ckj

OXFORD

Leading European Nephrology

Clinical Kidney Journal, 2015, vol. 8, no. 6, 766–771

doi: 10.1093/ckj/sfv079
Advance Access Publication Date: 3 September 2015
Original Article

ORIGINAL ARTICLE

Barriers to effective communication between veterans with chronic kidney disease and their healthcare providers

Swati Lederer[1,2,3], Michael J. Fischer[1,2,3], Howard S. Gordon[1,2,3], Anuradha Wadhwa[4], Subhash Popli[4], and Elisa J. Gordon[1,2,5]

[1]Center of Innovation for Complex Chronic Healthcare, Jesse Brown VAMC, Chicago, IL, USA, [2]Edward Hines Jr. VA Hospital, Hines, IL, USA, [3]Department of Medicine, University of Illinois at Chicago College of Medicine, Chicago, IL, USA, [4]Department of Medicine, Edward Hines Jr. VA Hospital, Loyola University Medical Center, Maywood, IL, USA, and [5]Center for Healthcare Studies and Comprehensive Transplant Center, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

Correspondence to. Elisa J. Gordon; E-mail e-gordon@northwestern.edu

Abstract

Background: Many patients with chronic kidney disease (CKD) have insufficient knowledge about CKD, which is associated with poorer health outcomes. Effective patient–provider communication can improve CKD patients' knowledge, thereby augmenting their participation in self-care practices. However, barriers to addressing CKD patients' information needs have not been previously characterized.

Methods: Adults with an estimated glomerular filtration rate (eGFR) of <60 mL/min/1.73 m^2 or on chronic dialysis or with a kidney transplant were recruited from a Department of Veterans Affairs (VA) nephrology clinic. Semi-structured telephone interviews were conducted to assess patients' CKD information needs and demographic characteristics. A qualitative approach was used to analyze interview transcripts and identify themes pertaining to communication dynamics.

Results: Thirty-two patients participated. The mean age of participants was 63 years; most were male (94%) and non-Hispanic white (53%). CKD severity groups represented included CKD-3 (eGFR 30–59 mL/min/1.73 m^2; 34%), CKD-4 (eGFR 15–29 mL/min/1.73 m^2; 25%), CKD-5 (eGFR <15 mL/min/1.73 m^2; 16%), end-stage kidney disease on dialysis (13%) and kidney transplant recipients (12%). Several key themes emerged about barriers to patient–provider communication based on patients' reported care at both VA and non-VA facilities, including patients perceived their role as a 'listener', reported limited CKD knowledge, did not understand physicians' explanations and were dissatisfied with the patient–provider relationship.

Conclusions: Several barriers to patient–provider communication prevent patients from meeting their information needs and perpetuate patient passivity. Future research should evaluate whether interventions that empower CKD patients to actively participate in their care increase knowledge and improve health outcomes.

Key words: barriers, chronic kidney disease, communications

Received: April 21, 2015. **Accepted:** August 3, 2015

Clinical Kidney Journal
ckj

Introduction

Effective patient–provider communication is of particular importance for chronic kidney disease (CKD) patients, as they require a wealth of knowledge to manage their comorbid health conditions, follow complicated medication regimens and participate in essential self-care practices (i.e. home blood pressure monitoring, weight loss and dietary changes) [1, 2]. Poor communication can result in inadequate CKD knowledge, insufficient preparation for dialysis and kidney transplantation, poorer self-care adherence and worse health outcomes [1, 3–8].

CKD patients desire more information about the disease process, self-care techniques, treatment options and psychosocial implications of end-stage kidney disease (ESKD), suggesting the need for improved patient–provider communication [1, 9]. Interventions designed to help healthcare providers to better educate patients about their CKD have been shown to increase patients' knowledge and stimulate discussion with physicians [10–14]. However, educational interventions that focus solely on provider-driven communication position patients to passively receive education. Such an approach is limited because effective communication is preferably bidirectional.

Active patient communication behavior (e.g. asking questions) is important because it can influence physicians to provide information (e.g. give explanations) [15–18]. Interventions that promote patients' question-asking have shown promise for improving health communication outcomes [19–21]. Asking questions is an important component of patient activation, which entails developing the knowledge, skills and confidence to engage in self-care management [22]. Studies in other chronically ill populations show that patients who actively seek health information and participate in disease management have better treatment adherence, greater satisfaction with care and improved health outcomes than their less active counterparts [22–25]. Barriers to patient activation include specific sociodemographic and clinical characteristics (e.g. male gender, inadequate knowledge, low health literacy and depression) [26, 27].

Identifying and developing interventions to overcome these barriers may be particularly effective in the CKD population because asking questions that address specific information needs could foster patient engagement in self-care practices and facilitate discussions regarding early planning for dialysis and kidney transplantation. Our study aimed to identify barriers to meeting information needs as reported by CKD patients. We conducted a qualitative study to assess barriers that contributed to CKD patients' unmet information needs during their visits with CKD providers.

Materials and methods

Participants and setting

Eligible participants were adults ≥18 years of age with advanced CKD [estimated glomerular filtration rate (eGFR) <60 mL/min/1.73 m^2], receiving chronic dialysis or with a kidney transplant. The modification of diet in renal disease equation was used to classify CKD according to conventional eGFR-based severity groups [28, 29]. All participants had visited the outpatient nephrology clinic at one Veteran Affairs (VA) facility within 3 months of study recruitment. Patients were excluded if they were cognitively impaired, unaware of their CKD diagnosis or participating in another VA study. We stratified the eligible population based on CKD staging, sex and race/ethnicity in order to oversample for racial/ethnic minorities and women, allowing for a more generalizable cohort.

Recruitment

Eligible participants were mailed an information sheet describing the study and then received a telephone call 1 week later to screen for cognitive impairment (six item screener) [30] and for awareness of their CKD diagnosis by asking, 'Do you remember going to a kidney doctor (or your renal doctor, or nephrologist)?' and 'What has your kidney/renal doctor (nephrologist) told you about your kidney disease/function? How well are your kidneys doing?' The institutional review board approved the study. All participants provided verbal informed consent.

Semi-structured interview

We sought to understand CKD patients' information needs and questions they had about CKD. We used an ethnographic approach to interviews to generate a rich description of their beliefs, values, patient–provider interactions and the impact of social contexts on their CKD experiences [31]. Semi-structured interviews were conducted via telephone and included 17 open- and 15 closed-ended questions on patients' experiences with physicians throughout their CKD treatment. The interview guide was developed by a multidisciplinary team of investigators (e.g. two nephrologists, one social scientist and one health communication expert), contributing to the guide's content and face validity. Interviews began with open-ended questions about the patients' general information needs, followed by specific questions regarding CKD topics: diagnosis, causes, disease progression, relationship between CKD and comorbid conditions, management, prevention, self-care practices, complications, ESKD treatment options and preferences regarding the optimal time for dialysis and transplantation education. Thereafter, additional open-ended questions assessed other questions that patients had, information that they believe is important to know about CKD and questions that they would advise other CKD patients to ask doctors. Closed-ended questions assessed demographic and clinical characteristics (e.g. sex, age, race/ethnicity, marital status, education, employment, income, language preference, overall health status and length of time on dialysis or with a kidney transplant).

All interviews were conducted between August and October 2014 by a female nephrologist trained in qualitative research (S.L.) and uninvolved in participant care. Patients' responses were recorded by handwritten field notes in detail, and when possible, verbatim. Interviews lasted on average 39 min (range 19–74 min). Participants were compensated $20 for their time.

Qualitative data analysis

Qualitative data were analyzed using an inductive process of thematic analysis [32, 33]. After each interview, the interviewer and a social scientist with expertise in qualitative analysis (E.J.G.) debriefed to identify and manually code themes and patterns emergent from the data pertaining to communication dynamics. Both investigators analyzed patients' transcripts for content (what patients said) and linguistics (how they said it) [31, 34]. Thereafter, an iterative process of constant comparison involving within-case and across-case review was used to refine and reveal further themes [32]. Illustrative quotations were identified. When investigators disagreed on the identified themes, interview transcripts were rereviewed until consensus was reached. Data collection and thematic analysis occurred throughout the course of data collection until reaching saturation—the point at which no new themes emerged [31, 35, 36]. An audit trail was maintained to document evolving themes, interpretations and supporting quotations. Theme frequencies, though not necessary for thematic

analysis, were reported when possible to provide information about theme magnitude. While frequencies reflect the number of individuals who voiced statements consistent with a specific theme, reported theme frequencies should not be misinterpreted as indicators that the remaining population did not support the theme.

Statistical analysis

Means and proportions for demographics and closed-ended questions were calculated with SPSS version 22 (Chicago, IL, USA).

Results

Demographics

One hundred twenty-six patients were invited to participate. Sixty-six potential participants were reached by telephone, four of whom were ineligible as they were unaware of their CKD diagnosis. Of the remaining individuals, 10 patients did not schedule an interview, 20 patients declined and 32 participated (62% participation rate). The mean age of participants was 63 years; most were male (94%) and non-Hispanic white (50%). CKD severity groups included CKD-3 (eGFR 30–59 mL/min/1.73 m^2; 34%), CKD-4 (eGFR 15–29 mL/min/1.73 m^2; 25%), CKD-5 (eGFR <15 mL/min/1.73 m^2; 16%), ESKD on dialysis (13%) and kidney transplant recipients (12%) (Table 1).

Table 1. Demographics and clinical characteristics of study participants ($n = 32$)

Characteristic	*n* (%)
Mean age, years	63 ± 9.55
Gender	
Male	30 (94)
Female	2 (6)
Race/ethnicity	
White not Hispanic	16 (50)
African American	12 (38)
White Hispanic	4 (12)
Level of education	
High school	8 (25)
Some college	24 (75)
Employment	
Employed	3 (9)
Not working	29 (91)
Income[a]	
>30 000	17 (53)
≤30 000	12 (37)
Marital status	
Not married	17 (53)
Married	15 (47)
CKD severity	
CKD-3 (eGFR 30–59 mL/min/1.73 m^2)	11 (34)
CKD-4 (eGFR 15–29 mL/min/1.73 m^2)	8 (25)
CKD-5 (eGFR <15 mL/min/1.73 m^2)	5 (16)
ESKD on dialysis	4 (13)
Kidney transplant recipient	4 (12)
Health status	
Excellent	0 (0)
Very good	4 (12)
Good	15 (47)
Fair	6 (19)
Poor	7 (22)

[a]Not all participants responded ($n = 3$); total does not equal 100%.

Thematic analysis

Almost all patients (91%) reported desiring more information to control their CKD. As patients discussed their unmet information needs, they offered perceptions of factors contributing to these unmet needs.

Several key themes emerged about barriers to patient–provider communication, including that patients perceived their role as a 'listener', had limited CKD knowledge, did not understand physicians' explanations and were dissatisfied with the patient–provider relationship. An important pattern pervading many themes was that patients perceived their own communication as passive. Patients' responses indicated that they mainly reflected on CKD care received from primary care providers and nephrologists at both VA and non-VA facilities.

Patients' perceived role as the 'listener'

More than one-third of patients (38%) did not actively seek information but relied on their physician to provide all CKD information. Two factors contributed to an expectation of unidirectional communication: (1) patients' belief that their role during healthcare conversations is to passively listen and (2) patients' trust in physicians to provide all the necessary CKD information. The following patient comments exemplify the concept of passive listening:

> I don't usually ask my doctor about CKD. They bring it up. (CKD-4, ID#01)

> I don't ask. I just listen to them and do what they tell me. (CKD-3, ID#02)

The first quotation demonstrates the patient's reliance on physicians to initiate CKD discussions. Similarly, when asked about his information needs regarding CKD treatment options, the second patient initially reported: 'I don't know'. His subsequent statement conveys the sentiment that he should listen to providers and follow their instructions rather than ask questions.

The passive behavior of patients and their role-based beliefs limit awareness of CKD, as exemplified by the quotation below:

> I didn't even realize why I was going to a kidney doctor for a long time. It's like they tell you to do this, do that. . . I just follow my orders! (CKD-4, ID#03)

One-third of participants ($n = 10$) justified taking a passive role in healthcare conversations because they 'trusted' their doctors to relay all relevant information. The following comments highlight this concept:

> Maybe I have too much faith in doctors, but if there was something to be done or something I should know about, they'll tell me. (CKD-3, ID#04)

> No, I didn't know about these things or ask. My doctors won't sugar coat anything. . . My doctors communicate and I do what they tell me – I just live my life. (CKD-5, ID#05)

Despite having unmet CKD information needs, patients report not engaging in two-way communication. They expect their physicians to make healthcare decisions and determine what information patients need to know.

Patients' limited CKD knowledge

Patients commonly reported not fully comprehending why certain medications were prescribed, what their laboratory measures indicated or how their chronic health conditions were related to each other. Many patients (47%) reported that the lack of CKD knowledge limited their ability to formulate informed

questions. This pattern emerged most strongly when we asked patients questions about CKD complications. For example, patients did not realize that anemia and bone disease were complications of CKD and thus had not inquired into this issue. Patients with knowledge gaps perceived that asking questions is challenging, particularly when they were unaware of their own lack of knowledge. For example, one patient with a kidney transplant commented:

> It [complications] was something I didn't know to ask at the time. I never associated anemia with kidney disease. (Kidney transplant, ID#06)

The following patient was shocked to learn about the relationship between CKD and bone disease:

> I didn't know it (CKD) could cause bone disease. You're telling me now!' (CKD-5, ID#07)

Other patients expressed difficulty grasping the concept of CKD as a chronic process, as exemplified in the quotation below:

> I was blown out of the water to learn that I had CKD. I didn't realize there was a process leading up to CKD. I didn't know there was a length of time between normal kidney function and dialysis. . . (CKD-3, ID#08)

Aside from knowledge gaps, patients doubted their ability to comprehend CKD knowledge and expressed justifications for not asking questions: 'I wouldn't understand it', 'I'm not too medically inclined' or 'I'm not the doctor'.

Not understanding physicians' explanations

Patients (28%) stated that they did not understand physicians' explanations because they were 'so involved' or 'lengthy' and included 'medical mumbo-jumbo'. For example, patients explained why they did not ask questions about their routine lab test results:

> You know, I never did ask my doctor what these tests meant. The doctors always ask 'do you have any questions?' and I always said 'none that I can think of'. But really, I didn't really understand what they had been explaining to me. I've only had one doctor that spoke to me at my level; most of them speak above my level. (CKD-4, ID#09)

> I didn't have questions. The nephrologist explained it, but it was so involved that I didn't know what to ask. . . (CKD-4, ID#10)

When asked about their general CKD information needs, the following patients expressed their frustration with the terminology that their physicians used:

> My biggest concern is not questioning the care, but he [nephrologist] expects you to know what he's talking about. . . the technical terms. . . and I'm lost. (CKD-3, ID#11)

> 'You have end-stage renal disease' – I didn't even know what 'renal' was! Talk to me like I'm a 6 year old. What questions can I ask if I don't even know what you're saying? (Kidney transplant recipient, ID#12)

The four quotations above demonstrate that physicians' complicated explanations and use of medical terminology contribute to poor patient comprehension during healthcare conversations and may discourage patients' question-asking.

Dissatisfaction with the patient–provider relationship

While some (41%) patients volunteered that they were 'happy' with their patient–provider interactions, others (25%) offered specific examples of how they were frustrated by difficult communication with providers. Patients mentioned the importance of having an empathic provider who tailors communication to individual patients according to their level of understanding and information needs.

> It was laid on me as insensitively as humanly possible – 'you know you'll be on dialysis in 6 months'. This was back in L.A. I didn't even know what dialysis was. . . I didn't even know I had problems with the kidneys! It was not discussed, I was told. (Kidney transplant recipient, ID#12)

> There was no sit down talk. I don't know how they [doctors] diagnosed it [CKD] or what the tests showed. I have 3 doctors – GU, Primary, and Renal – and none of them talk to each other. (CKD-3, ID#13)

These two patients express dissatisfaction with the way in which their physicians had communicated the diagnosis of kidney disease and felt uninvolved in their healthcare discussion. Similarly, another patient offered the following guidance:

> If you see a nephrologist and they don't want to share information or explain things, then find another one. Find someone who understands you as an individual. (Kidney transplant recipient, ID#06)

In addition to desiring empathy from physicians, patients related difficulty communicating when physicians used 'scare tactics', 'talked down' to patients or 'rushed' their clinic visit. Patients suggested that poor patient–provider rapport limited the sharing of kidney disease information.

Discussion

This qualitative study identified four barriers to addressing CKD patients' information needs, including that patients perceived their role as a 'listener', had limited CKD knowledge, did not understanding physicians' explanations and were dissatisfied with the patient–provider relationship. These barriers limited patients' active communication behaviors (e.g. asking fewer questions), thereby perpetuating patient passivity and contributing to less informative medical encounters (e.g. receiving fewer answers).

Many study participants maintained the belief that the patient's role is to passively listen and follow doctors' instructions rather than to actively seek health information. This barrier between physicians and chronically ill patients conflicts with the goal of shared decision-making, a process of collaboration between patients and their doctors [37–40]. Accordingly, many patients in our sample reported they did not speak up or provide feedback, which is associated with physicians better understanding their patients' information needs and more effectively providing patient-centered care [39, 41], as well as helping patients to engage in self-care practices and participate in shared decision-making [1, 8, 10, 38, 42].

Another key finding was that patients desired more information about their CKD. However, limited CKD knowledge deterred patients from taking an active role in communicating during clinic visits. Passive patients are less likely to request and receive information from their physicians, thereby perpetuating the cycle of their inadequate CKD knowledge [15, 18, 43]. Compounding the problem of inadequate knowledge is that CKD is a difficult diagnosis to comprehend and accept, owing largely to the asymptomatic nature of the disease [1, 6]. Addressing patients' knowledge gaps can facilitate patient participation in healthcare discussions [7, 8, 22].

Patients reported that a provider's approach to delivering information can impede their participation in healthcare discussions. Adverse information delivery characteristics included

Clinical Kidney Journal
ckj

style (rushed visits, talking down), content (above my level, medical terms) and quantity (lengthy explanations). Clinicians and other CKD stakeholders agree that improving communication between CKD patients and their doctors is a research priority [39, 44, 45]. Many interventions have been designed to help physicians effectively educate patients about their kidney disease and include, for example, an educational worksheet to guide providers in discussing patient-specific CKD information, use of web-based CKD resources and a multidisciplinary approach to supplement physician education [10–14]. These provider-centered interventions have improved and standardized physicians' CKD information delivery, improved patients' CKD knowledge and enhanced the quality of healthcare discussions [10, 11, 14]. While much attention has focused on improving CKD providers' communication with patients, no interventions have been developed to directly empower patients to seek health information and to state when they do not understand what the doctor is saying.

Interventions that educate and activate patients to ask questions about their CKD, voice their concerns when they do not understand physician' explanations and address their dissatisfaction with the clinical encounter may help foster a stronger and more balanced patient–provider relationship [16]. Studies show that more activated patients are more satisfied with their physicians and more adherent to medical treatment and follow-up care plans [22, 23, 46, 47]. By asking more questions, CKD patients may guide the healthcare conversation by focusing on their specific knowledge gaps. Our future research will focus on creating a question-asking aid for CKD patients and assessing the efficacy of the intervention in promoting patients' question-asking and improving patient–provider communication.

A major strength of this in-depth qualitative study is that we identified CKD patients' information needs and barriers to overcoming them. Further, we characterized barriers to CKD patient–provider communication among a vulnerable veteran population with a high prevalence of inadequate health literacy [48, 49]. Importantly, the VA is the largest single provider of CKD care in the USA [50]. However, this study has limitations. As a single-center study of a predominantly geriatric male population in the VA, the findings may not be generalizable to all CKD patients. However, we oversampled for women, Hispanic and African American patients to allow for a cohort that is more representative of the national ESRD population. While we assessed patients' information needs, their responses may have been subject to recall bias as in any study with a cross-sectional design. Further, we did not directly assess patient–provider interactions or providers' perspectives, which may offer additional insights into provider–patient communication. We cannot verify whether participants were referring to physician or non-physician providers from our results; however, we believe patients considered physician interactions given their responses and the direction of our CKD awareness screening questions. While the sample size was sufficient for qualitative research, future research with larger samples is needed to undertake subgroup analyses by CKD stage and other variables.

In conclusion, through semi-structured interviews with a cohort of CKD patients, we found barriers to patients' information needs emanating from knowledge deficits, expectation of physician-driven communication and dissatisfaction with physicians' information delivery. All of these barriers contributed to patient passivity in interactions with healthcare providers. Interventions are needed to improve patients' CKD knowledge and empower patients to actively participate in healthcare discussions.

Acknowledgements

An earlier version of this article was presented as a poster at the National Kidney Foundation's Spring Clinical Meeting in Dallas, TX, USA, on 26 March 2015. We acknowledge Andrew Narva, MD, for his input on an early draft of the interview guide. This work was supported by VA funding from the Center for Innovation in Complex Chronic Healthcare, Health Services Research and Development, Office of Research and Development: LIP #42-145 (PI: E.J.G.) and from the VA Office of Academic Affiliations, Advance Fellowship Program in Health Services Research. The funding source did not have a role in the design, conduct or reporting of the study. The contents presented in this paper do not represent the views of the U.S. Department of Veterans Affairs or the United States Government.

Conflict of interest statement

None declared.

References

1. Lopez-Vargas PA, Tong A, Phoon RK *et al*. Knowledge deficit of patients with stage 1–4 CKD: a focus group study. *Nephrology (Carlton)* 2014; 19: 234–243
2. Pai AB, Cardone KE, Manley HJ *et al*. Medication reconciliation and therapy management in dialysis-dependent patients: need for a systematic approach. *Clin J Am Soc Nephrol* 2013; 8: 1988–1999
3. Cavanaugh KL, Wingard RL, Hakim RM *et al*. Patient dialysis knowledge is associated with permanent arteriovenous access use in chronic hemodialysis. *Clin J Am Soc Nephrol* 2009; 4: 950–956
4. Wright-Nunes JA, Luther JM, Ikizler TA *et al*. Patient knowledge of blood pressure target is associated with improved blood pressure control in chronic kidney disease. *Patient Educ Couns* 2012; 88: 184–188
5. Kazley AS, Simpson KN, Chavin KD *et al*. Barriers facing patients referred for kidney transplant cause loss to follow-up. *Kidney Int* 2012; 82: 1018–1023
6. Tuot DS, Plantinga LC, Hsu CY *et al*. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. *Clin J Am Soc Nephrol* 2011; 6: 1838–1844
7. Gaffney H, Blakeman T, Blickem C *et al*. Predictors of patient self-report of chronic kidney disease: baseline analysis of a randomised controlled trial. *BMC Fam Pract* 2014; 15: 196
8. Prakash S, McGrail A, Lewis SA *et al*. Behavioral stage of change and dialysis decision-making. *Clin J Am Soc Nephrol* 2015; 10: 197–204
9. Lewis AL, Stabler KA, Welch JL. Perceived informational needs, problems, or concerns among patients with stage 4 chronic kidney disease. *Nephrol Nurs J* 2010; 37: 143–148; quiz 149
10. Wright Nunes J, Greene JH, Wallston K *et al*. Pilot study of a physician-delivered education tool to increase patient knowledge about CKD. *Am J Kidney Dis* 2013; 62: 23–32
11. Boulware LE, Hill-Briggs F, Kraus ES *et al*. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis* 2013; 61: 476–486
12. Wright Nunes JA. Education of patients with chronic kidney disease at the interface of primary care providers and nephrologists. *Adv Chronic Kidney Dis* 2013; 20: 370–378

13. Schatell D. Web-based kidney education: supporting patient self-management. *Semin Dial* 2013; 26: 154–158
14. Kurella Tamura M, Li S, Chen SC *et al*. Educational programs improve the preparation for dialysis and survival of patients with chronic kidney disease. *Kidney Int* 2014; 85: 686–692
15. Gordon HS, Street RL Jr, Sharf BF *et al*. Racial differences in doctors' information-giving and patients' participation. *Cancer* 2006; 107: 1313–1320
16. Tran AN, Haidet P, Street RL Jr *et al*. Empowering communication: a community-based intervention for patients. *Patient Educ Couns* 2004; 52: 113–121
17. Street RL Jr. How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Educ Couns* 2013; 92: 286–291
18. Street RL Jr. Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Soc Sci Med* 1991; 32: 541–548
19. Brandes K, Linn AJ, Butow PN *et al*. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psychooncology* 2015; 24: 245–252
20. Dimoska A, Tattersall MH, Butow PN *et al*. Can a 'prompt list' empower cancer patients to ask relevant questions? *Cancer* 2008; 113: 225–237
21. Kinnersley P, Edwards A, Hood K *et al*. Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. *BMJ* 2008; 337: a485
22. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)* 2013; 32: 207–214
23. Marshall R, Beach MC, Saha S *et al*. Patient activation and improved outcomes in HIV-infected patients. *J Gen Intern Med* 2013; 28: 668–674
24. Mitchell SE, Gardiner PM, Sadikova E *et al*. Patient activation and 30-day post-discharge hospital utilization. *J Gen Intern Med* 2014; 29: 349–355
25. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* 2012; 27: 520–526
26. Goodworth MC, Stepleman L, Hibbard J *et al*. Variables associated with patient activation in persons with multiple sclerosis. *J Health Psychol* 2014; doi:10.1177/1359105314522085
27. Manierre MJ. Gaps in knowledge: tracking and explaining gender differences in health information seeking. *Soc Sci Med* 2015; 128: 151–158
28. Levey AS, Bosch JP, Lewis JB *et al*. A more accurate method to estimate glomerular filtration rate from serum creatinine: a new prediction equation. Modification of Diet in Renal Disease Study Group. *Ann Intern Med* 1999; 130: 461–470
29. National Kidney F. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis* 2002; 39(2 Suppl 1): S1–S266
30. Callahan CM, Unverzagt FW, Hui SL *et al*. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care* 2002; 40: 771–781
31. Bristowe K, Selman L, Murtagh FE. Qualitative research methods in renal medicine: an introduction. *Nephrol Dial Transplant* 2015; 30: 1424–1431
32. Ayres L, Kavanaugh K, Knafl KA. Within-case and across-case approaches to qualitative data analysis. *Qual Health Res* 2003; 13: 871–883
33. Guest G MK, Namey EE. *Applied Thematic Analysis*. Thousand Oaks, CA: Sage Publications, 2012
34. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ* 2008; 337: a1020
35. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 2006; 18: 59–82
36. Morse J. Determining sample size. *Qual Health Res* 2000; 10: 3–5
37. Stiggelbout AM, Kiebert GM. A role for the sick role. Patient preferences regarding information and participation in clinical decision-making. *CMAJ* 1997; 157: 383–389
38. Orsino A, Cameron JI, Seidl M *et al*. Medical decision-making and information needs in end-stage renal disease patients. *Gen Hosp Psychiatry* 2003; 25: 324–331
39. Corrigan JM DM, Kohn LT (ed). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press, 2001
40. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expect* 2006; 9: 25–36
41. Bergeson SC, Dean JD. A systems approach to patient-centered care. *JAMA* 2006; 296: 2848–2851
42. Ladin K, Weiner DE. Better informing older patients with kidney failure in an era of patient-centered care. *Am J Kidney Dis* 2015; 65: 372–374
43. Sepucha KR, Belkora JK, Mutchnick S *et al*. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *J Clin Oncol* 2002; 20: 2695–2700
44. Manns B, Hemmelgarn B, Lillie E *et al*. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol* 2014; 9: 1813–1821
45. Patient and Professional Education. https://nkdep.nih.gov (24 September 2014, date last accessed).
46. Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Educ Monogr* 1977; 5: 281–315
47. Greene J, Hibbard JH, Sacks R *et al*. When seeing the same physician, highly activated patients have better care experiences than less activated patients. *Health Aff (Millwood)* 2013; 32: 1299–1305
48. Green JA, Mor MK, Shields AM *et al*. Prevalence and demographic and clinical associations of health literacy in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2011; 6: 1354–1360
49. Zullig LL, McCant F, Melnyk SD *et al*. A health literacy pilot intervention to improve medication adherence using Meducation® technology. *Patient Educ Couns* 2014; 95: 288–291
50. O'Hare AM, Choi AI, Bertenthal D *et al*. Age affects outcomes in chronic kidney disease. *J Am Soc Nephrol* 2007; 18: 2758–2765