



Patient Perspectives on Arteriovenous Fistula Placement, Maturation, and Use: A Qualitative Study

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Rationale & Objective: Arteriovenous fistula (AVF) use among US hemodialysis (HD) patients is suboptimal, especially among Black patients. We interviewed a group of predominantly Black HD patients to probe experiences and perspectives surrounding steps along the AVF care continuum, which includes placement, maturation, and use of AVFs.

Study Design: Individual semistructured interviews.

Setting & Participants: Patients with kidney failure receiving HD in Birmingham, Alabama.

Analytical Approach: Transcripts were coded and thematically analyzed.

Results: We interviewed 53 Black and 6 White patients at different steps of the AVF care continuum: 29 were dialyzing with a central venous catheter (15 had not undergone AVF placement, 9 had a maturing AVF, and 5 had a nonfunctional AVF) and 30 were dialyzing with an AVF. We coded

transcripts using qualitative thematic analysis. Three themes emerged: (1) the circumstances of dialysis initiation sometimes altered the timeline of AV access placement; (2) patients had variable levels of knowledge of steps along the AVF continuum; and (3) the life impacts of dialysis access were a significant factor in patients' experience of dialysis.

Limitations: Single-institution study; low number of non-Black participants limited comparison of patient experiences by race.

Conclusions: Among a group of predominantly Black HD patients, perspectives surrounding the AVF care continuum included consideration of the circumstances of dialysis initiation, patient knowledge, and the life impacts of dialysis access. These findings may inform targeted interventions aimed at optimizing dialysis access use and addressing disparities across the AVF continuum.

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Placement of functional vascular access is a key metric in the care of patients with kidney failure treated with hemodialysis (HD).¹ Although updated Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines emphasize placement of the “right access, in the right patient, at the right time, for the right reasons,” arteriovenous fistulas (AVFs) and arteriovenous grafts (AVGs) have been historically favored because of lower infection risk and lower mortality compared with central venous catheters (CVCs).¹⁻⁵ Compared with AVGs, AVFs that successfully mature may have an additional benefit of fewer vascular access complications such as loss of primary patency and need for interventions.^{1,6}

Despite the historical benchmark of establishing permanent vascular access (AVF or AVG) before HD initiation, over 80% of patients initiate HD with a CVC.^{7,8} Black patients, who in 2021 had 3.8 times higher incidence and 4 times higher prevalence of kidney failure compared with White patients, are less likely to successfully traverse the AVF care continuum, which includes multiple potential “hurdles” of AVF placement, maturation, and use.^{9,10} In a study of more than 40,000 HD patients, Black patients were 10% less likely to undergo AVF placement, 12% less likely to use the AVF after it was placed, and 22% less likely to maintain AVF patency after its successful use, compared with White patients.¹¹ Reasons behind these inequities, which are sustained even after controlling for income, education, and insurance status, are not clear.^{9,11}

To date, few studies have explored patients' perspectives related to AVF placement, maturation, and ultimately successful use. In this study, we conducted qualitative interviews of a predominantly Black sample of patients to probe patient perspectives surrounding traversing specific steps of the AVF care continuum, with a goal of understanding how patient experiences might explain observed disparities in AVF placement and use.

METHODS

Participant Selection

We conducted semistructured interviews of adult patients receiving in-center HD in one of 12 outpatient dialysis facilities affiliated with the University of Alabama (UAB). The overall UAB hemodialysis population includes 55% male and 84% Black patients, and their mean age is 53 ± 14 years. Potentially suitable patients were initially identified by M.A. and then approached for participation by study personnel during one of their HD sessions. Once the coronavirus disease 2019 (COVID-19) pandemic had started, the study coordinator recruited the patients via telephone.

Purposive sampling was used to ensure that patients with a range of dialysis access (pre-AVF placement, maturing AVF, prior failed/nonfunctional AVF, or AVF in use) were represented. With an objective of eliciting perspectives of participants along each stage of the AVF

PLAIN-LANGUAGE SUMMARY

People with kidney failure receiving hemodialysis (HD) rely on vascular access to undergo HD treatments. Though arteriovenous fistulas (AVFs) are preferred over tunneled dialysis catheters, AVF use is suboptimal especially among Black people with kidney failure. We interviewed 59 predominantly Black people with kidney failure who were at various stages of having an AVF placed. We aimed to understand their perspectives and experiences surrounding AVF placement, maintenance, and use. We learned that the circumstances of dialysis initiation, patient knowledge, and perceived life impacts of dialysis access contributed to perspectives on AVFs. These findings can help guide interventions that may address disparities in use of AVFs and optimize patient experiences around dialysis access.

continuum, we aimed to recruit 10-12 participants in each stage of the AVF continuum. An attempt was made to interview similar numbers of White and Black patients; however, most patients who were eligible (62 Black and 10 White patients) and consented (53 Black and 6 White patients) were Black, which reflects the demographic composition of the participating dialysis facilities. Patients were not approached for participation if they had reduced intellectual capacity as assessed by HD nurses or acute dialysis needs rather than chronic kidney failure. Three patients were excluded because they did not speak English. Participants were not remunerated for their participation.

Setting

Interviews occurred between December 2019 and November 2021, were initially conducted in person, and were then conducted via telephone after the onset of the COVID-19 pandemic. Except for some patient care partners, nonparticipants were not present at the time of interviews.

Interview Guides

We developed semistructured interview guides using questions tailored to the participants' status along the AVF continuum (Item S1). Questions were pilot tested with 2 participants. We first asked participants to share their experiences surrounding dialysis initiation, including initial conversations regarding vascular access. Subsequent questions were framed by knowledge/beliefs and concerns surrounding vascular access. Interviews were conducted with all consented participants regardless of data saturation, although we did achieve thematic saturation of concepts presented here.

Study Procedures

Participant characteristics, including comorbid conditions, dialysis vintage, and employment status, were obtained by the study coordinator. Verbal consent was obtained before

participant interviews. Interviews were conducted by a Black female study coordinator who was trained by D.C.C. in conducting interviews, and who had no established relationship with study participants. Participants were not provided with information about the interviewer. Field notes were not taken, and repeat interviews were not conducted. All interviews were conducted in English.

A digital audio recorder was used to record interviews. Audio recordings were transcribed by Ubiquitous Translation Services, and transcripts were redacted before analysis. Video recordings were not taken. Transcripts were not returned to participants.

Data Analysis

Descriptive statistics were used to describe participant characteristics. Continuous variables are presented as mean (standard deviation), and categorical variables are presented as n (%).

Three members of the research team (D.M.P., B.M.C., and D.C.C.) performed qualitative data analysis. The authors read transcripts to become immersed in the data, constructed and adjudicated a codebook (Fig S1), and performed thematic analysis through which authors identified themes relevant to patient experiences.¹² Data were analyzed with a deductive approach through which interview guide questions framed a conceptual model, as well as an inductive approach through which themes arose naturally as the authors reviewed transcripts.^{13,14} After D.M.P. and B.M.C. independently reviewed all transcripts to create and adjudicate the codebook, the codebook was applied to all transcripts by D.M.P. using MAXQDA qualitative software to manage data. Coded segments were then reviewed collectively by D.M.P., B.C.C., and D.C.C. to identify themes describing key patient experiences/perspectives.

Ethical Approval

This study was approved by the UAB Institutional Review Board (IRB-300002595).

RESULTS**Participant Characteristics**

Of 72 patients approached for enrollment, 59 participants consented and were interviewed. Individual semistructured interviews lasted 5-15 minutes each. Participants were categorized by dialysis access: "pre-AVF" for patients who were dialyzing with a CVC with no AVF created, "maturing AVF" for patients who had undergone AVF placement but were dialyzing with a CVC while the AVF matured, "non-functional AVF" for patients who did not achieve primary AVF patency or who experienced loss of AVF patency and were dialyzing with a CVC, and "AVF in use" for patients dialyzing with an AVF. Of the 59 patients included in the study, 29 (49%) had nephrology follow-up before starting HD, and 55 (93%) started dialysis with a catheter.

The demographic characteristics of the participants were similar to those of the entire UAB hemodialysis population, with 59% male and 90% Black patients and a mean age of 52 ± 13 years (Table 1). The mean dialysis vintage of the participants was 3.5 ± 3.9 years. Dialysis vintage time was shortest for pre-AVF participants and longest for participants with nonfunctional AVFs. Common comorbid conditions included diabetes (44%), coronary artery disease (25%), and congestive heart failure (37%).

Qualitative Assessment of Patient Perspectives

We derived a coding tree framed by 3 categories of the patient experience: the circumstances of dialysis initiation, patient knowledge surrounding dialysis vascular access, and patient perspectives on dialysis access options and life impacts (Fig S1). We reviewed coded transcript segments to identify 3 themes describing shared experiences of participants regarding AVF placement, maturation, and use (Table 2).

1. The circumstances of dialysis initiation sometimes altered the timeline of AV access placement.

We asked participants about experiences surrounding dialysis initiation and initial conversations about dialysis access. Several participants reported being hospitalized at the time of dialysis initiation. Some were unaware of their kidney disease and presented to the hospital for evaluation of symptoms including flu-like symptoms or lower back pain, only to find out that they were in kidney failure needing to start dialysis.

The vast majority of participants started dialysis with a CVC. In some cases, participants were being monitored by nephrologists but still initiated dialysis in a hospital setting because of accelerated declines in kidney function, which reduced the time available

for predialysis access placement. Even when participants had been planning for kidney replacement therapy and pursuing an “optimal” start of dialysis with AV access, acute illnesses such as COVID-19 accelerated the progression of kidney disease and resulted in dialysis initiation with a CVC.

For some, the significant psychosocial impact of dialysis initiation influenced the timeline of access placement. Participants reported a significant emotional impact of being diagnosed with kidney failure, citing a lack of understanding about how dialysis worked and how it would impact their personal lives. In some cases, this distress and required adjustment period influenced the timing and utility of conversations surrounding vascular access, with some participants acknowledging that they were not ready to have conversations about access for several months after dialysis initiation.

2. Patients had variable levels of knowledge of steps along the AVF continuum.

Multiple participants acknowledged the positive influence of conversations with their nephrology care teams, who provided information surrounding access placement and maintenance. One patient who was dialyzing with an AVF reported a high level of trust in members of their care team who had advised AVF placement. Knowledge surrounding the benefits of AV access placement (eg, better clearance of toxins and less infection risk compared with CVC), as well as visual education materials that demonstrated how AVFs would be used for treatment, were noted as having a positive influence on the experiences of participants who were actively using an AVF.

However, some participants had limited knowledge of AVF placement and recommendations to encourage maturation, even when they were scheduled for an upcoming AVF procedure. Participants expressed a desire for more knowledge

Table 1. Participant Characteristics

Participant Characteristics ^a	CVC in use (n = 29)			AVF in use (n = 30)	Total (n = 59)
	Pre-AVF (n = 15)	Maturing AVF (n = 9)	Nonfunctional AVF (n = 5)		
Age in years (mean \pm SD)	48 (11)	52 (16)	58 (8)	53 (14)	52 (13)
Sex (n, % male)	9 (60%)	6 (67%)	2 (40%)	18 (60%)	35 (59%)
Race (n, % Black)	12 (80%)	7 (78%)	4 (80%)	30 (100%)	53 (90%)
Comorbid conditions (n, %)					
Diabetes	6 (40%)	5 (56%)	2 (40%)	13 (43%)	26 (44%)
Coronary artery disease	4 (27%)	1 (11%)	2 (40%)	8 (27%)	15 (25%)
Congestive heart failure	6 (40%)	4 (44%)	2 (40%)	10 (33%)	22 (37%)
Body mass index (mean \pm SD)	27.1 (10.2)	30.7 (9.5)	26.8 (6.6)	30.9 (9.4)	29.5 (9.4)
Dialysis vintage in months (mean \pm SD) ^b	23.8 (29.0)	26.1 (53.2)	90.7 (64.4)	48.3 (48.2)	42.1 (47.7)
Full-time or part-time employment (n, %) ^c	2 (14%)	2 (22%)	1 (20%)	3 (10%)	8 (14%)

Abbreviations: AVF, arteriovenous fistula; CVC, central venous catheter; SD, standard deviation.

^aSex, age, comorbid conditions, dialysis vintage, and employment status are provided for participants, categorized by dialysis access at the time of interview.

^bDialysis vintage data were not available for 7 participants (3 in the “pre-AVF” group, 2 in the “maturing AVF” group, and 2 in the “non-functional AVF” group).

^cEmployment status was unknown for 2 participants (1 in the “pre-AVF” group and 1 in the “AVF in use” group). For calculations of employment status, n = 14 for the “pre-AVF” group and n = 29 for the “AVF in use” group.

Table 2. Themes Describing Patient Perspectives and Experiences Surrounding the Vascular Access Continuum**Theme 1: The circumstances of dialysis initiation sometimes altered the timeline of AV access placement.**

Subtheme: Acute illnesses reduced time available for predialysis access placement	<ul style="list-style-type: none"> - They really started talking to me about it before, a little bit before I started dialysis, and was telling me there were different kinds that I could choose from, because they had already told me like in 6 months I was probably going to have to start dialysis... but it wasn't until I actually had to get on dialysis, because I contracted COVID, so that accelerated my kidney disease. (Black female, 40s, pre-AVF)
Subtheme: Significant psychosocial impact of dialysis initiation influenced timelines of access placement	<ul style="list-style-type: none"> - Oh, Lord have mercy, when I first learned about it, I broke down. I cried so bad. I didn't know what to do. I thought my life was ending. And, I was thinking of my family and myself, and then, after a while, I kind of got over it. It was like in between embarrassed, and at times it still bothers me, because I had never thought I would have to go this far dealing with my kidneys and that my kidneys went bad. (Black female, 40s, maturing AVF) - The early stage, you know, I'm coming into something new and it might be my problem not asking a lot, enough questions, you know? I need to put it on me, make it my business, and I should have. I guess I'm just shock about knowing what it would do for me and just shocked enough not to... I guess my complications starting out—I don't know if it silence me or what... (Black male, 60s, nonfunctional AVF) - [When asked, "When did you first learn about ways to access your blood for dialysis?"] Probably about 5 months into dialysis. Five months because I was so mean, I didn't want to talk to somebody... They was trying to tell me about it earlier, but I didn't want to talk about it. (Black female, 50s, AVF in use)

Theme 2: Patients had variable levels of knowledge of steps along the AVF continuum.

Subtheme: Nephrology care teams facilitated discussions surrounding dialysis access	<ul style="list-style-type: none"> - I was going to my kidney doctor. We were taking classes on it. And it was, the lady was showing us like pictures of how the machine do when they hooked up to you and showing us how the blood flow through the machine and how they stick the needles in the arms. Even though it's nasty, okay, I can deal with it. (Black female, 50s, AVF in use) - The catheter, after you have it for a while, there's more chance of it getting an infection, and I definitely—I'm having enough issues with the kidneys. You know what I'm saying? I didn't need an infection to go along with this. So, the doctors, they explained it to me that keep this for a minute, but as soon as possible, as soon as we can, we'll get you a fistula put in your arm, because we want to eliminate the chances of you getting an infection. So, that was my biggest reason I got the fistula, because I didn't want that infection in my chest. (Black male, 50s, AVF in use) - The use of the needles, and it was explained to me, using the fistula would clean my blood better than the one in my chest. And, that made me feel better to hear. (Black female, 50s, AVF in use) - I had [a] good doctor that put it in. He's 100%, and I trust him. I put my life in his hands. And, I have a good team, the nurses that take care of me every day, 3 times a week. (Black female, 80s, AVF in use)
Subtheme: Patients desired more knowledge surrounding steps along the AVF continuum	<ul style="list-style-type: none"> - That's another issue I was concerned about, because how often would you have to keep coming back in for replacement or adjustment or... That is a concern I have as well. (Black male, 30s, pre-AVF) - They said keep my hand on it to make sure I feel it. Like ain't nobody ever told me about feeling, what they mean... That's what scared me too. So I always do try to put my hands on it. Know what I'm saying, don't nobody explain that to you. (Black male, 30s, maturing AVF) - ...my biggest concern is how many times am I going to actually have to keep on going back to have it... I wish I would have had a little bit more understanding, like exactly what needed to be done. (Black female, 70s, maturing AVF) - I'm a be honest with you: I don't remember. I don't know. I don't remember when. And I think I made that clear, you know? I forget who I talked with but when I got here that was my thing I needed to know. And every time I would tell them, I'd say, "Well ain't nobody set me down and told me how this work or nothing. They just say, 'Get in the chair' and they hook me up and—" you know what I'm saying? I don't think that work like that. (Black male, 60s, nonfunctional AVF) - Actually, I didn't believe it. I was like what is this, and what is all about? Why am I going through this? Those questions. But, once I started, actually, that's when it really kind of sunk in. And, once I started, I was sitting there, and I guess I was just trying to soak up so much knowledge at the same time, because I wanted to know everything that was going on. I mean everything that they told me, I was reading books, watching videos, just to try to figure out what was going on. (Black male, 50s, AVF in use)
Subtheme: Some patients perceived a lack of shared decision making	<ul style="list-style-type: none"> - I would tell [other patients] to ask what are their options... it is a choice. Because, I know the first thing - - doctor was trying to push the fistula, even though I was telling him that I would like to have the [graft]... in my family, they have diabetes, but had the fistula, and they hated it, so they had to go back and get the [graft] anyway. So, I felt like if he would have just done the [graft] first, maybe I wouldn't be having to go back. This like my fourth time going back to have this... (Black female, 70s, maturing AVF)

(Continued)

Table 2 (Cont'd). Themes Describing Patient Perspectives and Experiences Surrounding the Vascular Access Continuum

	<ul style="list-style-type: none"> - Instead of a needle, I don't want to get stuck with – I don't know. I had a lot of thoughts. I didn't know where they was gonna put it at. They don't say none of that. They don't really say nothing. They just tell you your kidneys don't work, and we got a solution, but they don't really tell you nothing. (Black male, 30s, maturing AVF) - I didn't learn about them...when I had it done is when I actually knew about it, when they put the fistula in my arm; I guess that's the only place it goes. But when I had the surgery done on my arm they just told me I had to have surgery, and I went in and they did one down here, and evidently it didn't work. And then they had to come back and do another surgery, put one up here. So I didn't know anything about what it was called, exactly how it worked or anything. I was just drawn into the file. (Black female,60s, AVF in use)
Theme 3: The life impacts of dialysis access were a significant factor in patients' experience of dialysis.	
<p>Subtheme: AVFs can result in neuromuscular symptoms</p>	<ul style="list-style-type: none"> - My second concern is how much pain is it? I'm not sure how much pain it would be after the surgery, when they get ready to stick the needles in your arm. I was concerned with that pain each time that I go for treatment, would that be an issue? (Black male, 30s, pre-AVF) - ...I don't want to get stuck. I've seen them needles. They huge. But they keep telling me they'll start out small, I ain't seen the small ones. The people around me get stuck with big ones, so I don't know what small is to them...I think I can keep something they can just screw on me real quick, I think I'll like that better than being stuck. (Black male, 30s, maturing AVF) - ...when they stick me it's just so many areas they can stick you in and I just feel like a pincushion. And it going in the same little hole every time they stick me...but I know there's nothing I can do about it because it's something they have to do. (Black female, 60s, AVF in use) - My hand. It's like my hands are numb. They lock up. They're blocked from sticking you in your arm and stuff. And you know, it'll change you. Listen to your arm, and it sounds like something's running in there like running water. (Black male, 20s, AVF in use) - It's on a nerve. My arm be numb. My whole arm, going down to my hand, it be numb 'cause he told me he put on a nerve. I don't know why he set it on a nerve. (Black female, 60s, AVF in use) - Just sometimes there are pains in it, but it's not unbearable pain, just something you'll notice every now and then. Sometimes it'll bleed a little bit longer than it probably should...I got a lot of nerve endings in there, so I can feel those nerves that they're accessing and sometimes it's up off of my wrist or something like that, feel all nerves and that. But you get past the nerve part you're okay. (Black male, 40s, AVF in use)
<p>Subtheme: Dialysis access requires care and maintenance</p>	<ul style="list-style-type: none"> - ...as far as the port-a-cath is, you know it's hard. I have to keep it taped down and keep from pulling on it and making sure it's covered up and that kind of thing. And they keep the fistula wrapped up, and it's up under your skin, so there's really not too much that you can do to bother it, but I think it's easier. (Black male,40s, pre-AVF) - Well, with a fistula, you can – you have more freedom to take a bath or swim or things like that that I can't do with a perm cath. So I am in the process of being ready to have one put in. (White male,60s, pre-AVF) - I've heard people say that's had a graft that says that the graft was great and they never had some problems. And then I've heard people say that it's always giving them problems... I don't know how to put this. The professionalism of whatever the staff that they're dealing with as far as the workers, as far as your tech and your nurse when it comes down to it. And I've heard a lot of people say that...something wrong with my access. And so that nurse, that tech started messing up over there. And they messed up and blew my access, and they're telling me I got to get another access, because something went wrong. But they're telling him that something went wrong as far as on the patient end. But the patient's feeling like, No, it was the staff that did this. (Black male, 40s, pre-AVF) - Well with the risk of an infection from a port...I'd say fistulas are inevitable so sit back and enjoy. (White male, 70s, maturing AVF) - I don't know if you're supposed to rotate during hot or cold pressures on it, so I don't do either. There was a time I would put the numbing cream on before I go to dialysis. I reached the point where I don't even do that anymore... And I've been able to take it so far, keep it clean, take care as best you can because it's basically a lifeline, you know? Even when you're dealing with some of the techs you have to pay attention to that. You don't want to stand over their shoulder and things like that but you still have to pay attention to what they're doing because we're all human; we could make a mistake. (Black male, 40s, AVF in use) - ...that catheter in my chest, I always make sure it was clean, didn't get no infection. It was outside of my body. With my fistula, it's inside my body, so the chances there are less of getting infected than that catheter, because that catheter, I couldn't swim in the pool...It was a bunch of maintenance...With the fistula, they put it in. It healed. We use it. Bingo. (Black male, 50s, AVF in use)

(Continued)

Table 2 (Cont'd). Themes Describing Patient Perspectives and Experiences Surrounding the Vascular Access Continuum

Subtheme: Changes in appearance from AVFs can be distressing	<ul style="list-style-type: none"> - I had to take a minute before I decided to do it because it just threw me, and I wasn't ready for it. I wasn't ready...I was just feeling too bad about having the surgery done and looking at my arm, thinking about the scar that's there, and it was just bothering me at the time. (Black female, 50s, nonfunctional AVF) - ...my fistula [inaudible] starting to swell. For a long time it was flat, but I expected this to happen. I've seen some where theirs are, man, like a grapefruit and stuff and I'm like, damn. (Black male, 40s, AVF in use) - The lumps get on your nerves a little bit, but not really. But I think other people judge you for it though. When they see you, they don't know what it is, basically. They don't have any kind of knowledge about it. (Black male, 50s, AVF in use) - You have the bandages on your arm and you're at risk of people always asking you what happened to you, you know: "You been in an accident? Did you cut yourself? Did you have surgery?" And it draws attention to a degree....I just told them I had surgery done...it depends on how you handle it. (Black male, 40s, AVF in use) - And where at first my family was asking me like man, what's that bump on your arm? And I'd just tell them, that the technicians, they have to stick me through my fistula to get my blood clean. So friends and family and people that I just didn't really know were asking me about it. Well sometimes I feel sad, sad, depressed about it. And then you're sitting around thinking and wondering about why did this happen to me? (Black male, 50s, AVF in use)
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Note: Quotations are presented for participants at different stages of the AVF continuum and are accompanied by participant race, sex, and age in decades. Abbreviation: AVF, arteriovenous fistula.

surrounding steps along the AVF continuum. Lack of knowledge surrounding methods to optimally monitor and care for AVFs at home (including measures to address access bleeding), as well as expectations surrounding potential AVF revisions, may have contributed to hesitation to proceed with AVF placement for some participants who were dialyzing with a CVC.

Similarly, some participants cited a lack of shared decision making surrounding access placement. In many cases, participants described fistula placement as a necessity, stating that they had "no choice" but to have a fistula placed. Some participants were told that CVCs could only be temporary and were not an option to use on a longer-term basis. One participant had requested to be referred for AVG placement because of members of their family having a history of requiring AVGs instead of AVFs, but was still instructed to proceed with AVF placement which was ultimately unsuccessful despite multiple revisions. One participant who was dialyzing with an AVF commented that they only learned more about AVFs after they had undergone their vascular access surgery.

3. The life impacts of dialysis access were a significant factor in patients' experience of dialysis.

Many participants expressed concern surrounding the life impact of dialysis access. Participants from each stage of the AVF continuum raised concern about neuromuscular symptoms of AVFs. Participants who were dialyzing with a CVC commented that the anticipated pain associated with AV access cannulation was a reason to continue using CVCs. Some participants with an AVF in use experienced ongoing difficulties with pain and/or numbness.

Requirements for dialysis access care and maintenance influenced some participants' perspectives on access options. Most patients acknowledged the

greater risk of infection with CVCs compared with AVFs. AVFs eliminated work required to keep CVCs covered and secure. Placement of AVFs was supported by patients who wanted to be more active (eg, being in water or playing with children). However, some participants expressed concern that they needed to closely monitor AVF cannulation and use, out of fear that the AVF would be compromised by improper cannulation or cleaning by dialysis care team members.

Although several participants with an AVF in use reported that the AVF had no or minimal impact on their daily life and interactions with others, some participants reported significant distress associated with changes in their arm appearance after AVF placement. In some cases, the presence of a fistula or bandages after treatment drew attention to the dialysis access, which they felt could potentially reveal their diagnosis of kidney failure to others. Enlarged fistulas were also distressing to participants, who were reminded of their kidney failure whenever looking at their access arm.

Considering participant experiences and perspectives, we outline perceived facilitators of traversing the AVF continuum in [Fig 1](#).

DISCUSSION

Among a group of predominantly Black patients receiving HD, we explored perspectives on the placement, maturation, and use of AVFs. We identified 3 themes influencing patient experiences throughout the AVF care continuum: (1) the circumstances of dialysis initiation sometimes altered the timeline of AV access placement; (2) patients had variable levels of knowledge of steps along the AVF continuum; and (3) the life impacts of dialysis access were a significant factor in patients' experience of dialysis. Our findings point to opportunities to improve the care

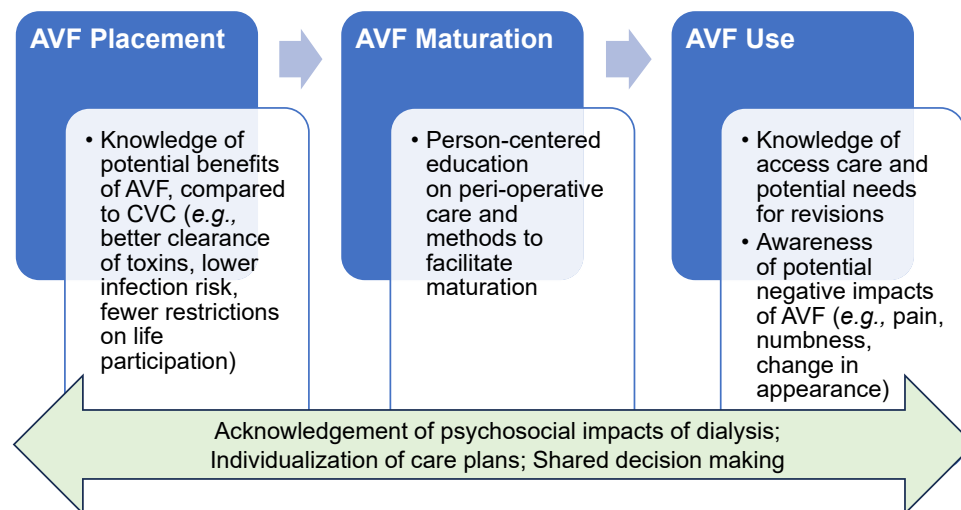


Figure 1. Perceived facilitators of successfully traversing the AVF care continuum, as identified by participants. Abbreviations: AVF, arteriovenous fistula; CVC, central venous catheter.

experiences of people with kidney failure and have potential implications for understanding and addressing racial disparities in dialysis vascular access.

First, we found that many of our participants “crashed” into dialysis, which we interpret here as any dialysis initiation requiring an inpatient admission and/or dialysis initiation without predialysis care, which both disproportionately impact Black patients.^{8,15-17} The establishment of predialysis nephrology care has been associated with a higher likelihood of dialyzing with an AVF and avoiding a CVC, and some participants in our study who were dialyzing with an AVF alluded to the benefit of predialysis classes focused on access planning.^{7,18-20} Consistency in care and timing of modality decision making have been shown to predict patient survival and facilitate actions toward permanent vascular access, respectively.^{21,22} However, establishment of regular outpatient nephrology care remains limited, with only ~14% of young adult Medicaid beneficiaries and ~40% of older Medicare beneficiaries with chronic kidney disease (CKD) stage 5 having an outpatient nephrology visit in 2021.⁸ The overall prevalence of predialysis nephrology care in the United States has increased over time, but disparities remain: in 2021, 26% of Black incident dialysis patients had >12 months of predialysis nephrology care, compared with 35% of White incident dialysis patients.⁸ Although interventions are needed to reduce these disparities, we note that some of our participants required inpatient dialysis initiation with CVCs, even when they had established predialysis nephrology care. A previous study found that patients who lacked social support, or who received late referrals to nephrology care, were more likely to undergo inpatient dialysis initiation with CVCs.¹⁵ Patients with advanced CKD under the care of nephrologists may still need assistance to traverse several barriers encountered while obtaining dialysis access, including processes related

to vascular surgery referral, evaluation, and procedural scheduling.²³

Next, we found that the circumstances of initiating dialysis were associated with significant distress which impacted patients’ perspectives on dialysis access. In the setting of an already overwhelming situation, patients may not be ready to discuss a transition from a CVC to permanent dialysis access. Some participants reported they could only discuss vascular access after having time to process and accept their kidney failure. Revisiting vascular access decisions over time has been shown to align patient and care team preferences.²⁴ Prior studies have suggested that interventions to address emotional concerns and misperceptions of dialysis may improve treatment satisfaction and dialysis-related outcomes.^{25,26} Although understudied in nephrology, Black patients with human immunodeficiency virus (HIV) treated in primary care settings been shown to experience less communication about their emotions.²⁷

Shifting to a person-centered approach may also allow for greater shared decision making.^{28,29} Shared decision making can enable patients to identify the dialysis access option most suitable to them, which in some cases differs from their provider’s choice of access.³⁰ Patients may choose to dialyze with a CVC given concerns for issues such as pain with cannulation or AVF maintenance.³¹ Recent KDOQI vascular access guidelines recommend establishment of “the right access, in the right patient, at the right time, for the right reasons,” which may depend on comorbid conditions and patient preferences including the perceived life impact of dialysis access.¹

Black patients have been shown to experience less shared decision making than other populations, with contributing factors including clinician mistrust and patient–physician race discordance.^{32,33} Black patients experience poor communication quality and information-

giving from their clinicians, which can also impact trust.^{17,34} Black patients may also experience systemic bias in physician perceptions of their credibility.³⁵ In addition, disparities have been shown in shared decision making involving caregivers of patients with critical illness, with Black caregivers experiencing less emotional support and receiving less medical information compared with White caregivers.³⁶ Interventions facilitating shared decision making with people with CKD and their care partners may lead to more optimal and equitable vascular access experiences for patients.

A major component of shared decision making is the use of person-centered/patient-friendly education materials and practices, which can increase overall knowledge of dialysis and result in higher use of permanent vascular access.³⁷ Most participants in our study who were dialyzing with a CVC endorsed a lack of sufficient knowledge regarding steps of the AVF care continuum. Some alluded to a potential lack of communication regarding possible side effects of vascular access procedures. Stakeholder engagement has been used to identify educational resources and support structures that are most impactful and relevant to establishment of permanent vascular access.³⁰ The use of education materials that are developed with stakeholder guidance and/or integrate shared decision making tools and involvement of patients' care partners may increase the effectiveness of such programs, which can be tailored to patients from a variety of socioeconomic and educational backgrounds.^{38,39} Nephrology care teams should ensure that this vital knowledge is disseminated to patients who are approaching the need to initiate dialysis or who are receiving hemodialysis through a CVC.

Our study had limitations. This was a single-institution study of patients receiving HD at 12 dialysis facilities in Birmingham, AL. Experiences of patients in other settings may differ, although we would anticipate many similarities. We did not capture data on factors that may have influenced participants' experience across the AVF continuum, such as the timelines of referrals for access placement or the availability of support to navigate the process of access placement. We were not able to draw direct conclusions on potential racial differences in patient perspectives on AVFs because we had a limited number of White participants. Interviews were relatively short which may have limited the richness of qualitative data; however, this was balanced by a large number of total interviews. Qualitative analysis was conducted after the conclusion of all interviews, and we did not use a constant comparative method.⁴⁰ The number of interviews required to reach thematic saturation was not quantified. We focused our analysis on perspectives surrounding AVFs, which are not the ideal vascular access for all people with kidney failure.⁴¹ Finally, we did not assess longitudinal perspectives of individual participants as they experienced the AVF care continuum.

The primary strength of our study was qualitative assessment of perspectives of HD patients who are at

different stages of the AVF care continuum, which differs from prior studies of patient preferences surrounding vascular access.^{42,43} We present perspectives from 59 predominantly Black patient participants, providing insights on potential reasons for racial disparities in vascular access. These participant perspectives are important to consider when optimizing implementation of national guidelines, which advocate for more person-centered vascular access care.¹

In conclusion, among a group of predominantly Black dialysis patients, we identified themes that framed patient perspectives of AVF placement, maintenance, and use. We highlighted facilitators and barriers to successfully traversing the AVF care continuum, with emphasis on the potential roles of predialysis care, patient support, education, and shared decision making. These findings may inform interventions designed to optimize patient outcomes and address disparities surrounding dialysis vascular access.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Figure S1: Coding tree for qualitative analysis.

Item S1: Interviewer's guide for semistructured interviews.

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