

Integrating Patient Activation Into Dialysis Care

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Patient activation, the measure of patients' readiness and willingness to manage their own health care, is low among people receiving in-center hemodialysis, which is exacerbated because such centers are commonly set up for patients to passively receive care. In our pursuit of person-centered care and value-based medicine, enabling patients to take a more active role in their care can lead to healthy behaviors, with subsequent reductions in individual burden and costs to the health care system. To improve patient activation, we need to embrace a patient-first approach and combine it with ways to equip patients to thrive with self-management. This requires changes in the training of the health care team as well as changes in care delivery models, promoting interventions such as health coaching and peer mentoring, while leveraging technology to enable self-access to records, self-monitoring, and communication with providers. We also need health care policies that encourage a focus on patient-identified goals, including more attention to patient-reported outcomes. In this article, we review the current status of patient activation in dialysis patients, outline some of the available interventions, and propose steps to change the dynamics of the current system to move toward a more active role for patients in their care.

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Delivering value-based care that improves efficiency by delivering better care with improved experience at controlled cost, the so-called triple aim, has gained traction in the dialysis community because of the escalating costs of dialysis care despite limited improvements in outcomes. The move from paternalistic medicine to person-centered care, in which the focus is on what patients and families need and want, has gained greater traction recently.¹ However, is the patient ready to take on this role? This is not just a matter of education²; as the saying goes, “When the student is ready, the teacher will appear.” When the patient is not ready, the teaching is a wasted effort and, in some instances, can be counterproductive, confusing, and disappointing.

This implicates the importance of “patient activation,” which refers to how involved patients are in their care.³ One needs knowledge to understand why and what to do, skill to manage the “how,” and confidence to be able to do it. Activated people demonstrate healthy behaviors such as exercise and healthy eating. They engage in healthy actions such as receiving immunizations, keeping their doctor appointments, and adhering to their medications. Activation is associated with healthier body mass index, glycated hemoglobin, and blood pressure. Consequently, activation is associated with fewer emergency room visits, fewer unplanned hospitalizations, and lower cost of care.^{4,5} As activated people understand their condition and treatment and know how to navigate the system, it is not surprising that they report more provider satisfaction than less activated people.⁶ Figure 1 illustrates a framework for how patient activation fits in strategies to improve patient care.

The US Centers for Medicare & Medicaid Services have signaled their interest in patient activation by proposing a new quality metric that will apply to participants in the Kidney Care Choices payment model. Participating programs are required to collect patient activation measure

(PAM) surveys in at least 50% of Kidney Care Choices patients, excluding patients with a documented diagnosis of dementia. The model also proposes repeating PAM surveys in all patients except those at the highest activation level (level 4; described in more detail later) in the initial survey. Nephrology practices will receive capitated payments based on changes in patient PAM scores.⁷ Although patient activation has been studied extensively in many chronic diseases, little is known about it in kidney disease, and even less is known in hemodialysis (HD) care. As the culture of in-center HD care is unique, activation interventions that work in other populations may have limited transferability. In this perspective, we review what is known about patient activation in the literature, and we propose a pragmatic framework for how patient activation could be incorporated in care for HD patients.

What Patient Activation Is and How It Is Measured

Patient activation is defined as the individual's readiness, willingness, and ability to manage their own health and health care, and can be measured by the 13-item PAM survey known as PAM-13.⁸ The survey is scored on a scale from 0 to 100, with higher scores denoting greater activation. Scores translate to 4 activation levels: level 1 (score ≤ 47.0 ; disengaged and overwhelmed), level 2 (47.1-55.1; becoming aware but still struggling, lacking the knowledge and confidence to take action), level 3 (55.2-72.4; beginning to take action), and level 4 (≥ 72.5 ; proactive and engaging in many recommended health behaviors).⁴ The survey has been translated into more than 40 languages,⁹ and it can be self-administered or assistance can be given to those who require it. People introducing the survey to patients need training to learn how to explain the purpose of the survey and how to complete it.

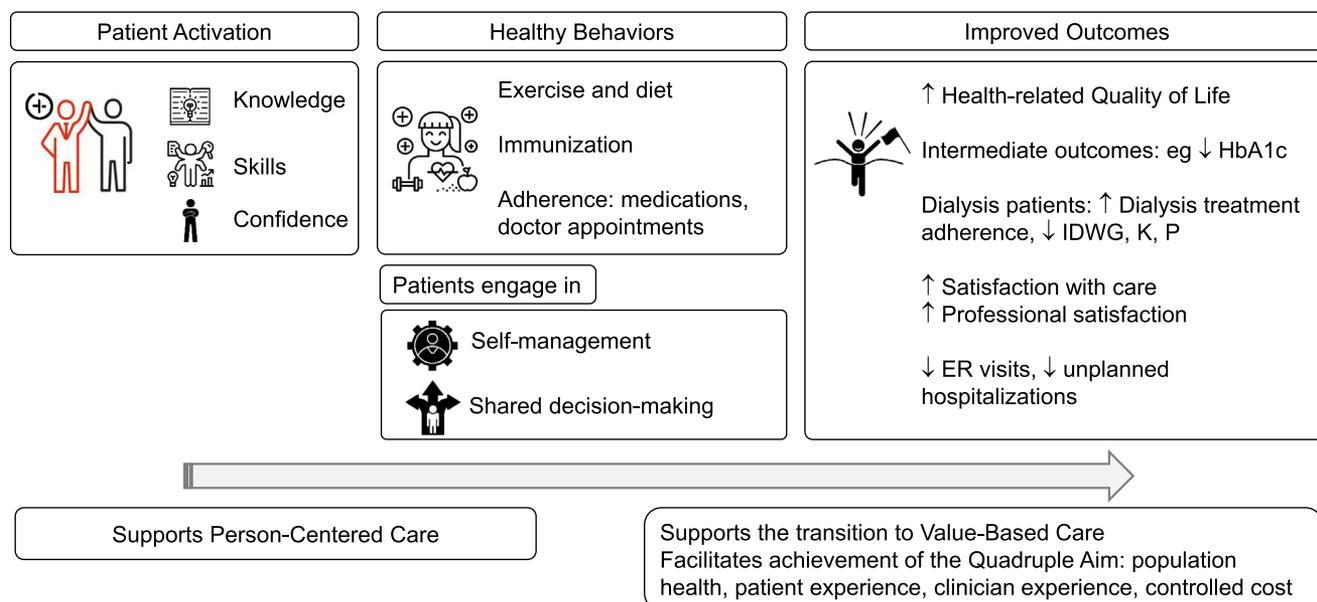


Figure 1. Patient activation is key to person-centered care and delivery of the “quadruple aim.” Abbreviations: IDWG, interdialytic weight gain; K, serum potassium; P, serum phosphorus; ER, emergency room.

PAM-13 has been validated extensively in different clinical settings and multiple patient populations,^{7,10} and was recently found to be reliable and valid in patients with chronic kidney disease (CKD) who are not receiving dialysis.¹⁰ It is yet to be validated in patients receiving maintenance dialysis.

Status of Patient Activation in Dialysis Patients

Patients with kidney disease have lower activation than patients with other chronic diseases, and activation is lowest among those receiving in-center HD.¹¹⁻¹³ One of the largest reports on activation in dialysis patients comes from the Transforming Participation in Chronic Kidney Disease Program in the United Kingdom.¹³ Patient activation was measured across 14 renal units, resulting in data from 921 patients receiving in-center HD, 51 peritoneal dialysis patients, 320 patients with CKD not receiving dialysis, and 617 transplant recipients. Patients receiving in-center HD reported lower activation (53% at levels 1 and 2) than the patients undergoing peritoneal dialysis (32%), those with CKD (40%), and those with a kidney transplant (25%). Repeating the survey (743 patients completed the survey at least one more time) showed that the greatest improvements were in patients who were initially at levels 1 and 2.¹³

Smaller studies have been reported from other parts of the world. In a study from Belgium, the mean PAM score for 192 prevalent HD patients was 51 (standard deviation, 10).¹¹ From Australia, a study that assessed activation in patients with CKD included 59 dialysis patients (among 305 patients with kidney disease). This study did not report findings in the subgroup of dialysis patients, but, in the whole population, 46% reported low activation (levels

1 and 2).¹⁴ The only study we were able to identify from the United States included 19 HD patients among a total of 84 patients with CKD. This study reported that patients with more advanced kidney disease had lower activation.¹⁵ A recent US survey of prevalent HD patients reported that 64% were in the low activation range.¹⁶ Overall, the field remains poised to gain more information about activation status, outcomes, and interventions in dialysis patients.

What Is Different About In-Center Hemodialysis in Relation to Patient Activation?

The culture of HD centers is unique because there is no other clinical context in which patients spend so much time with the same health care professionals over such a long period of time,¹⁷ and people receiving dialysis at in-center HD facilities are frequently responsible for very little of the clinical care.¹⁸ The culture of safe and quick dialysis treatment is driven by dialysis providers, staff, and the person receiving dialysis.¹⁹ It is much quicker for the clinician (technician or nurse) to do everything for the person receiving dialysis rather than taking the time to teach and coach. This results in very limited patient involvement in clinical care and can inhibit the capacity for in-depth meaningful application of coaching and self-management interventions.

How to Improve Patient Activation

In the quest to deliver person-centered care, the dialysis community needs to have a strategy for engaging and enabling patients to be in charge of their own health care. We provide an overview of potential interventions. However, an isolated individual solution will not be sufficient to influence change.²⁰ To achieve a meaningful and

sustainable cultural shift, we propose a multifaceted model of care that involves people receiving dialysis, their health care team, dialysis providers, and policy makers^{20,21} (Fig 2 and Table 1).

Identification of High-Risk Groups

Having records of patients’ activation status can help direct resources and guide interventions. Patients with low activation are less likely to recognize early warnings of impending complications or more rapid deterioration in their condition, are less motivated to act, and are less likely to know what to do if they decide to do something about these warnings. Intensified surveillance with frequent check-ins, repeated reminders, and close follow-up is warranted for this group of patients.²²

Health Coaching Techniques, Including Motivational Interviewing

Health coaching, or the use of behavior-changing principles and techniques to promote health management, can promote lifestyle changes and adherence to treatment to achieve better health outcomes.^{2,23,24} This is distinct from counseling, which is delivery of health education with rigid instructions, without accounting for the patient’s own goals or desire to change.²⁴ The usual persuasion techniques rely on arguments, judgements, advice, and orders that try to convince the patient to change, relying on extrinsic motivation, eventually leading to resistance.²⁵ Coaching aims to encourage people to take actions and succeed,³ which in turn encourages them to take more action and more ownership, increasing their activation.

Coaching and education programs targeted according to PAM score, rather than uniformly developed and implemented, can assist clinicians to interact more effectively to strengthen a patient’s role in managing his or her health care.²⁶ People with high activation are active seekers of information, and our role is mainly to direct them to the right resources and respond to their questions when they

ask. At the other end of the scale, people with low activation can be overwhelmed, confused, and unmotivated.⁴ They are unable to act on a large amount of information from multiple providers. They benefit from working on small pieces of information. As patients succeed in achieving small goals, they build confidence and take on more actions,²¹ and their activation level increases over time. As an example, a medication management plan can be customized to PAM levels to improve phosphate management (practice point A in Box 1).

Motivational interviewing is a commonly implemented health coaching technique.² Motivational interviewing is used to help people resolve ambivalent feelings toward change. The coach assesses the patient’s readiness to change, then elicits the patient’s intrinsic motivation to change. Coaching then follows a series of setting and implementation of an action plan, follow-up and assessment, and building confidence every time a goal is achieved.^{27,28} Motivational interviewing has been shown to influence dialysis attendance adherence,²⁹ completion of full dialysis time,²⁹ and phosphate levels,^{29,30} but has limited sustainable effect on interdialytic weight gains.²⁹⁻³¹ Practice point B in Box 1 illustrates how the principles of motivational interviewing were implemented by a social worker in the care of a patient who had been nonadherent to dialysis treatments.

Self-Management Programs

There is limited experience about self-management programs in dialysis care. A well-established program in self-management, the Stanford Chronic Disease Self-Management Program (CDSMP), consists of 6 weekly 2.5-hour sessions for groups of 10-15 patients facilitated by 2 trained coaches who themselves have a chronic disease. The facilitators help patients in making their own disease-management choices to reach self-selected goals.³² In a pilot study involving 14 patients undergoing HD who participated in the CDSMP, gains were seen in self-

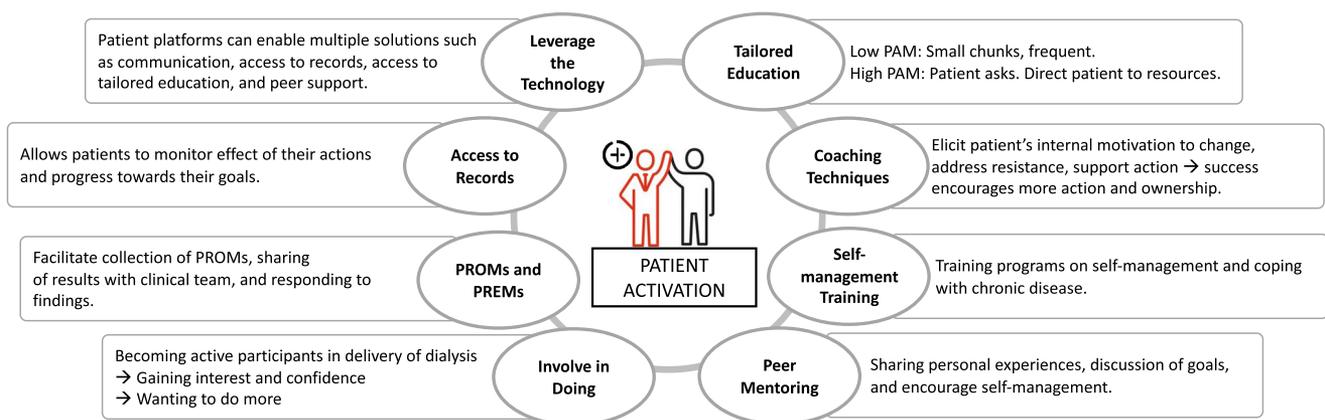


Figure 2. Patient activation care intervention strategies. Abbreviations: PAM, patient activation measure; PREM, patient-reported experience measure; PROM, patient-reported outcome measure.

Box 1. Practice Points Related to Patient Activation^a**A: Using patient activation measure surveys to modify a medication plan for phosphate management**

- Patients with lower activation (levels 1-2)
 - Offer frequent (eg, weekly) medication education sessions
 - Avoid overwhelming the patient
 - Focus on one simple goal per session, such as taking phosphate binders with each meal
 - Focus on one medication per session
 - Encourage achievements and use family to reinforce education and implementation
 - Communicate the small stepped goals with dialysis staff to ensure consistent messaging
- Patient with higher activation (levels 3-4)
 - Aim for less frequent coaching sessions (these patients can feel patronized by ignoring their capacity to undertake new concepts)
 - Include more information per session and can go into more depth, such as when discussing the relationship with bone and vessel health

B: Implementing motivational interviewing; example of approach by a social worker for a patient with non-adherence to dialysis treatments

- Express empathy: listen with empathy, understand the patient's worries and perspectives
 - Patient described how tired he was
- Develop discrepancy: allow the patient to reflect on his situation, surface the discrepancy between his goals and behavior (ambivalence), and accept it (does not mean to agree with it)
 - Patient described not wanting to come to dialysis, but also listed that as a possible reason for not feeling well
- Roll with resistance: instead of offering a solution (eg, "You should come to dialysis regularly"), the social worker asked: "What do you think might help?" This elicited his internal motivation to change
 - Patient proposed: "Maybe I should come in to dialysis more regularly"
- Support self-efficacy: support self-efficacy and optimism; our role then is to support the patient to achieve his goal

^aAs a foundation that allows person-centered care, the starting point for all interactions should be a focus on what is important for the patient and family.

management behaviors, self-efficacy, health status, health care utilization, and medical literacy.³³ The challenges of conducting such a program in the dialysis population were highlighted by the fact that 2 of the 14 patients dropped out after 1 session and the remaining participants each missed approximately 1 of the 6 sessions of the CDSMP. Despite widespread application of the CDSMP to improve self-management in chronic disease, a meta-analysis from 2013 reported clinically minimal short-term improvements in quality of life, healthy behaviors, and self-efficacy compared with usual care.³⁴ A more recent meta-analysis of studies examining the effect of patient activation interventions, including CDSMP and other interventions,

reported significant psychosocial and behavioral effects, but only minor physiologic improvements.^{2,3}

Testing a different program, Griva et al randomized 259 HD patients in Singapore to receive usual care (control arm) or an intervention with 4 group sessions carried out over a 5-week period.³⁵ Sessions focused on items related to fluid intake, diet, and medication through goal setting, barrier identification, and problem solving, and involved peer support. Facilitators (social worker and renal nurse or dietician) completed a 2-day training course. Resulting changes in interdialytic weight gains, phosphate, and potassium were modest, but the authors argued that the intervention should be considered in regular practice given its low cost. It is important to note that a large proportion of eligible patients declined to participate, with the main reasons being lack of interest or time and a perception of themselves as being too frail or old. Participants in the study had a mean age of 54 years, and 46% were employed. It is not clear what the effect of such an intervention would have on those less interested at the start. These are likely patients with low activation, who may be more difficult to recruit and retain in the program, but who may also benefit more from the intervention.

Actively Involving Patients in Their Own Dialysis Care

In a larger study currently under way in the United Kingdom, investigators are examining the effect of applying principles of person-centered care (SHAREHD program) to center-based HD patients.³⁶ The health care team provides choices for patients and supports their participation in their own treatment. Fourteen tasks were defined for this study, ranging from simple (eg, obtaining observations such as blood pressure and weight) to more complex tasks involving other aspects of the treatment (eg, setting up and programming the dialysis machine). Patients with low levels of activation were supported to engage with simple tasks, and this led to increased confidence and reduced anxiety. As patients acquired greater independence and enhanced experience, a number chose to move to home dialysis. A very important finding was that "shared hemodialysis care is a simple concept but a complex intervention."²¹ A successful intervention requires a cultural shift in the locus of control and requires involvement from all members of the care team. This cultural shift could include novel models such as transitional care units,³⁷ home HD trials,³⁸ and assisted peritoneal dialysis³⁹ that can incorporate motivational interviewing, peer mentoring, and other self-management training interventions.

Preparing the Dialysis Health Care Team

The role of the health care team needs to evolve away from rigid protocol-driven transactions with limited patient involvement toward the roles of educators and facilitators, supporting patients to undertake an active role in their

care.^{36,40} Clinics may choose a team member to be the patient activation leader, who oversees the local development and implementation of these initiatives, teaches other team members, and monitors success of the program. It is vital to have consistent self-management and goal-setting messaging, together with an understanding of the patient's activation status by those who spend the most time with the patients. Social workers and dietitians may be best positioned to offer motivational interviewing but are often constrained by large patient loads and spend less time with the patients than technicians and nursing staff members do.⁴¹ With all these considerations, the choice of who among the care team leads the integration of activation can be decided at a clinic level.

A vertical change that involves patients, health care workers, administrators, and policy-makers is necessary to influence and sustain change.^{40,42} A cycle of implementation and evaluation, such as the frameworks developed by PCORI,⁴³ with involvement of all stakeholders needs to be adopted. The SHAREHD program (discussed above)²¹ implemented a series of learning events with multiple team members at each dialysis unit (including patient partners) supported by a nursing training course, teleconferences, a newsletter, and other channels. Importantly, to maintain a patient focus, a patient advisory group was formed to support their involvement.³⁶

Peer Mentoring and Peer Support Programs

Experienced patients are a relatively untapped resource who can supplement a staff-initiated activation intervention to enhance the promotion of self-management.⁴⁴ Peer support can facilitate authenticity through patients sharing their experiences together and enhancing the discussion of future life goals.⁴⁵⁻⁴⁷ Although the evidence is limited in dialysis populations, peer mentoring has led to increased patient activation and self-management in other chronic conditions.^{44,48-51}

Integration of Patient-Reported Outcomes

Measuring patient-reported outcomes (PROs) is key to person-centered care, as they measure symptom burden and quality of life from a patient's perspective, facilitate communications between patients and staff, improve patient engagement, support shared decision-making, and enable patient self-monitoring.⁵²⁻⁵⁴ A culture of emphasizing PROs shifts care toward a model in which a patient has more information and knowledge about their health care priorities.

Challenges to integration of PROs in patient care remain, particularly in the field of dialysis care.^{53,54} Randomized trials are currently under way to inform the use of PROs in dialysis care.^{54,55} The feasibility of integrating PROs in the care of HD patients and providing the reports to treating nephrologists and nurse unit managers is being evaluated in SWIFT (the Symptom Monitoring with Feedback Trial).⁵⁵ The

EMPATHY (Evaluation of Routinely Measured Patient Reported Outcomes in Hemodialysis Care) study is evaluating the effect of linking PRO measures to treatment aids for clinicians and patients in HD units in 3 kidney care programs in Canada.⁵⁴ Both studies will provide guidance on how to best incorporate PROs in dialysis care to assist patients with their own health care priorities.

Leveraging Technology

With the increased use of mobile health in dialysis patients, these technologies can be leveraged to support patient activation.^{56,57} Patient information portals provide multiple advantages that can increase self-management, including allowing patients access to their own laboratory and clinical data, facilitating medication management, managing appointments, and communicating with providers. These tools improve self-monitoring and increase the patient's locus of control,⁵⁸ which in turn would increase activation and self-management. Patient portals have been associated with increased appointment attendance,⁵⁹ decreased health care costs,⁶⁰ and decreased time to kidney transplant.⁶¹

Challenges and Gaps

The integration of patient activation in clinical practice has a great potential to improve patient care, but there are many unknowns that require research to guide this integration.^{7,24} In **Box 2**, we list research priorities to facilitate integration of patient activation in the care of dialysis patients.

Box 2. Key Gap Areas Requiring Research to Integrate Patient Activation in Dialysis Care

Instrument validation

- Validation in different modality populations: home dialysis, in-center dialysis, and transplant patients
- Validation among different demographic groups, such as age groups, educational levels, race and ethnicity backgrounds

Is patient activation related to outcomes?

- Patient-reported outcomes including quality of life
- Dialysis modality choice
- Dialysis access type
- Adherence to medications, dialysis treatment, fluid and dietary recommendations
- Hospitalizations and mortality

How can patient activation be improved?

- What types of interventions increase activation levels?
- What are the most effective activation delivery options?
 - Mode: face to face, groups, web-based, hybrid
 - Frequency of interactions and duration of the intervention
- What are the most effective activation interventions (cognitive behavioral therapy, peer mentoring, education)?
- What are the best implementation strategies to integrate patient activation in management of dialysis patients?

Table 1. Integration of Patient Activation Requires Changes to the Current Standard of Care

	Current Standard of Care	In a System That Integrates Patient Activation
Responsiveness to patient's goals	Focus on disease guidelines (operation metrics, biological metrics)	Include family; incorporate social determinants of health; integrate PROMs and PREMs
Delivery of education	One size fits all: passive delivery of a predetermined curriculum with little or no adaptation of content or pace to individual patients	Tailored to the level of patient activation; guided by patient-identified goals and priorities
Resource allocation	Guided by comorbidities and disease severity	Adjusted to patient activation (low activation patients require more resources)
Staff training	Efficient in delivering disease-centered care	Experienced in person-centered care
Time	Volume-based model: faster to "talk at" the patient and to do things for the patient instead of engaging the patient; faster transactions ≠ long-term efficiency	Taking time to empower the patient and deliver shared care; more time upfront proposed to save time down the line
Communication	Fragmented: patient goals not solicited and not communicated across care teams	Fostering communication and coordination of care between care team members locally and across organizations may help with patient activation
Billing	Fee-for-service	Fee-for-performance; value-based care system

Abbreviations: PREM, patient-reported experience measure; PROM, patient-reported outcome measure.

Although self-management approaches can require upfront education and motivation efforts, these efforts are frequently rewarded with increased ownership of care by people receiving dialysis, resulting in reduced burdens and costs downstream. Stakeholders involved in kidney care need to recognize that evidence of the effects of patient activation on hard outcomes and cost of care will require long observation periods. While awaiting such evidence, we should focus, at least temporarily, on patient outcomes such as changes to quality of life, improved engagement and satisfaction with care, and whether patients are undertaking the right actions that will ultimately improve their health. It is also important to recognize that one of the challenges facing programs that aim to improve patient activation is that patients with low activation, although more likely to benefit from these programs, are also less likely to participate for the very same reason: low activation is associated with less action.⁶² Efforts to encourage, facilitate, and support these patients are of utmost importance.

Conclusions

Activation is fast becoming a key principle in patient-centered care and an integral piece in our pursuit of value-based care. More work is needed to guide the appropriate use and interventions to incorporate this principle in regular practice and care delivery models. Initiatives that aim to tackle activation need to consider the challenges of including patients with low activation, the complexity of implementing a solution that considers the physical and emotional status of dialysis patients, and the competing demands on patients and staff time. We are moving forward with a sense of hope, away from a paternalistic delivery of care, and closer to care that is directed by individual patient-identified goals.

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