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The patient experience of hemodialysis vascular access decision-making

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Abstract

Background: To describe vascular access (VA)-related decision-making from the patient perspective, in patients who have already chosen hemodialysis as their renal replacement modality, and identify areas where physicians can improve this experience.

Methods: In-person, semi-structured interviews with 15 patients with end-stage kidney disease were systematically analyzed by two independent researchers using thematic analysis. Interviews were conducted until systematic analysis revealed no new themes.

Results: Patients had mean age 57 (range 22–85), with seven males and diverse racial/ethnic/marital status. All (15/15) patients viewed VA as “intertwined and interrelated” with dialysis, prioritized the dialysis, described the VA merely as the “hookup” to life-preserving dialysis and gave it minimal consideration. Three themes were identified: consolidation of dialysis and VA, reliance on supportive advisors and communication with physicians. Although 14/15 patients described processes common to medical decision-making, including information seeking, learning from the experiences of others, and weighing risks and benefits, they did not apply these processes specifically to VA. While all participants took ownership of the VA decision, they lacked clear understanding about the different types of VA and their consequences. Most patients (14/15) depended on family and friends for reinforcement, motivation and advice. Patients all described physician characteristics they associated with trustworthiness, the most common being listening and explaining, demonstrating empathy and making an effort to meet the patient’s individual needs. Perceived arrogance, unavailability and lack of expertise represented untrustworthiness. The majority (14/15) accepted VA recommendations from physicians they found trustworthy and authoritative.

Conclusions: The study participants were minimally engaged in VA decision-making. Educational aids and shared decision-making tools are needed to empower patients to make better-informed, self-efficacious VA decisions.

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Keywords

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Introduction

In 2017, there were 808,159 prevalent patients with end-stage kidney disease (ESKD) in the US.[1] Just over a third of patients (35.2%) are treated with transplant, 6.9% use peritoneal dialysis, and the remainder (58.9%) use hemodialysis.[1] For hemodialysis-dependent patients, vascular access (VA) is required, for which there are two options that are considered permanent, arteriovenous fistula and arteriovenous graft.

A patient-centered decision-making dialysis access algorithm was proposed previously in 2007.[2] However, for over 15 years, clinicians have strongly prioritized fistula over grafts for VA, based on the 2006 *National Kidney Foundation Dialysis Outcomes Quality Initiative* (NKF K-DOQI) *Clinical Practice Guideline for VA*,[3] in conjunction with "*Fistula First*."[4] Acknowledging that recent data have challenged the appropriateness of the "Fistula First" approach in all ESKD populations, an update of the K-DOQI *Clinical Practice Guideline for VA* advocates for a substantial shift in treatment recommendations towards a patient-centered approach by focusing on the ESKD Life-Plan.[5,6] Life-Plans are to be developed by the provider team in conjunction with the patient and detail the patient's planned VA for the remainder of their hemodialysis-dependent life.

However, despite a number of studies investigating the decision-making process around dialysis modality (hemodialysis vs peritoneal dialysis),[7-11] decision-making preferences of patients in the area of hemodialysis VA are unknown, presenting a key knowledge gap that impedes implementation of the new guidelines. To overcome this barrier, the objective of this study is to describe VA-related decision-making, in patients who have already chosen hemodialysis as their renal replacement modality, from the patient perspective and identify areas where physicians can improve this experience.

Methods

Methods in brief:

English-speaking adult patients with ESKD requiring hemodialysis were recruited from the vascular surgery practice at a single academic institution between February and November of 2019. Following approval by the Institutional Review Board, one investigator (KW) conducted in-person interviews (mean 45 min, range 29–89) using a semi-structured interview guide designed for this research (Table 1). Throughout the process of the study, the authors acknowledged that we bring professional knowledge and experience to the data collection and analysis. Potential a priori assumptions and potential biases stem from our backgrounds. The first author is a vascular surgeon who provides care to patients who require VA. The quantitative analysis of individual factors that lead to VA outcomes is the focus of the first author's outcomes research program. The second author, a registered nurse and a clinical psychologist was not providing clinical care at the time of the study and does not have recent experience with patients with ESKD or VA. Both investigators were keenly aware of their backgrounds as a potential bias. To limit bias, we reflected on our thoughts, comparisons, connections, hunches, and speculations[12,13] with particular care to identifying meanings that could possibly be a result of the our own world view rather than the participant's experience. These memos were discussed with one another to minimize bias throughout the investigative process.

Study participants received a $50 gift card at the conclusion of the interview. Interviews were conducted until saturation was reached, where no new themes were identified. Thematic analysis was used as the analytic method and all available steps were taken to ensure rigor.[14] (Table 2) Full details of the methods are available in Supplemental Appendix 1.

Results

Sample characteristics

Fifteen patients with ESKD participated in the study. All patients were referred to a vascular surgeon for creation of VA, having already made their decisions regarding dialysis modality with their nephrologist and/or other provider. Saturation was reached at twelve interviews and three additional interviews were performed to confirm no new themes. Patient characteristics varied widely. (Table 3) Eight patients had a median of 1 (range 1–4) previous permanent VAs in addition to their current VA. The fifteen patients had their current dialysis VA cared for by six vascular surgeons.

Background of hemodialysis experience

When patients recalled their initial impressions upon learning they were going to require chronic dialysis, patients commonly expressed despair, as they associated dialysis with death. Despite the fact that most participants had extensive previous interactions with the health care system in managing their other co-morbidities and having known about their chronic renal insufficiency for some time, understanding the intricacies of being dialysis dependent posed significant challenges. A patient who had retired after many years as a healthcare provider and was a cancer survivor, described the initial struggle by remembering, "I'm not stupid. I have a pretty good mind and I'm very medically astute in a lot of ways. Not with dialysis. I had to learn a new language." (Participant #011) (See Table 4 for additional quotations.) The immense burden of going to the dialysis center three times a week, reflected in words such as "interruption," "inconvenience" and "inundated," weighed heavily on this sample. Patients highlighted the strain that transportation to and from the center and feeling fatigued and physically drained after dialysis sessions add to the hours spent in the dialysis center. One elderly patient succinctly summarized the experience as, "That's my life, dialysis." (#002)

It was within this context of intense, complex emotions, and physical fatigue, that patients considered their options for dialysis VA. We identified three common themes that were described across participants regarding the decision-making process around dialysis VA:

consolidation of dialysis and VA, reliance on supportive advisors and communication with physicians.

Theme: Consolidation of hemodialysis and VA

Nearly all (14/15) patients described processes common to medical decision-making, including purposefully seeking treatment-related information, learning from the experiences of others, and weighing potential risks and benefits. The exception was participant #002 who accepted the recommendations of the provider team without question in all healthcare decisions and did not seek outside information. The remainder of the patients had applied these decision-making processes in the course of managing their co-morbid conditions that included diabetes, cancer and lupus. However, in the process of prioritizing dialysis over the VA, participants did not apply these familiar mechanisms specifically when deciding about VA.

Information seeking

Patients utilized traditional decision-making strategies to varying degrees and sought information from diverse sources, including pamphlets and handouts from providers, the internet, other dialysis patients and support groups. Specific to dialysis, when patients were just starting with chronic dialysis, the focus was to obtain information regarding the process of dialysis itself, rather than the VA. Furthermore, for patients starting the dialysis journey, there were so many unknowns associated with the dialysis itself that they did not know what questions to ask about VA. Patients who had previous failed VA or had VA complications, sought information about planned VA revision procedures or a new type of VA.

In seeking information, 14/15 patients turned to the internet at some point (exception participant #002). However, a common complaint was that there was no centralized, authoritative and trustworthy resource. What patients found helpful was pictures, diagrams, videos and other visual aids, whether presented on the internet, in pamphlets or hand-drawn images by providers. Nevertheless, despite the amount of information available, particularly for patients starting on their dialysis trajectory, there was a lack of understanding of VA options. A young participant using a graft as a first VA admitted, “I'll be very honest. I don't really know the difference between a graft and a fistula, but they explained it that it's just different material.” (#014)

Weighing risks and benefits

While all patients weighed the potential risks and benefits of VA to some degree, the considerations that they weighed varied by the amount of experience they had with dialysis and VA. The considerations of patients at the beginning of their dialysis trajectory, were more focused on whether they should or should not proceed with the creation of a fistula/graft. Participants who had experience with previous VAs had preferences related to anatomical location, type of access and cosmesis based on their previous experiences. One patient preferred a graft because she had negative experiences in the past with infiltration of a previous fistula. Another patient, knowing that she valued function and physical appearance, based her decision on previous positive experiences with having a thigh graft.

She preferred the thigh location to the arm as it was easier to cover with clothing and allowed more arm mobility during dialysis sessions.

Prioritizing dialysis over VA

Patients in our sample viewed the choice to proceed with chronic dialysis as choosing between life and death and consequently as not much of a choice. This was exemplified by a participant who had just started dialysis and said he decided to proceed because, “Well it’s either that or die. So, it wasn't much choice.” (#003) Once the decision to commit to dialysis was made, VA was deemed a necessary, albeit secondary, part of dialysis. A young patient who had been dialysis dependent for several years, described dialysis and VA as “a connected unit.” Similarly, VA was commonly described as a “lifeline” and considered to be a necessary tool to receive dialysis, the primary concern.

This sample of patients saw the decision to initiate and continue with dialysis as not a choice, with the decision-making process around VA being secondary to dialysis. This was particularly notable when the patient had no previous experience with VA to influence personal preferences. All (15/15) patients gave the VA minimal consideration in the decision-making process because they viewed VA as “intertwined and interrelated” with dialysis and as the “hookup” to life-preserving dialysis.

Theme: Reliance on supportive advisors

Each study participant emphasized that they were the ultimate decision-maker regarding their VA. Simultaneously, the participants repeatedly and naturally interlaced the important role of their family and friends in their decision-making process.

Reinforcement

Patients relied on supportive advisors, including spouses, children, friends, siblings and parents, during their dialysis journey for recurrent emotional and physical reinforcement. Additionally, participants derived emotional strength from the presence of their supportive advisors and relied on them extensively for assistance through all aspects of the dialysis experience from transportation, to doctor’s visits to providing food when they are too fatigued after dialysis to manage a meal on their own. Working to manage the complexities of being dialysis dependent, participants were grateful and appreciative of the instances where a supportive advisor shared the burden of trying to understand the complexities of dialysis and advocated for them. Often, patients would describe their supportive advisor stepping in to ask questions of healthcare providers or intervene on their behalf.

Motivation

Patients consulted with supportive advisors extensively to serve as self-motivation in initiating and continuing their dialysis journey. In particular, patients with spouses and families used them as reasons for choosing dialysis. A middle-aged patient, who was newly dialysis dependent, became emotional when recalling the decision to choose dialysis. Describing the fluctuation of feelings during the initial adjustment period and ultimately using family as motivation to persevere, the participant said, “It’s been up and down. There were moments when I was, especially at first, I was a bit depressed. But, I got two kids and I want to walk my daughter down the aisle if she chooses to get married.” (#009)

Advice

In this sample, participants used their supportive advisors as a means to talk through the complexities of dialysis and VA. Patients valued input from supportive others, particularly if they had a medical background or experience with dialysis. A participant with a close family member who was a biomedical scientist described the family member as a trusted, valuable resource for assistance in decision making and said: “If I have a question about anything, my (family member) will go back and check it out and call (their) colleagues and stuff. I really wouldn't do anything serious without (their) help.” (#008)

Most patients in this sample (14/15) depended on family and friends for physical and emotional reinforcement, motivation to persevere with dialysis and advice about dialysis and VA. Supportive others played significant roles in the lives of these participants, encompassing a range of aspects of their health, dialysis and VA decision-making. The exception was participant #012 who valued independence and did not want to be a burden to family and friends.

Theme: Communication with physicians

A prior assumption of the investigators was that both the patient and the physician would play a role in the VA decision-making process. To explore this assumption, the interviewer asked, “Would you walk me through how the decision was made to use that type of access?” Unexpected responses such as “They [physicians] just said, ‘This is what we have to do’” (#012), indicated that physicians, in particular the VA surgeon, played a decisive role in the patient’s VA decision-making process.

Trustworthiness

In general, patients with ESKD have extensive interaction with a wide range of physicians and the study participants had clear, firmly held beliefs regarding what perceived qualities constituted trustworthiness and competence in a physician. Participants placed great value on physicians who spent time with them, explained everything thoroughly and listened carefully. In identifying careful listening, the participants noted instances when the physician followed up at a later visit on an issue that the patient brought up on a previous visit. Another example participants described of careful listening was when the physician gave an opinion and explained the risks and benefits of a request made by the patient. In gathering data about their physicians, patients also made determinations regarding the people that surrounded the physician in the practice environment, including trainees, nurses, medical assistants and administrative staff. When patients perceived trainees and staff as being competent and trustworthy, they attributed those characteristics to the leadership of the attending physician.

Lack of trustworthiness

Patients perceived impatience and lack of thorough explanation on the part of the physician as arrogance. They also attributed incompetence from the staff, for example making an appointment on the wrong day, to incompetence of the attending physician. Most of all, patients were alienated by physicians who did not follow up appropriately after significant events, including surgery and hospitalizations. Each of these were cited as driving factors for why a patient sought to switch care to a different physician.

Accepting the recommendations of a trustworthy physician

Ultimately, when a patient developed a relationship with a trusted physician, nearly all (14/15) patients accepted the VA recommendations of that physician. The exception was participant #005 who had family members who were dialysis dependent and based on that experience, had strong preferences prior to meeting with providers regarding type and location of VA. Acknowledging deference to a trusted physician with perceived expertise, a patient who resisted transitioning from a tunneled catheter to a fistula stated, “I had to understand that they [physicians] know much better than I do. That their decision-making was probably right.” Patients who had long-term relationships with their provider teams placed great value on those relationships. Those participants came to see the physician and the physician’s staff as “my team” and entrusted their care to “my team.” The patient’s trust in their provider team further extended beyond the immediate actions and recommendations of the team to the recommendations of other providers that were endorsed by the provider team.

The study participants repeatedly and spontaneously acknowledged that they chose to seek care at the academic institution because of its reputation for high quality medical care and provider skill and expertise. However, if they had unsatisfactory interactions with a physician at the institution, patients were quick to seek out a new physician that they experienced as honest, empathetic and caring, highlighting the importance of the patient-physician relationship to the participants.

In this sample, participants greatly valued physicians who offered generosity with time, thorough discussions and careful listening. These attributes formed the basis of a trusted relationship with the physician. Within the background of the overwhelming influence of dialysis, a trusted relationship between the patient and the provider served as a reliable foundation that significantly influenced the patient’s VA decision-making.

Discussion

Shared decision-making (SDM) has been described as “the pinnacle of patient-centered care.”[15] The results of our study suggest that shared decision-making is not occurring during the dialysis VA decision-making process. SDM requires that the physician and patient both actively participate in the decision-making process.[16] It is incumbent upon the physician to share information with the patient, and at the very least, describe the risks and benefits of treatment alternatives.[16] Our study participants described experiences more consistent with a paternalistic model of decision-making where the physician “is seen as dominating the medical encounter and using his skills to diagnose and recommend tests and treatments for the patient."[16]

The patient experience of decision-making around VA has been minimally investigated in the literature. Other investigators have studied very specific decision-making processes in Canadian ESKD patients regarding why they refused fistula[17] and the degree of patient certainty regarding the VA decision to switch from catheter access to a fistula/graft.[18] However, these studies do not provide insight into the VA decision-making process of contemporary American ESKD patients with varied access circumstances. By gaining understanding into the broad VA decision-making process from the patient perspective, we took a first step towards improving the VA SDM experience for the patient.

Some factors that may account for the paternalistic nature of decision-making that we found in our study are the Fistula First Initiative[4] and the previous NKF K-DOQI guidelines,[3] which both strongly advocated the use of fistulas over grafts and catheters. More importantly, the Medicare End-Stage Renal Disease Quality Incentive Program (ESRD QIP) reinforces these initiatives by financially punishing dialysis centers with lower prevalence of fistula use.[19] It is unclear whether these reimbursement issues drive VA surgeon recommendations to patients. Nevertheless, as we shift from "Fistula First" towards a more patient-centered approach of VA decision-making, an important next step to increasing patient involvement in the VA decision-making process will be to understand how VA surgeons counsel patients regarding VA and how providers will alter their communication practices to be more patient-centered.

Another aspect that may account for the finding of paternalistic decision-making was our focus on the patient only. While this study was not designed to include data collection from supportive others and we did not ask participants how they would want their supportive others to be included in shared decision-making, the participants naturally introduced the important role of supportive advisors. Our findings suggest that supportive advisors fulfill an important role in decision-making about VA access as has been found in other clinical conditions.[16] To off-set what may otherwise appear as patients who passively accept what the clinician say, other researchers suggest that clinicians take a dyadic approach and approach the patient and support person as one unit to reflect the essential role of the supportive other.[20] Our findings suggest the importance of including supportive others who accompany patients to participate in the decision-making conversation with the clinician if that is what the patient prefers.[21-23] These participants took pride in their personal autonomy when making decisions, so collaborating with the supportive other needs to be handled with sensitivity

Oftentimes, the decision-making process can involve more than an individual clinician and patient. Furthermore, in some cases, there may be more than one physician involved in the SDM process.[16] This is particularly relevant to the VA decision-making process where the nephrologist is responsible for the patient's overall ESKD care and the surgeon is responsible for the VA. Other providers, such as interventional radiologists, may also be involved in the maintenance of VA. While our participants did not describe physicians other than their VA surgeon playing a significant role in the VA decision-making process, the updated K-DOQI guidelines stipulate that the multidisciplinary team work together with the patient to develop the Life-Plan. However, the guidelines do not provide direction as to how these various specialists should work together with the patient. Future work must address the composition of the provider team and how to optimize the functioning of the provider team.

Our study participants reported lack of availability of a trustworthy decision aid. While extensive shared decision aids exist for a number of medical conditions, including cardiovascular disease, colorectal cancer, breast cancer, dental health conditions and infectious diseases, no such aid exists for hemodialysis VA.[24] Randomized trials of shared decision-making have shown that decision aids increase patients' knowledge, decrease decisional conflict related to feeling uninformed and have a positive effect on patient-clinician communication.[25] Patients who used a decision aid were more satisfied with their decision, the decision-making process and the preparation for decision-making.[25] Development of a widely accessible, trustworthy VA decision aid for patients and their supportive others is a critical next step in improving the VA shared decision-making for patients.

This sample described in-depth the characteristics of a trustworthy relationship with their VA surgeon. The qualities that these patients associated with trustworthiness are consistent with those that have been described previously.[26] The patients of this sample focused on finding a trustworthy surgeon and then appeared to relinquish the VA decision to that surgeon. Nevertheless, the study participants asserted that they were the ultimate decision-makers. However, their descriptions of the VA decision-making process did not support that assertion and suggested blind trust in the physician associated with more passive decision-making. Similarly, a cross sectional survey of 606 patients demonstrated that those with blind trust in their physician were significantly more likely to prefer passive decision-making.[27] However, those with blind trust constituted a small minority (6.3%) of the study population. In order to clarify and quantify VA decision-making preferences in ESKD patients, future studies should employ validated measures such as the Problem Solving Decision-Making Scale.[27]

A primary limitation of this study is that it was a singlesite study that recruited patients from one vascular surgery practice in large urban academic medical center. The VA decision-making experiences of patients at smaller, rural and/or non-academic facilities may be significantly different. In the vascular surgery practice where the patients were recruited, the practice is for the surgeon to consult with the patient, perform the informed consent and see the patient in follow-up after the VA operation. In other practices, some of these steps may be performed by advanced practice providers other than the surgeon. Future investigation should include other practice patterns.

The focus of our study was the patient's perspective of deciding about VA, but, although we did not ask about caregivers specifically, participants spontaneously introduced the relationship with partners and/or family who helped them make decisions. Given that our study identified supportive others as important participants in the patient experience of VA decision-making, it is critical that future studies include an examination of the preferences and experiences of supportive others and how patients want their supportive others in the VA decision-making process. As the provider is required for shared decision-making to occur, future investigation into the provider experience as well as the patient-provider interaction will provide further insight into how the decision-making experience can be improved. Furthermore, our study participants were limited to English-speaking patients. Thus, future research that includes patients from varying practice types and non-English speakers will enhance our understanding of the VA decision-making experience of a broader ESKD patient population.

Conclusion

These participants were minimally engaged in VA decision-making. It is incumbent upon VA surgeons to take responsibility for engaging patients in the VA decision-making process. Educational aids and shared decision-making tools are needed to empower patients to make better-informed, self-efficacious VA decisions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Representative interview guide questions with potential associated follow-up questions.

Subject	Question	Follow-up
Initial access decision	Would you walk me through how the decision was made to use that type of access as your first access?	Please tell me about anyone in particular that supported you during the decision-making process?
Weighing options	Looking back, would you describe how you weighed the pros and cons of your options?	What are your preferences about the location of the access (where it is on your body)?
Information sources	Where did you get information about your access options?	Please describe anything that you remember in particular about the content of that information?
Decision-making preferences	When it comes to making decisions about your health in general, how much do you want to be involved in the decision-making process?	Could you tell me about any people in your life that help you to make decisions about your health?
Experiences with providers	In general, as a dialysis patient, you interact with a lot of health care providers, such as nurses, doctors, aides and technicians. Could you describe any interactions or relationships with health care providers that stand out to you?	What would you change about the interactions that you have had with health care providers?
Relationship between dialysis and VA	When you think about dialysis, how does the dialysis itself and the access relate?	If you were to explain to someone else how dialysis and access are related, how would you describe it?

Table 2.

Ensuring research integrity and rigor*.

Issue addressed	Action taken
Informed consent	Interviewer (KW) reviewed informed consent form and Health Insurance Portability and Accountability Act (HIPAA) authorizations with potential study participants immediately prior to each interview
Separation of research and clinical care	**1** Interviewer (KW) assured participants that: • no interview data would be shared with their clinical care team • nothing said in the interview would affect the patient’s clinical care **2** Interviewer did not participate in any of study participants’ clinical care **3** Instead of professional clinical attire, the interviewer wore street clothes and an identification badge during the interview
Transferability/ External validity	**1** All interviews were audiotaped and transcribed verbatim. **2** Each transcription was reviewed for accuracy against the corresponding recording by an investigator.
Protecting patient privacy	Proper names were replaced with pseudonyms
Reliability	Both investigators analyzed transcriptions independently and assigned initial codes
Credibility	Investigators met regularly to review the analytic codes and resolve discrepancies through discussion
Derivation of themes	Constant comparison was used to examine data within the same interview and across interviews
Confirmability	Audit trail included field notes and memos: • Interviewer recorded field notes before and after each interview[15] • Interviewer recorded Initial memos after each interview reflecting on analytic thoughts, comparisons, connections, hunches, and speculations of the interviewer[5] • Analytical memo was written after initial coding for each interview • Ad-hoc memos were written whenever a significant theme was identified
Objectivity	Field notes and memos emphasized self-reflexivity (the process in which the researcher critically examines how their own values, attitudes, and biases may influence their experience, conduct and interpretation of the interview)

*The presentation of results meets the standards of the COREQ Checklist for Reporting Qualitative Studies.[16]

Table 3.

Patient characteristics.

Characteristic	***n* (sample *n* = 15)**
Age, mean (range)	57 years (22–85)
Male	7
Race/Ethnicity	
White	5
Black	5
Asian	4
Hispanic	1
Marital status	
Married	6
Never married	5
Widowed	2
Divorced	1
Legally separated	1
Dialysis status	
Pre-dialysis	2
Failing transplant	1
Dialysis dependent	12
Length of dialysis dependence, mean (range) (*n* = 12)	7.8 years (0.16–28)
Current VA	
Tunneled catheter	4
Fistula	3
Graft	5

Table 4.

Representative quotes supporting the themes and subthemes.

Theme	Sub-theme	Exemplar
Consolidation of dialysis and access	Information seeking	I went to a lupus support group, for lupus, and there were dialysis patients there, and they would talk about dialysis, and … it eased you, you know? (#008 *) And I didn't ask enough questions. I didn't know what questions to ask but I didn’t ask. (#002) He [surgeon]didn’t tell me that. He just said they’re [arteriovenous grafts] “problematic.” He did not explain what that meant and I didn’t think enough to ask what “problematic” meant. (#008)
	Weighing risks and benefits	I want it up here [upper arm] because I’m a guitar player. (#015) I didn’t want something that was showing all the time. (#010) This one I had, the fistula I had it for 3 years and I was already getting balls, like bumps and everything. (#006)
	Prioritizing dialysis over access	They’re so intertwined and interrelated but the thing is, when I went to have dialysis, they explained to me that they have to access my body somehow. (#012) I personally don’t think of them [dialysis and access] separately because, like I said, I think they go hand in hand. (#014) It's real simple. If this thing’s [fistula] not working, I’m done. So it’s my hookup to the external kidney, which keeps me alive. (#015)
Reliance on supportive others	Reinforcement	My husband is a rock like I’ve never seen. Supportive in anything and everything. (#001) If I didn’t have that support system, I don’t think I would be mentally where I’m at today if it wasn't for them [family]. (#014)
	Motivation	I know that if I didn't have my husband, I wouldn’t go on dialysis. (#011) I tell her [mother] all the time that she’s my strength. She’s what keeps me going. (#014) The only reason why I agreed to do dialysis and still agree to do dialysis is ‘cause of my Mom and my sisters. (#006)
	Advice	He [friend] gave me good advice. He comforted me on a level that I went to my parents [for] and not that I didn’t feel comfort from my parents, but I felt more comfort [from friend]. (#007) I never make a decision by myself. I always clear it by my mom and my dad, my sister. (#014) My husband and I sit down and talk about it before we come. He goes to every doctor’s appointment with me. (#011)
Communication with physicians	Trustworthiness	I trusted their [provider team] judgment because of their experience and the relationship that I had [with them]. (#001) He’s [vascular surgeon] always there when you need him. He's there, and if he’s not going to be there, he’ll let you know ahead of time. If he’s going to be out on vacations or whatever. He gives you time to think and have questions for when you see him before he leaves. He actually listens to you and gives you your opinion about what you want. If it’s a good decision or if it’s not a good decision, the benefits and the cons of what you want and what could be done. (#006) He’s [vascular surgeon] just a really good man. He sits you down at a table, you’re not sitting on a thing and he talks to us. I never felt that he was rushing out. (#009)
	Lack of trustworthiness	I went in one day and had a surgery and had another one the next day. I mean, not one time, all this time, has he [nephrologist] ever called me. And he knows about it. Because I know he knows about it. Never once has come in to see me in dialysis. He’s always traveling or he’s doing something. But, I don't feel that I'm his patient anymore. (#011) There are doctors who were arrogant and egotistical and they don’t communicate very well. (#015)
	Accepting recommendations of a trustworthy physician	The doctor made the decision [about the access], they made it here at [medical center] because these are my doctors. (#002) My doctor decided for me, and I trust him a hundred percent. (#007) I accept that doctors know a lot of stuff that I don’t, honestly, I have to defer. (#012)

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[*] Denotes participant number.