examples of studies dating from 1980–2000 that investigate the role of nonmedical factors in referral decisions can be found in an annotated bibliography by Flynn et. al.[51]

While previous studies provide information about associated physician and patient factors that may be involved in referral decisions, the empirical evidence on how these factors affect decisions for older patients is limited. In particular, factors such as cognitive status, functional status (especially effects on instrumental activities of daily living or activities of daily living), patient preferences, and quality of life that are extremely important for older patients have not been addressed adequately and will likely impact the upstream decisions of referral to the specialist. We also still do not know how PCPs approach the decision to refer CKD patients based on age, the trajectory of progression of renal disease, or competing medical co-morbidities.

MODEL FOR CKD REFERRAL DECISIONS

Based on the literature, our clinical experience, and discussions with colleagues, we have developed a conceptual model of CKD referral decisions for older adults experienced by the PCP (Fig. 1). This model is similar to previous descriptions of decision models developed from illness script theory.[52] Illness script theory developed as a means of understanding the complexity of physician diagnosis and management of patient illnesses. In illness script theory, there are 2 main domains: (1) enabling conditions that include medical and nonmedical patient factors that influence the probability of disease and (2) consequences that include signs and symptoms of the illness thought to influence the diagnosis of disease. In modeling referral behavior, van Schaik et al.[53] added physician characteristics as another important contributor to the decision outcome. Our model similarly describes patient characteristics, including enabling conditions and consequences, and physician characteristics that interact to influence a referral decision.

We make some simplifying assumptions in this model: (1) The patient is asymptomatic from the condition of concern, as is generally the case in moderate to severe CKD, (2) the patient has no strong preferences with regard to the decision to refer them to a nephrologist (i.e., they will follow the PCPs recommendation), and (3) the physician's sole motivation is the best care for the patient.

The conceptual model presented in this study (Fig. 1) identifies the referral decision faced by the PCP for an individual patient encounter. At this encounter, the PCP can decide to either make a referral of the CKD patient to the nephrologist or to continue to follow the patient in clinic. If the physician chooses to refer the patient, then the decision allows for exit from the model. If the physician chooses to follow the patient then 1 of 3 clinical scenarios may occur, the CKD may improve, stabilize or worsen. Any of these scenarios may be readdressed at the next clinical encounter; therefore, the referral decision may be a recurrent decision, and the decision tree is not different between early and late referral, although the variables associated with that decision may differ or be weighted differently. Also, it may be that the referral decision is a "silent decision," meaning the physician decides without the input of the patient, which may occur if the physician feels that the harm from the explanation to the patient outweighs any clinical benefit at that particular encounter.[54]

The patient characteristics that are thought to influence the physician's referral decision include not only enabling and consequence factors as described in the illness script theory but also demographic factors previously shown to influence either general referral decisions or decisions about dialysis initiation, 'geriatric-appropriate' factors like cognitive and functional status, and patient preferences. For example, a patient with moderate–severe dementia who requires assistance with all instrumental activities of daily living and 2 activities of daily living might be less likely to be referred than a person of the same age who lives independently. While we acknowledge that the patient's preferences are important, it is more likely that the decision to refer the patient to a nephrologist will be made by the physician after taking into account patient factors (including preferences),

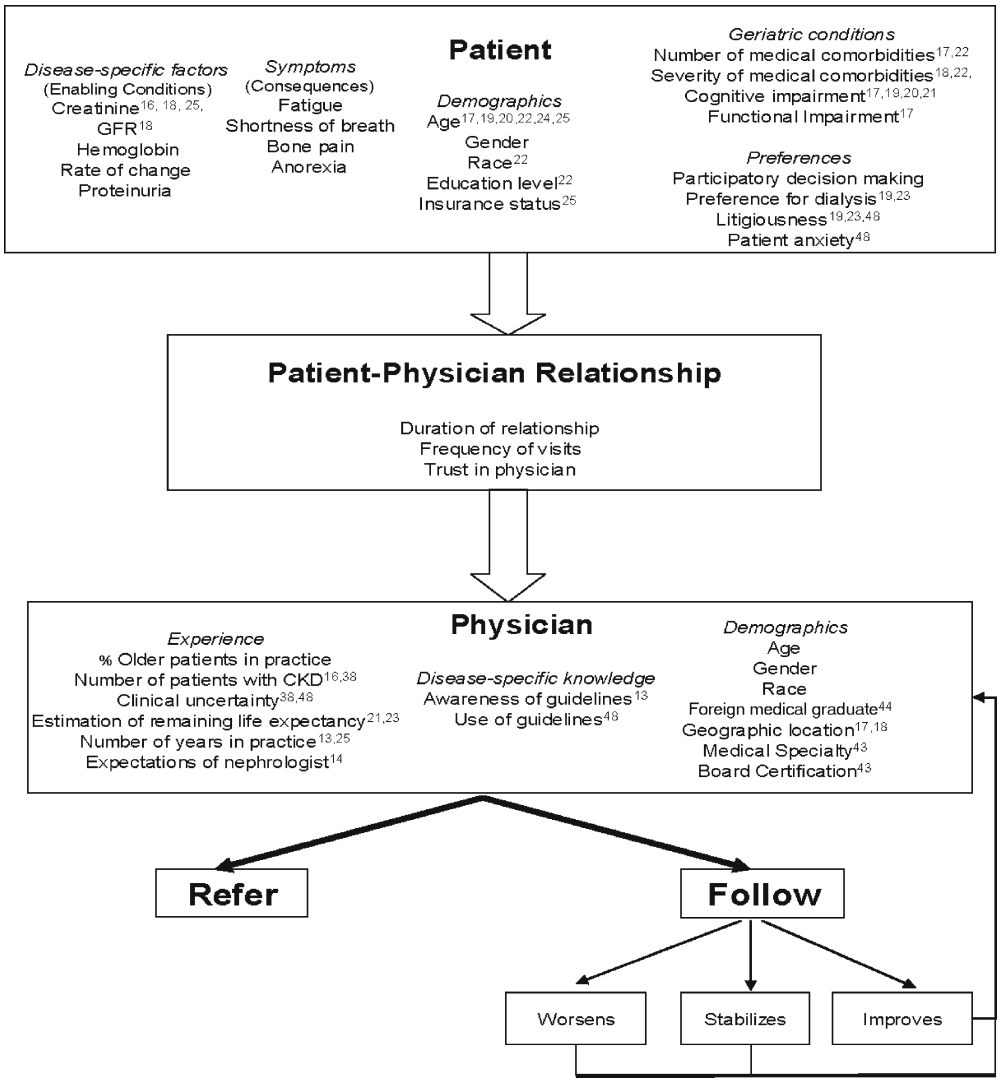

Figure 1. Conceptual model of referral decision making for chronic kidney disease. *Arrows* represent hypothetical direction of influence. References are for factors previously evaluated in either general referral decisions or in decisions about initiation of dialysis.

especially given that patients often do not know their renal function and are less likely to have well-formed preferences regarding treatment issues upstream from dialysis.[55,56] We also have included physician-specific factors that also might influence referral decisions including experience, demographics, and disease-specific knowledge previously thought to play a role in physician decision making, as well as physician management of clinical uncertainty and expectations of specialists. Finally, the effect of patient variables on physicians may be modified or mediated by the relationship between the patient and the physician. Most of these factors have yet to be explored for CKD, including the duration of the patient–physician relationship, the patient's level of trust in the referring physician, and health behaviors.

Because of the nature of CKD in which physicians have significantly more information about the stage and consequence of the disease than patients (especially given the lack of public awareness about renal disease and lack of symptoms until very advanced disease), other better known models of decision making are less applicable.[3] For example, the health belief model is patient-centered and focuses on patient-perceived health and preventive behaviors, whereas the transtheoretical model of change generally focuses on patient behavior changes.[57,58] Neither model applies to CKD referral choices by PCPs. Despite the emphasis on shared decision making in the broader literature on the patient–physician encounter, fewer than 10% of therapeutic decisions are arrived at with clear inclusion of patients, and in most cases, patients behave passively.[59,60] Little is known about shared decision making in the referral decision, although 1 study indicates that there is increased participatory decision-making for patients when referrals are made; however, the level of this participation has not been quantified.[61]

PROPOSED RESEARCH AGENDA ON CKD REFERRAL DECISIONS

Further studies are needed to understand how physicians make referral decisions for patients with CKD. As illustrated in the Fig. 1, there are several areas of focus that could lead to improved understanding of this referral decision process and

allow for the development of programs to ensure that patients are appropriately evaluated for CKD and referred for specialty care.

Physician decision making is critical to understanding which patients are referred for specialty care and when this referral should occur especially in a condition like CKD where the patient is frequently unaware of the disease. Potential research questions to address this are

What role do medical co-morbidities, cognitive status, and functional status have in the referral decision for older patients with CKD?
How do medical co-morbidities, cognitive status, and functional status relate to other factors known to influence decisions about initiation of dialysis?
What role does clinical uncertainty play in PCP decisions to refer CKD patients for specialty care? Does increased clinical uncertainty raise the threshold for referral?
Do PCP expectations of nephrologist management plans affect referral decisions?
How does the patient–physician relationship affect referral decisions?

The authors recognize that these referral decisions do not take place in a vacuum. The processes and systems in which the PCP and patient encounters take place are also important for understanding referral decisions. The role of patients' perceptions and emotional reaction to a diagnosis and anticipated treatment may also affect the physician's decision making, as well as the patient's follow through of recommendations. Finally, the communication between physician, specialist, and patient are critical to facilitating informed decisions and reducing unrealistic expectations.

A specific focus on the increasingly geriatric population may provide greater insight into the factors upon which physicians base their decisions and how these factors are weighted in different clinical scenarios. Future work may lead to the identification of target areas such as information distribution and physician prognostication, which could be improved through system-level changes and/or educational tools. With the impending deluge of older patients with CKD, the appropriateness of PCP referrals is of growing importance.

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