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Veteran and clinician experiences with Veterans Health Administration (VA) and non-VA community-based care for liver and kidney transplantation following implementation of the MISSION Act

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Title
Veteran and clinician experiences with Veterans Health Administration (VA) and non-VA community-based care for liver and kidney transplantation following implementation of the MISSION Act

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Abbreviations
Advance Practice Provider (APP); Corporate Data Warehouse (CDW); Maintaining Internal Systems and Strengthening Integrated Outside Networks (MISSION), National Surgery Office (NSO); Veterans Health Administration (VA), VA Medical Center (VAMC), VA Transplant Center (VATC), United States (U.S.)

Keywords
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Author contributions
CD performed data analysis, interpretation of results, and manuscript drafting. KH and NB conducted qualitative data analysis. KH and AMS conducted participant interviews. SW and SR contributed to study conception, design, and supervision. All authors contributed to interpretation of findings, critically reviewed and revised the manuscript, and approved the final version.

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Data availability statement
The data generated and analyzed during this study are not publicly available because interview transcripts contain sensitive information and may include potentially identifiable participant information. Requests for access to de-identified data may be considered on a case-by-case basis, subject to U.S. Department of Veterans Affairs policies, applicable regulatory and ethical approvals, and data use agreements.

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Abstract

Purpose:
The Veterans Health Administration (VA) historically provided transplant care through regional VA Transplant Centers (VATCs). The 2018 MISSION Act expanded access to community-based healthcare, allowing Veterans to receive transplant care through VA, community programs, or both. Factors shaping Veterans' choice of and experiences across care settings remain poorly understood.

Methods:
We conducted semi-structured interviews (08/2022-06/2024) with Veterans, VA transplant clinicians, and clinician-leaders nationwide to identify barriers and facilitators of VA and community care for kidney and liver transplantation. Interviews were analyzed using deductive and inductive coding.

Results:
We interviewed 66 Veterans and 52 VA clinicians, including 10 leaders. Veterans cited personal preference (56%), lower cost (30%), program outcomes/reputation (21%), and travel/lodging assistance (20%) as VA care facilitators, while travel burden (35%) was the most common barrier. Clinicians emphasized continuity/communication (75%), travel support (48%), patient preference (40%), and VATC familiarity (39%) as facilitators, while travel limitations and caregiver requirements (each 54%) were the most common barriers. For community care, Veterans identified trust (32%) and proximity (20%) as facilitators, while clinicians cited improved geographic access (50%) but noted administrative barriers (50%), communication gaps (33%), and variable oversight (17%) as barriers. Across groups, participants emphasized the need for improved patient education, care coordination and navigation, and earlier referral.

Conclusion:
VA care was facilitated by continuity, coordination, and travel support but limited by travel burden. Community care improved geographic access but introduced administrative and communication barriers. Strengthening education, care coordination/navigation, and travel support may improve Veterans' transplant experiences and access across care settings.

Introduction

For over six decades, the Veterans Health Administration (VA) Transplant Program has provided comprehensive transplant care for Veterans enrolled in the VA healthcare system.[1] In recent years, the VA has received more than 2,500 referrals for transplant evaluation, placed over 800 Veterans on the transplant waitlist, and performed more than 400 solid organ transplants annually, predominantly kidney and liver transplants.[2, 3] Historically, Veterans in need of organ transplantation were required to travel to VA Transplant Centers (VATCs) for evaluation and surgery. To increase Veterans' access to care, the Maintaining Internal Systems and Strengthening Integrated Outside Networks (MISSION) Act of 2018 expanded eligibility for community-based care across a broad range of healthcare services, with explicit provisions for all facets of transplant-related care.[1, 4, 5] As a result, Veterans may now receive transplant care through the VA, community programs, or a combination of both (dual care) at different stages of the transplant process.

Although the MISSION Act was designed to improve healthcare access, little is known about Veterans' experiences or the factors influencing decisions about whether to pursue transplant care through VA or community transplant programs in the post-MISSION era. Concerns regarding expanded community-based care have included potential variation in access to and quality of transplant care, as well as increased care fragmentation—challenges that have adversely affected care delivery in other healthcare settings.[6-13] These concerns are compounded by the fact that the VA has a longstanding, well-resourced transplant program with a demonstrated ability to deliver timely, high-quality care within an integrated health system.[5] However, the VA Transplant Program's centralized structure may require Veterans to travel substantial distances to a VATC for evaluation, transplantation, and follow-up care, potentially leading to reduced access.[14] How Veterans and their care teams navigate these tradeoffs remains poorly understood.

To better characterize transplant care decision-making following the MISSION Act's expansion of community care, we conducted a qualitative study examining the perspectives of Veterans, VA clinicians, and VA clinician-leaders on facilitators of and barriers to liver and kidney transplantation through VA care, community care, or dual care. Understanding the experiences of these key shareholders and the contextual factors that shape transplant care decisions may inform strategies to improve care across the transplant continuum and more effectively meet the needs of Veterans.

Methods

Overview

We conducted semi-structured interviews to explore the experiences and perspectives of Veterans, VA clinicians, and VA clinician-leaders regarding barriers to and facilitators of Veterans' use of VA, community, and dual transplant care. We used a qualitative approach to capture the complex experiences and perspectives that influence transplant care decisions and identify barriers and facilitators not readily captured through quantitative data. The VA Pittsburgh Healthcare System (VAPHS) Institutional Review Board approved this research as a minimal risk study.

Study Participants

Study participants included Veterans, VA clinicians, and VA clinician-leaders. Veterans who were listed for or received kidney or liver transplantation between November 20, 2020 and November 20, 2022 were sampled, excluding Veterans who had died, based on purposeful sampling by organ type (kidney vs. liver), transplant status (waitlisted vs. transplanted), and location of transplant care (VA vs. community vs. dual care).

VA clinicians were eligible if they were involved in liver or kidney transplant care at either a VA transplant center or a non-transplant VA referring center. Eligible clinicians included transplant coordinators, advanced practice clinicians (APPs), transplant surgeons, transplant nephrologists, and transplant hepatologists. VA clinician-leaders were clinicians with administrative or leadership roles in VA transplantation and/or community transplant care, including directors and other national organizational leaders.

Recruitment

We mailed Veterans a letter informing them that, unless they opted out, a study coordinator would contact them by telephone to assess interest in participation, confirm eligibility and transplant status, obtain verbal consent, and schedule an interview. Veterans received $25 in compensation for participating. We recruited eligible VA clinicians and clinician-leaders by email. An initial email explained the study and provided study

contact information and a second email was sent after 4 weeks to those who did not respond. We scheduled interviews with clinicians who contacted the study team and agreed to participate.

Interviews

We developed semi-structured interview guides to obtain perspectives and experiences from Veterans, VA clinicians, and VA clinician-leaders regarding liver and kidney transplantation and transplant-related care (**Appendices 1-2, 3, and 4, respectively**). We were particularly interested in understanding perceived barriers and facilitators for obtaining transplant services from VA and non-VA clinicians through the VA Community Care Program. Interview questions were informed by prior studies and Andersen's Behavioral Model of Health Services Use, which posits that utilization of healthcare services is determined by predisposing factors, enabling factors, and need.[15] The guides included structured demographic questions and questions about role in transplantation, as well as semi-structured questions with follow-up probes designed to ensure that relevant issues were covered consistently across participant groups while allowing flexibility to pursue the richness and nuances of details salient to individual participants.[16] Our multidisciplinary study team developed and refined the guides with input from a Veterans Transplant Advisory Board (a group of 6-8 transplant recipients from the VA Pittsburgh Healthcare System). Two trained qualitative interviewers (KLH and AMS) conducted one-on-one interviews via Microsoft Teams from 08/2022-06/2024. Veteran interviews lasted an average of 40 minutes, while clinician and clinician-leader interviews lasted an average of 37 minutes.

Coding and Analysis

We audio-recorded and transcribed interviews for analysis in NVivo 12 Plus (Lumivero, Denver, Colorado). Two trained qualitative analysts (KLH and NMB) performed content analysis using a combined deductive and inductive approach to systematically examine factors specified by an established conceptual framework while remaining open to additional themes and explanations emerging from participants' experiences. Deductive coding drew on Andersen's Model and included *a priori* categories for contextual factors, individual predisposing and enabling factors, and provider factors, while inductive coding used the constant comparative method to identify additional themes and categories that emerged from the data.[15, 17] The analysts first developed a codebook for clinicians and clinician-leaders through iterative open coding and organization of categories into broader domains.[18] They then adapted this codebook for Veterans by refining terminology and adding categories specific to Veteran experiences. The analysts resolved discrepancies through joint critical review and negotiated consensus.[19] We used matrix analysis to examine patterns in the recurrence, distribution, and inter-relationships of categories[22] and compared findings by transplant type (kidney vs liver), transplant stage (waitlisted vs transplanted), location of transplant care (VA vs community vs dual), and clinician and leader subgroups. We also compared findings between patients and clinicians/leaders to identify cross-cutting themes. Due to overlapping themes, VA clinician and clinician-leader responses were combined into one group.

Sample size ranges were predetermined based on published standards for in-depth qualitative research.[19] The qualitative team iteratively assessed sufficiency and consistency of the interview content as data collection progressed and concurred that the final sample provided adequate information power to answer the research questions.[20]

Results

Participant characteristics

We interviewed 118 participants, including 66 Veterans, 42 VA clinicians, and 10 VA clinician-leaders. Among Veterans, 29 (44%) had been listed for or received kidney transplantation and 37 (56%) had been listed for or received liver transplantation. At the time of the interviews, 27 (41%) Veterans were active on the transplant waitlist and 39 (59%) had undergone transplantation. By location of care, 30 (45%) Veterans were waitlisted or underwent transplantation through a VATC, 24 (36%) through a community transplant program, and 12 (18%) remained dually waitlisted. Clinicians included 11 (21%) transplant nephrologists, 11 (21%) transplant hepatologists, 1 (2%) transplant surgeon, 13 (25%) transplant coordinators, and 7 (14%) APPs. VA clinician-leaders included 4 (8%) administrative directors and 6 (12%) other VA leaders. Participant characteristics are summarized in **Table 1**.

Veteran perspectives

Most Veterans reported being offered transplant services through either a VA Transplant Center (VATC) or through a combination of VA and community care (39% and 44%, respectively), while fewer Veterans described being offered community care alone (17%). More than three-fourths of Veterans (77%) reported exploring transplant referral options with their provider, with fewer than 10% reporting that clinicians encouraged one pathway over another.

Veterans identified personal preference (56%), lower cost (30%), positive outcomes or center reputation (21%), and assistance with travel and lodging (20%) as the main facilitators of VA transplant care, while travel feasibility (35%) was the most commonly reported barrier. In contrast, the most common facilitators of community transplant care were trust or confidence in community programs (32%) and greater travel feasibility (20%), with few reported community-specific barriers (all ≤6%). Beyond factors specific to VA or community care, Veterans identified clinical outcomes and quality (46%), waitlist times (29%), and hope or a positive feeling about a particular program (11%) as additional considerations when choosing where to receive transplant care.

Veterans also described several challenges that extended across care settings. They characterized navigating the transplant process as logistically burdensome (18%), due to the complex requirements and numerous appointments needed for pre-transplant testing, and emotionally overwhelming (18%). Veterans also identified social determinants of health (20%), such as language barriers, employment-related constraints, and housing concerns, as well as mental health or addiction disorders (14%), as barriers to accessing or navigating transplantation.

Finally, Veterans identified several opportunities to improve transplant care across all settings, most commonly increased patient support and education (26%), additional caregiver support (11%), improved post-transplant care (9%) and better communication between patients and clinicians (9%). Representative quotations illustrating major themes from Veteran interviews are presented in **Table 2**.

VA clinician and clinician-leader perspectives

Clinicians, including those with leadership or administrative responsibilities, identified several facilitators and barriers of both VA and community transplant care. The most common facilitators of VA transplant care were continuity of care and communication (75%), travel and lodging assistance (48%), patient preference (40%), and provider experience with VATCs (39%). Additionally, 42% reported that VA services help mitigate social determinants of health affecting transplant access and care, such as socioeconomic challenges, housing instability, and limited transportation. One provider explained, “Because there are so many resources available on the VA side that are not available in the non-VA community sector, those issues are typically already addressed or available as a resource”. The most commonly reported barriers to VA transplant care were difficulty identifying a caregiver (54%) and feasibility of travel (54%).

For community transplant care, clinicians and clinician-leaders most commonly identified the ability to minimize travel and receive care closer to home (50%) as a facilitator. Commonly reported barriers included administrative obstacles to community care referrals (50%) and communication difficulties between VA and non-VA clinicians (33%).

Beyond factors specific to VA or community care, clinicians and clinician-leaders identified several additional factors influencing Veterans’ decisions about transplant care, including patient preference (54%), location or travel feasibility (52%), transplant outcomes or quality (50%), medical complexity and eligibility criteria (31%), and waitlist times and organ availability (29%). Finally, they offered several suggestions for improving transplant care for Veterans, including increasing patient support and education (58%), earlier identification and referral of transplant candidates (29%), implementing a transplant navigator position or strengthening care coordination (27%), and streamlining VATCs referral processes (25%). Representative quotations illustrating major themes from clinicians and clinician-leader interviews are presented in **Table 3.**

Veteran perspectives by group

Veteran perspectives differed by transplant type, transplant status, and location of care. By transplant type, several differences emerged in the factors influencing Veterans’ preferences for VA care. Liver candidates and recipients were more likely to describe the importance of provider-patient relationships (11% vs 4%),

communication or continuity of care (14% vs 0%), and support of the unique needs of Veterans (16% vs 4%) as reasons for choosing VA care. In contrast, kidney transplant candidates and recipients more commonly emphasized proximity to a VATC (28% vs 8%) and were less likely to report health-related barriers to travel (0% vs 8%). Recommendations for improving care also differed by transplant type, where liver patients more commonly suggested that the VA provide more support and education for patients than kidney transplant patients (35% vs 14%, respectively).

Perspectives also differed by transplant stage. Waitlisted Veterans more commonly expressed a preference for VA care (74% vs 44%, respectively) and were more likely to describe the process as emotionally overwhelming than Veterans who had already undergone transplantation (30% vs 10%, respectively). Waitlisted Veterans also more commonly suggested that the VA increase both access to and the number of transplant centers (11% vs 0%) while providing more robust caregiver support (19% vs 5%).

Differences were also observed according to location of transplant care. Among Veterans who were waitlisted or transplanted at a VATC, the most commonly reported reasons for choosing VA care were personal preference (73%), center reputation (43%), lower cost (40%), distance (37%), and travel/lodging assistance (30%). Dually listed Veterans similarly identified personal preference (50%), lower cost (25%), and greater travel feasibility (25%) as facilitators of VA transplant care. In contrast, Veterans receiving care through community transplant programs frequently cited travel limitations (71%) and negative prior experiences with the VA (21%) as barriers to choosing VA care. Negative experiences with the VA included poor surgical and procedure outcomes, dissatisfaction with the physical environment of the hospital, and lack of trust in the VA clinicians and system. Among these Veterans, 58% reported trust or confidence in their community transplant program, 46% cited greater travel feasibility, and 25% reported a VA affiliation with a local community transplant center as facilitators of receiving community transplant care. Confidence in community programs was also a commonly reported consideration among dually listed Veterans (50%).

Additionally, Veterans receiving community or dual care more commonly identified mental health or addiction-related barriers to transplantation than those receiving VA care alone (21% and 17% vs 7%, respectively). Veterans receiving VA or dual care were more likely to recommend increased patient support and education than those receiving community care (33% and 25% vs 17%, respectively). Despite these differences, experiences with transplant care were mixed across care settings, with similar proportions of patients reporting positive and negative experiences in the VA (33% vs 29%, respectively) and community settings (21% vs 14%, respectively).

VA clinician and clinician-leader perspectives by group

Among VA clinicians and clinician-leaders, perspectives differed by transplant type and professional role. By clinical specialty, several differences emerged in the perceptions of factors influencing VA and community care. Compared with kidney transplant clinicians, liver transplant clinicians more commonly identified travel limitations as a barrier to VA transplant care (73% vs 46%), but also more commonly emphasized the value of VA travel and lodging assistance (60% vs 31%). Liver transplant clinicians more commonly described using community care for specific surgeries or clinical circumstances (27% vs 0%), yet they were also more likely to cite communication difficulties with non-VA clinicians (40% vs 23%). Beyond factors specific to VA or community care, liver transplant clinicians more commonly discussed additional insurance options (40% vs 23%), clinical outcomes or quality of care (73% vs 39%), and patient factors such as age or acceptance of blood transfusion (20% vs 0%) as considerations for transplant care. They also more frequently recommended additional provider education about the transplant process (33% vs 4%) and suggested additional programmatic investment and provider support (27% vs 4%).

While perspectives on the barriers and facilitators to VA and community care were generally similar across professional roles, specific groups raised distinct concerns. Hepatologists from non-transplant VAs noted communication challenges with VATCs (27%), while transplant coordinators commented on Veterans' limited awareness of their benefits (23%) as barriers to VA care. For community care, transplant coordinators frequently identified a formal VA affiliation with a local community transplant center (69%) as a facilitator, whereas both coordinators and APPs commonly described administrative barriers in the community care referral process (69% and 71%, respectively). Clinician-leaders recognized Veteran's preferences for local care

and reduced travel (67%) but also reported concerns about quality assurance and described concerns about poor outcomes at community programs (83%).

In addition, transplant nephrologists and APPs also frequently emphasized the importance of Veterans' support systems (both ≥70%). Although a majority of those interviewed discussed the need to increase patient education and support (>50% for all positions except transplant coordinators), APPs also commonly requested additional resources for caregivers (57%), while transplant nephrologists and leaders focused on earlier referrals (both ≥50%), and administrative directors concentrated on clinical processes such as care navigation and referral procedures (each 50%).

Cross-cutting themes across shareholder groups
Despite differences in their roles and experiences, Veterans, VA clinicians, and VA clinician-leaders identified several shared considerations that shaped transplant care decisions between VA and community settings. These cross-cutting themes included perceived transplant program quality, trust, reputation, and outcomes; patient-provider relationships; communication and continuity of care; familiarity and established relationships with community transplant centers; Veteran-centered aspects of VA care; geographic access and travel feasibility; VA support for travel and lodging; and other financial considerations. Representative quotations illustrating these shared perspectives are in **Table 4**.

Discussion

This study explored Veteran and VA clinician perspectives, including those of clinician-leaders, about VA, community, and dual care for liver and kidney transplantation. The MISSION Act of 2018 aimed to expand eligible Veterans' access to healthcare, allowing for transplant evaluation, waitlisting, surgery, and post-transplant care both within and outside of the VA.[4, 5, 21] Consistent with the goals of this legislation, our findings highlight that patient preference remained a key determinant of transplant site selection. Veterans, clinicians, and clinician-leaders consistently emphasized the importance of individualized choice when deciding where to obtain or refer for transplant care. Key factors influencing these preferences included trust, medical complexity, distance from VA vs. non-VA transplant centers, and caregiver support. Our study also highlights the critical role of services, such as transportation, lodging, and patient navigation, as well as opportunities to improve access and care coordination.

Trust, reputation, and prior healthcare experiences frequently shaped Veterans' decisions about where to receive transplant care. While Veterans often focused on clinical outcomes and quality of care, subjective factors like hope or a positive impression of a program also influenced their preferences. VA clinicians and clinician-leaders similarly highlighted the importance of clinical outcomes, largely citing concerns about limited familiarity, lack of trust, and minimal quality oversight for non-VA programs. Recent studies suggest that overall transplant outcomes at VATCs are favorable compared to community transplant centers, including patient survival, graft function, and quality of life.[22-24] Our findings suggest that perceptions about care quality play a central role in referral decisions and underscore the importance of the UNOS requirement to incorporate objective outcome data into discussions about transplantation. Shared decision-making is an evidence-based approach that integrates patient values with unbiased evidence and reasonable treatment alternatives to support individualized care. While shared decision-making has been widely studied across medical fields, its role in solid organ transplantation remains poorly characterized.[25, 26] Given the complexity of transplant decision-making and its implications for access to a limited, life-saving treatment, this study addresses a critical knowledge gap by improving our understanding of the factors that influence access to and outcomes after solid organ transplantation.

Our findings underscore the importance of ongoing financial support for transportation and lodging for Veterans seeking transplantation. Despite VA's comprehensive travel assistance program at the time of data collection, geographic distance and travel feasibility remained significant structural barriers to transplant care for many of the interviewed Veterans. A Veteran's residential location often determines where they receive care, especially when advanced disease or limited mobility impair long-distance travel. Policies requiring Veterans to pay transportation costs upfront and await reimbursement may further exacerbate these barriers, particularly for those with limited financial resources.[27] Prior to the MISSION Acts, transplant care was largely limited to VATCs, with 40% of referrals coming from centers >500 miles away.[5] Veterans experienced lower rates of kidney waitlisting and transplantation compared to privately insured patients,[28, 29] and distance from a VATC

was associated with decreased access to liver transplantation.[14] Although the MISSION Act was designed to mitigate these disparities by expanding access to local community (non-VA) care, our findings suggest that travel burden continues to be a challenge and reinforce the importance of ensuring transportation support for Veterans seeking transplantation.

Across patients, clinicians, and clinician-leaders, the complexities of navigating transplant care emerged as a common theme. Patients felt that the transplant process was both logistically burdensome and emotionally overwhelming, while VA clinicians and clinician-leaders emphasized the challenges of coordinating care. Clinicians noted that referrals to VATCs were a familiar and well-established process that supported communication and continuity of care. In contrast, they described administrative obstacles in the community referral process and communication barriers with non-VA transplant clinicians, although formal affiliations with local community transplant centers were often helpful. These findings align with prior concerns outside of transplantation that dual care may contribute to care fragmentation through communication barriers, a lack of shared medical records, duplication of tests, and delays in care, resulting in higher rates of hospital admissions, worse clinical outcomes in cancer and cardiovascular disease, medication errors, increased costs, and greater utilization of low-value care.[6-13] To address these challenges, participants frequently suggested the need for improved care coordination, such as implementing a transplant navigator or streamlining the referral process for VATCs.

In our interviews, the most common suggestion for improving transplant care was the need for greater patient support and education throughout the transplant journey. This recommendation was strongest among liver transplant patients compared to kidney recipients or candidates, as well as for those navigating VA or dual-care pathways compared to those in exclusively community care. This highlights a need for future research into how different programs approach patient education, which may provide insight into how to address patient knowledge gaps and better support Veterans. Prior studies have suggested that approaches such as multidisciplinary care teams, educational videos, culturally tailored interventions, and peer support programs can improve patient understanding about transplantation.[30-34] Health literacy is also an important consideration, as over half of Veterans (55%) have limited or inadequate proficiency.[35] Our findings underscore the need to identify and implement effective strategies to improve transplant education, increase patient understanding of their health, and reduce the burden associated with navigating complex transplant care.

Beyond patient education, further research is needed to explore the role of external support in the VA transplant process. While clinicians identified difficulty finding a caregiver as a major barrier in transplant eligibility, Veterans themselves rarely mentioned this as a factor influencing their transplant-related care. Because our study included only Veterans who were already waitlisted or transplanted, participants had successfully completed the evaluation process and therefore may not reflect the experiences of patients still undergoing initial transplant evaluation and those who were not deemed eligible, who often face challenges demonstrating adequate social support. Additional research is needed to evaluate barriers from the perspective of Veterans who do not progress to the waitlist and explore how transplant programs can better facilitate access to social support resources to ensure equitable access to transplantation for Veterans.

Our findings must also be considered within the context of the unique challenges faced by Veterans. While the VA offers a robust infrastructure of transplant-related support, resources, and programs that are tailored for Veterans, Veterans using VA experience a disproportionate burden of chronic health conditions, mental health comorbidities, substance use disorders, and housing and financial instability compared to non-Veterans.[36-41] In addition, racial disparities in access to transplantation in the US are well established outside of VA, and Veterans are more likely to belong to racial and ethnic minority groups compared to the general US population.[42-44] Notably, in other research studies some racial disparities in healthcare access and quality are less within the VA healthcare system versus in the US at large.[45, 46] It is critical to understand the determinants of disparities and ensure that eligible Veterans can access transplant evaluation and services. Given the subjective nature of transplant candidacy and variable listing criteria by center, long-term listing and transplant outcomes should be studied with a focus on strategies that improve access to and quality of care. That said, Veterans, clinicians, and clinician-leaders spoke about the VA's ability to meet the unique needs of Veterans during the transplant process. Specifically, VA clinicians and clinician-leaders reported that VA services help mitigate barriers related to social determinants of health, while Veterans waitlisted or transplanted at a VATC less frequently identified mental health or addiction as barriers to transplantation than those receiving

community or dual care. These findings underscore the continued importance of VA's transplant infrastructure in supporting the complex medical and psychosocial needs of Veterans, even in the setting of expanded access through the MISSION Act.

Finally, our study identified shifting perspectives across various stages of transplantation. Veterans on the waitlist (compared to those who had undergone transplantation) more frequently discussed feeling overwhelmed compared to transplanted patients, which is not unexpected given the uncertainty of awaiting a donor organ and the physical and emotional burdens of living with end-stage liver or kidney disease. However, these stressors may influence how Veterans perceive their care and highlight a stage where additional support may be beneficial.

There are several limitations of this study. While it represents a large, national sample of Veterans, clinicians, and clinician-leaders, qualitative work is dependent on the representativeness of the sample, which limits our ability to draw conclusions beyond the study participants. We did not have adequate samples to evaluate the differences in experiences between affiliate VATC programs (where the transplant surgery occurs at an associated university) and in-house VATC programs (where surgery occurs on VA property). However, the planned follow-up quantitative study may provide additional insights into these differences. While coding consistency can be challenging in qualitative research, our team achieved strong, consistent agreement between coders. Despite this, it is important to interpret percent differences between groups with caution, since interviews are unique and follow a series of probes, rather than using uniform closed ended question formats that ensure that each respondent answers the same questions. Another potential limitation was that we did not capture perspectives of patients or clinicians outside the VA system. Finally, as noted above, we included only Veterans deemed eligible for transplantation, meaning that the patients who potentially faced the greatest barriers to transplantation were not included in the sample. While this was aligned with the goal of this study was to understand the decision-making regarding transplant referral and location of care among eligible candidates, these findings should be interpreted within the context of the study population. Despite these limitations, the richness of the quotes and the alignment of patients, clinicians, and clinician-leaders regarding challenges and opportunities for improvement offer actionable strategies to improve transplant care for Veterans, regardless of where they receive care, demonstrates the value of this relatively large qualitative study.

The landscape of VA transplantation changed significantly following the passage of the MISSION Act, which expanded Veterans' access to community medical centers for transplant-related care. This qualitative study sought to characterize the experiences and perspectives of patients, clinicians, and clinician-leaders, regarding experiences with transplantation pathways in VA, community care, and both. Personal preference, geographic considerations, and patient support and education were central to Veterans' overall experiences and their decisions about where to receive transplant care. Insights from these interviews are critical to future efforts to improve access to transplantation for Veterans and ensure that Veterans' experiences, voices, and needs are meaningfully incorporated into care delivery and policy.

Table 1: Study participant characteristics

Veterans (N=66)	
Transplant type	
Kidney	29 (44%)
Liver	37 (56%)
Transplant status	
Transplanted	39 (59%)
Waitlisted	27 (41%)
Transplant care location	
VA Transplant Center	30 (45%)
Community	34 (36%)
Dual	12 (18%)
Age (*1 missing, N=65)	60.4 (10.6)
Sex	
Male	56 (85%)
Female	10 (15%)
Race/ethnicity	
White	31 (47%)
Black or African American	16 (24%)
Hispanic	9 (14%)
Multiple races	6 (9%)
American Indian or Alaskan Native	3 (5)
Asian	1 (2%)
VA clinicians and clinician-leaders (N=52)	
Transplant surgeon	1 (2%)
Transplant nephrologist	11 (21%)
Transplant hepatologist	11 (21%)
Transplant coordinator	13 (25%)
Advance practice provider	7 (14%)
Administrative directors	4 (8%)
Other operational leaders	6 (12%)

Table 2: Veteran-reported facilitators of and barriers to VA and community care for liver and kidney transplantation

	Total Cohort (N=66)	Representative Quote(s)
VA facilitators		
Patient preference	37 (56%)	"[The VA] has been there for me, so I can't really say anything bad about them. I'm for the VA big time. And I won't change that."
Lower cost of care	20 (30%)	"For me, it would be an economical decision, and with me being a veteran and 100% covered, it would only make sense to go to the VA."
Positive clinical outcomes or reputation	14 (21%)	"I got on the internet, and I found out that [VATC university affiliate] was like one of the top four hospitals in the United States for transplants. And so I said, well, this ain't even a choice. I'm gonna take [VATC university affiliate], and that's the way I went."
Travel and lodging assistance	13 (20%)	"That's why I'm kind of sticking with the VA system because [the VATC], they'll fly me and my wife out, and they'll handle all the transportation needs. And then all that, they'll put us up in a resort or whatever while I recover."
Geographic proximity	11 (17%)	"I just chose the [VATC] that was closest to me. I didn't have to deal with any additional steps in order to get outside care because there wasn't a facility near enough. [VATC] just happens to be in my backyard, so to speak."
VA resources and Veteran-centered care	7 (11%)	"My feeling all along was that I'm a Veteran, and the people working there at the VA transplant hospital, in my opinion ... they either were there because possibly they had been Veterans or they really cared for Veterans and wanted to help Veterans out more so than just a regular facility that treated everybody."
VA barriers		
Feasibility of travel	23 (35%)	"I would have to fly to [VATC] every single time. And who would come see me? My family wouldn't be able to come see me. Friends wouldn't be able to come see me. Who could afford to come out? So, I'd essentially be by myself and just my caregiver."
Negative perceptions or prior adverse experiences	8 (12%)	"I had a procedure, two procedures at the VA before, and I didn't like the way they performed their procedures on me. So, I use them because I served the country, but I'm not a fan of how they operate on people."
Community facilitators		
Trust in community programs	21 (32%)	"[I am] 100% confident in [community program's] abilities. I mean, they do transplants daily. Multiple transplants … they have a tremendous reputation."
Feasibility of travel	13 (20%)	"When they told me that under the [community] care network I would be able to go [community program], that was the perfect location for me, as it's only 35 minutes away."
VA affiliation with a community program	7 (11%)	"And the connection that [community program has] with the VA, and that they are right across the street from each other, and a lot of the VA doctors work at both facilities or see

		patients at both facilities is very, very, commendable. And it's just a great system that they have there."
Other decision factors		
Social determinants of health	13 (20%)	"The only barrier, maybe is that [my caregiver] doesn't know too much English. So, she mostly needs an interpretation and translator for her. And in regards of my decisions or talking with any specialist doctor, that's the only thing."
Logistical challenges	12 (18%)	"All the testing that I do every month to stay ready for surgery … it seems like a never-ending progression of appointments that sometimes I just forget because there's so many of them, and they schedule them four or five, six months out, and my memory span is no longer capable of retaining something for six months."
Emotional burden	12 (18%)	"The main challenge is keeping my mind focused on this is what I have to do and don't let my depression gets to me and maintain a solid mind that the things I'm doing is what I need to do and I have to do in order to be here … It's not an easy thing to go through this. It takes a lot of dedication to want to be here."
Mental health or substance use considerations	9 (14%)	"For me, the sobriety level, it's pretty easy. Because I quit cold turkey. They said, 'Well, you continue drinking and live a short life or you stop drinking today and live.' So it was like hmm, a no brainer. I guess the hardest part was getting the help I needed for my PTSD. Seeing a therapist, then going through all that."

Abbreviations: VA=Veterans Health Administration (VA), VATC=VA Transplant Center

Table 3: VA clinician and VA clinician-leader-reported facilitators and barriers to VA and community care for liver and kidney transplantation

	Total (N=52)	Representative Quote
VA facilitators		
Communication and continuity of care	39 (75%)	"I encourage them to stay within the VA healthcare system because the communication is so much better." (Transplant Referral Coordinator)
Assistance with travel and lodging	25 (48%)	"If they choose a VA transplant site, service connected or not, we're gonna cover that 100% for both them and their support person to fly or drive—whatever they choose at that time. So I think that's huge in the decision-making process too, knowing what their options are as far as being able to get reimbursed for travel and such." (Transplant Referral Coordinator)
Patient preference	21 (40%)	"I feel like for the most part Veterans do have a lot, a great deal of confidence in the care that they're receiving, including transplant related care." (Transplant Hepatologist)
Familiarity with VA care	20 (38%)	"I think familiarity with what kind of quality and care is provided by the transplant center. I definitely think whether the center is known to us…and the physicians [are] known to us. So, I may have a particular bias for the VATCs because I know the nephrologist there, and I know the kind of care they provide…If there was a transplant center where the Veteran lived halfway in between, but I didn't know the transplant physicians there or the kind of care and follow up received there, I might be less enthusiastic about making that referral." (Transplant Nephrologist with Administrative role)
Lower cost of care	15 (29%)	"I think that the patients receive better financial support through the transplant process and in post-transplant care by keeping their care within the VA system in terms of reimbursement for travel, medications, and other testing compared to when they're in the community." (Transplant Hepatologist)
Positive outcomes or reputation	13 (25%)	"We do mention to them that the VA does have excellent care and does provide excellent transplant care…That the physicians there are highly qualified and highly trained. They follow strict procedures that are standards of care. And that the outcomes have been excellent in VA care. So, they should feel comfortable no matter which center they go to in terms of Veterans' hospitals to get their transplant care. We tell them that these are selected centers through the VA because they have proven and shown that they have not just the capability to provide standard of care but also the strength and the ability to continue with their care should they need further follow up." (Transplant Nephrologist with Administrative role)

VA resources and Veteran-centered care	11 (21%)	"I think because the VA has so many support groups available, so if there is (sic) any issues with substance abuse in the past or mental health issues that we have the support within the infrastructure to provide that for them. So, I think that's a definite advantage that the VA offers. And our assessment then is more comprehensive to look for these kinds of issues that could impact their success of their transplant afterwards. Again, especially since we do have such detailed involvement with all of the mental health providers within the VA system, as well as the support person for that individual." (Kidney Transplant Coordinator)
Provider preference	7 (13%)	"I think the VA does do a very good job for transplants, and I strongly encourage Veterans to think of the VA option because we do a good job." (Transplant Referral Coordinator)
VA barriers		
Lack of caregiver	28 (54%)	"Support services are challenging for a lot of our Veterans. If we can't find a solid support, you're not technically allowed to just hire somebody [to be a caregiver]. It has to be someone like emotionally involved with the patient that agrees to take care of them after the transplant." (Nurse Manager for Transplant Referral Coordinators)
Feasibility of travel	28 (54%)	"But the disadvantage is that you have to travel. And the VA will pay for all that travel and it won't be out of pocket. But you will have to travel. You may have to, you and your support person, there may be times that you're staying in a hotel rather than at your own home." (Transplant Hepatologist)
Community facilitators		
Feasibility of travel	26 (50%)	"[A] large fraction of patients choose to do one or the other, and it's usually going to be the local [community center] over the VA because of the burden of travel to the VA centers." (Transplant Hepatologist)
Patient preference	8 (15%)	"I'll leave it up to the patient to decide where they want to go because it's an equal opportunity. Some people already have a referring, existing relationship with a provider who may be through [non-VA hospital] or through the other non-academic center, and that's purely up to the patient where they want to go." (Transplant Nephrologist)
VA affiliation with a community program	7 (13%)	"I think we like centers where we have a connection. So for instance, our VA is affiliated with [two university medical centers]. And so usually we work with those two transplant centers just because we have some shared staff [and access into] their electronic medical records, so we can see what's going on. Usually we want some kind of connection that makes it a little bit easier to work with the outside transplant centers." (Transplant Nephrologist)
Trust in community programs	6 (12%)	"As I said, we have excellent transplant centers locally. I have very good confidence in them." (Transplant Nephrologist)
Community barriers		

Administrative and referral obstacles	26 (50%)	"Under the Mission Act, Veterans can be referred outside of the VA for transplant at VA expense. However, there have been issues with getting those transplant programs covered through the third-party coverage. And you need both the hospital and the providers to be within network in order to be able to be referred. And there's been a lack of clarity as to how patients get referred" (Nephrologist, Organizational Leader)
Communication difficulties	17 (33%)	"I think it's logistically easier, technically easier for the Veteran to receive continuity of care and for the whole team to have a full access to clinical information if the program operates in house. We do not have perfect connectivity and interoperability among the electronic health records and electronic data stores among the in-house VA systems and all of the out of house civilian transplant centers. So, one big obstacle in terms of getting in the way of high quality, timely patient care is information flow." (Transplant Hepatologist)
Variable quality assurance or poor outcomes	9 (17%)	"I can't speak to all of them, but I think quality control is another big issue with sending Veterans into the community. We have no control over the quality of organ that they're getting and then a lot of times after the transplant takes place, they'll come back to the VA for care, and we're forced to deal with any complications." (Nurse Manager for Transplant Referral Coordinators)
Lack of travel support	9 (17%)	"There is no travel reimbursement to and from the Community Care Center." (Transplant Hepatologist)
Limited familiarity	8 (15%)	"I'm not as confident with the Community Care sites just because I haven't worked with them as much." (Transplant Referral Coordinator)

Abbreviations: VA=Veterans Health Administration (VA), VATC=VA Transplant Center

Table 4: Cross-cutting themes among Veterans, VA clinicians, and VA clinician-leaders regarding barriers and facilitators of VA and community care for kidney and liver transplantation

Cross-Cutting Themes	Veterans	Providers and Organizational Leaders
Perceived Outcomes, Quality, Trust, and Reputation	"But at the end of the day, I got to talk to [surgeon], which was the chief of surgery, and I got some stats from those guys--what their success rates were, how many operations they performed per year, what's the average age was, how long the longevity of the transplants from those guys. You know, I got a lot of data from those guys and then compared to some other places too, and it seemed to be pretty legit."	"I think in my personal opinion, the most important piece of information the Veterans need to know is the quality metrics of any transplant program, VA or non-VA.…and be able to educate the Veterans when they are in the process of making decisions regarding where to get the transplant care, within VA or outside of VA."
Patient-Provider Relationships	"I had a really good doctor for all these years. He was like the main [liver] doctor in [VA medical center]. And he had been there so long, like 30 years or something. He had a lot of pull, so he helped me a whole lot and he made things just super easy."	"If they trust the information that you give them like as their nephrologist, I think we find that most of the people that we take care of are very happy with the care that they receive here. So many of them, even after they get treatment outside of here, they will call here and get our input just to make sure that the other nephrologists are doing what they should out there. So, we feel that we have a bond with our patients and that we feel that we provide, apparently we provide good care so that they have trust in the VA. And when we refer them to a VA center or tell them that they will get good care even if they choose an outside center based on what we know, based on what they might have done – but they need to believe in where they're going."
Communication and Continuity of Care	“I’m mostly swinging everything to the VA because it’s just less confusing when it comes to keeping track of what doctor is doing what and who.”	"So on the VA side, Community Care side it is, it’s just a lot of chasing... I feel like it's just easier between VA providers, rather in the community they don't really know exactly what VA has to have. And the private process and the VA process can be very different. For instance, like we have to have mental health for liver transplant; they don't have to have that in the private sector unless like social work deems them needing it. And sometimes it's like the outside providers don't really, I don't know, understand all of that."
Familiarity and Affiliation with a Community Transplant Center	"I think that's mostly in part because the people at [community transplant facility] have a working knowledge of my nephrologist. So they have been used to dealing with the VA through him. So that relationship that he had already established before me	“I think we like centers where we have a connection. So, for instance, our VA is affiliated with [two university medical centers]. And so usually we work with those two transplant centers just because we have some shared staff. …Usually, we want some kind of connection that

	played a vital role in it. So it helped me. I benefited from whoever came before me and had to walk that role before me because it was effortless for me ... it seemed like one fluid hospital."	makes it a little bit easier to work with the outside transplant centers."
Veteran-Centered Care (Unique Aspects of VA Care)	"I felt the VA, being Veterans, made me feel like I was with family because they're Veterans. And understood what a veteran goes through."	"I think within VA there is a better understanding of the Veteran population and some of the psychosocial challenges they face, and I think it can be a more favorable environment for transplant candidacy."
Geographic Barriers and Feasibility of Travel	"Initially I was approved to go to [VATC]. That was the quickest, they say, 'Hey, we want you to come to [VATC]. You'll be here for three months'. My wife would have had to go on FMLA and go away from her job. And we have three dogs at the house. We tried to make [VATC] work. We really did. So being that [community transplant facility] is only two hours away from me that became a more logical place as far as far as geographics go."	"Well, so I do inform them that they do have to be close to the transplant center for two to three months after transplant. And just leave it to them whether or not that's gonna be an issue with them having to be in [city where VATC is located] versus being able to be local here. So that plays into the, my experience is that plays heavily into the patient's decision. But not mine. But I do inform them of that."
Support from VA for Travel and Lodging	"They said, 'You'll go to [VATC], but we'll pay for everything.' And that made it very, very simple. They put me up in a penthouse apartment. [Laughs] It was nice. And then transportation to and from the facility."	"So yes, so the first thing that a patient is always concerned about...who's paying for it? How will I get there? Where will my support person be staying at for the time that they're there? So you know, that is a big part of the conversation. Some patients are concerned about going further, having to go further away than staying closer, going to a transplant center closer...It's understood that...our medical center covers the cost of the transportation, and the transplant."
Other Financial Considerations	"I knew I had the insurance, knew I had VA care. I also had Medicare and all that. So that portion was not really a stressor. The stressor was just still being able to [maintain] employment and income from the employment [during transplant]."	"The whole notion in the VA where you need a support system, which I think is great, but that you know that person has to up and go with you potentially 3 or 4 hours away, or even you know, 5 or 6-7 hours away by driving. I don't know that that's the best thing to do for the patient, especially if they are young and have, like a family, a mortgage, a job, right."

Abbreviations: FMLA=Family and Medical Leave Act, SRTR= Scientific Registry of Transplant Recipients, VA=Veterans Health Administration (VA), VATC=VA Transplant Center

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