Examining Mobility Among People Living with HIV in Rural Areas

JUAN F. MAESTRE, Indiana University, USA

TAWANNA R. DILLAHUNT, University of Michigan, USA

ALEC ANDREW THEISZ, Indiana University, USA

MEGAN FURNESS, Indiana University, USA

VAISHNAV KAMESWARAN, University of Michigan, USA

TIFFANY VEINOT, University of Michigan, USA

PATRICK C. SHIH, Indiana University, USA

The rise of ridesharing platforms has transformed traditional transportation, making it more accessible for getting to work and accessing grocery stores and healthcare providers, which are essential to physical and mental well-being. However, such technologies are not available everywhere. Additionally, there is a scarcity of HCI work that investigates how vulnerable populations such as rural-dwelling people with HIV face and overcome transportation barriers. To extend past research, we conducted 31 surveys and 18 interviews with people living with HIV (22 surveys, 14 interviews) and their case coordinators (9 surveys, 4 interviews) in rural areas. Contrary to past research, we found that the use of alternative vehicles, extensive support networks, and nonprofit health organizations facilitated transportation. However, distance, the lack of trust and infrastructure, stigma, and other cultural underpinnings made popular forms of urban transportation unappealing. We contextualize our findings with prior research and contribute implications for future research and design.

CCS CONCEPTS • Human-centered computing~Collaborative and social computing~Empirical studies in collaborative and social computing.

Additional Keywords and Phrases: Mobility, Transportation Barriers, Rural Communities, HIV Care and Management.

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1 INTRODUCTION

Sociotechnical advances have transformed transportation, and HCI research has contributed to these advances. HCI researchers have sought to improve the user experience and safety of driving cars [29], motorcycles [36,57], and riding bicycles [59]. Today, there are driverless cars [78] and electric vehicles that are more environmentally-friendly than gasoline-powered vehicles [34]. Technology has also improved public transportation access by providing additional information such as bus location, routes, and arrival times for

users [4,28,89]. In particular, real-time ridesharing services like Uber and Lyft have been widely explored as a potential opportunity to improve user experiences and the accessibility of transportation. However, these technological advances have primarily benefited those who live in urban areas with adequate transportation infrastructure and access, and where technology literacy levels are higher in comparison to those in rural areas [32]. Transportation access in rural areas is extremely challenging because of the limited access to public transportation, buses, taxis and real-time ridesharing services [32,75]. Thus, people living in rural areas rely more on personal vehicles to cover their transportation needs than urban dwellers [44,70]. Yet, not all rural residents have access to personal vehicles, especially those living in marginalized conditions. The effects of poverty are amplified in rural areas because of long distances to services in addition to lesser transportation access [38,53]. In fact, our findings suggest that the introduction of technology-enhanced transportation models like ridesharing services could bring more negative consequences to rural communities due to trust issues and higher costs than in urban settings.

Thus, it is important that HCI research assess the potential viability of sociotechnical transportation interventions of urban origins for rural areas as the implications for the former may not be applicable or relevant to the latter. In rural regions, the lack of transportation access and barriers are more pronounced (i.e., longer distances and lack of interpersonal trust). Accordingly, our paper contributes to and extends research that focuses on rural dweller's transportation needs. When imagining sociotechnical interventions for rural transportation challenges, it is also important to assess what currently facilitates transportation access in rural areas and to propose ways in which technologies could support existing facilitators and address current barriers. As part of this, given previous work in urban areas with marginalized populations [21], it is necessary to understand the role of stakeholders such as community-based and healthcare organizations in transportation access to health-enhancing resources in rural communities. Access to transportation to health-enhancing resources such as employment, food, and healthcare [21] is especially critical to rural-dwelling people living with HIV. On the one hand, greater transportation barriers are negatively associated with HIV treatment adherence [60,63,82] as individuals living with HIV are less likely to take their antiretroviral medication consistently, which could lead to drug resistance and negative long-term health effects [68]. On the other hand, the HCI field has not studied the impact of transportation access on the wellbeing of people living with HIV. Thus, with a focus on heath-enhancing transportation resources for rural people with HIV, we investigate the research questions below:

RQ1: How do people living with HIV in rural areas travel to healthcare appointments, grocery stores and employment?
RQ2: What role do community-based and healthcare organizations serve in these forms of travel used by rural-dwelling people with HIV, if any?
RQ3: What facilitators and barriers underlie these modes of travel to healthcare appointments, grocery stores, and employment?

To address these questions, we conducted 22 surveys and 14 semi-structured interviews with people living with HIV who reside in rural areas and 9 surveys and 4 interviews with case coordinators from a non-profit HIV support center serving rural areas. Results of this study contribute to the HCI literature in several important ways. First, it empirically describes how a vulnerable population, rural-dwelling people living with HIV, access

and use different transportation models in order to get to jobs, grocery stores, and health care appointments. Second, our work provides a novel description of transportation facilitators and barriers experienced by rural-dwelling people living with HIV. Third, we contrast our findings with those found in similar, urban-based HCI research to identify unique design considerations for rural, technology-enhanced transportation services. Lastly, based on our findings, we present design implications to address transportation barriers while leveraging facilitators of health-related transportation for rural people living with HIV.

2 LITERATURE REVIEW

2.1 Transportation and Wellbeing in Rural Areas

Lack of adequate transportation hinders access to health-enhancing resources such as employment, healthy food, and healthcare [21]. People living in rural areas depend primarily on automobile ownership in order to address their transportation needs; this is due to limited, or absent, public transportation infrastructure [35,70,79]. Consequently, low-income individuals who cannot afford to drive their own cars may face more transportation barriers in rural than urban areas [56,61].

Access to Healthcare. Given that rurality is characterized by long distances between locations and lack of population density [32], people living in rural areas tend to travel greater distances to healthcare appointments than those living in urban areas. This is particularly the case for appointments with medical specialists [9,17,87]. With greater distances, rural dwellers' trips to healthcare appointments may be more expensive [76]. Independent of medical need, people who do not have access to transportation use healthcare less often than those who do have access to transportation [3].

Access to Food. Rural people may have less access to grocery stores than is optimal for their health. A study conducted in rural Iowa [49] found that more than 45% and 66% of residents were not consuming adequate amounts of fruits and vegetables, respectively. This was due to a lack of transportation access and higher costs at small grocery stores close to home. Longer distances and lack of transportation to grocery stores affect low-income people more [13,69], as they are more likely to have fewer grocery stores nearby and are more likely to experience barriers to transportation access [56].

Access to Employment. In rural areas, transportation to jobs usually requires traveling longer distances and spending more money [79]. This situation affects low-income people in particular as they may not have the financial means to commute to jobs [27,37,79]. Moreover, due to limited access to public transportation, rural employees may not be able to use it as an option for their traveling to work. This affects economic opportunity, since employers may be reluctant to hire people who do not have access to reliable transportation [27].

The aforementioned research outlines the existence of barriers to transportation to health-enhancing resources for rural residents, and some of their implications. However, prior research has paid little attention to rural residents' methods for navigating these barriers, and how such methods might be leveraged to provide expanded transportation access. Thus, we extend prior research by focusing on both transportation barriers and facilitators in rural areas.

2.2 Transportation for People Living with HIV in Rural Areas

People with HIV can live longer, healthier lives if they are linked to health care, and remain adherent to antiretroviral medication therapy [83]. Care linkage and treatment necessitate that people living with HIV travel

to medical facilities, where they can complete required laboratory tests and visits to their HIV-specialist physicians [54,63,66]. Travel to obtain medications may also be necessary, depending on insurance plans [48]. Regardless of place of residence, people who experience fewer transportation barriers miss fewer doses of their antiretroviral medications [60,63,82].

Notably, people living with HIV who reside in rural areas face greater healthcare-related transportation barriers than their urban counterparts [48,54,63]. For example, [60] found that 58% of rural-based case coordinators for people with HIV in North Carolina indicated lack of transportation services as a major problem for their patients, as opposed to 30% of case coordinators indicating the same in urban areas. These transportation barriers are exacerbated because the distant locations of HIV specialist providers result in longer travel times [54]. In some cases, people living with HIV in rural areas may travel to distant locations to ensure confidentiality [54,84].

These aforementioned barriers are worsened because public transportation is often unavailable in rural areas [48,63]. Moreover, even if public transportation is available, it may not be easily accessible due to long travel distances to get to bus stops or because of unreliable schedules [63]. Thus, people living in rural areas are more likely to drive their own cars to meet healthcare-related needs rather than use public transportation [32,63,66].

Transportation may be more difficult for people with HIV due to their high poverty levels, advanced ages, and disability rates. Almost a third of people with HIV are over age 55 [58], and HIV prevalence is highest among people who are living at or below the poverty line and/or unemployed [55]. Furthermore, those with advanced HIV or AIDS may be living on a disability income [55]. Those with lower incomes are less likely to own cars, and even if they own cars, lack of money for gas or repairs may impede car usage [48,54]. As one possible solution to lack of vehicle access, scholarship focused on urban areas has noted the importance of the exchange of favors to obtain transportation to health care appointments [21]. Other methods, such as paratransit supplied by insurance companies, ridesharing, and nonprofit volunteer drivers, have also been explored for meeting transportation needs for health care in urban areas [21]. However, it is unclear how applicable these methods may be for rural people living with HIV. The stigma associated with HIV, which has been shown to be higher in rural than urban areas [54,60], may affect willingness to seek transportation assistance from individuals or services provided by those who are neither close family members nor protected by confidentiality policies. Accordingly, there is a need to investigate the potential usage of alternative transportation services among rural people with HIV, and to understand the barriers and facilitators that are important when designing alternatives for this group. Moreover, prior work primarily focuses on transportation to healthcare appointments; yet, this is not the only use case of import to the health of people with HIV. As mentioned, poverty is prevalent among people with HIV, and for those who are able to work, travel to employment may provide important health-enhancing resources (e.g., medical insurance). Food security and diet quality are also associated with health outcomes among people with HIV [55]. Hence, we expand the lens of prior work by considering a wider range of health-related transportation needs among people with HIV than in prior research, including food and employment.

2.3 Transportation in HCI Research

HCI research on transportation has primarily been conducted with respect to urban contexts. For example, researchers have investigated how to improve the user experience when using urban public transportation and

ridesharing transportation services. Studies have looked into the design of technology that could provide ubiquitous and detailed information about bus stops, routes, and arrival times [4,14,23,28,39,89]. Studies have also explored how to improve ridesharing services through novel approaches to matching rivers and riders [12,15,88]. A class of work has also focused on the problem of building well-founded trust between drivers and riders; investigational approaches have included rating and reputation systems [7,16,19,80], making the payment process more transparent to riders [18], and limiting the amount of personal information shared between passengers, drivers, and the technology [80,81].

More recently, HCI research on transportation in urban areas has assessed technology or suggested design implications for technology that would allow vulnerable and underserved populations to overcome barriers to transportation. [20] found that online food delivery systems (e.g., Shipt) help low-income people get access to healthier food options in spite of living in areas that lack access to transportation services. [18] also found that ridesharing can benefit low-income people by reducing costs of transportation, while also providing social interaction between drivers and passengers. Researchers also identified key barriers and facilitators related to participants' use each of those transportation models. These included interpersonal trust, fears of safety, affordability, service availability, and spatial and temporal mismatches [21]. Yet, the transferability of these urban-based models to rural areas is unclear. This work offers implications for public policy and design of new technology-based transportation models that could leverage existing private and interpersonal models. We focus on designing technologies to enhance existing facilitators as they pose the fewest barriers of adoption for the vulnerable populations who are already low on a variety of resources.

The limited prior HCI research on transportation in rural areas has focused on technologies that increase transportation service riders' awareness of the ongoing status of services upon which they are relying. For instance, some work has concentrated on the design of prototypes of technology that could track location and availability of transportation options [52,72,77]. [77] co-designed with older adults both living in urban and rural areas a prototype that would provide them with contextual information regarding different transportation options available depending on their location at any given time [72,77]. With people living in a rural area in the UK, [52] also co-designed a smartphone app and an SMS-based prototype to let users know about public transportation disruptions in real time. Additionally, research conducted in the Global South has also explored the use of SMS-based technology to facilitate connections between drivers and riders [1,2,24]. Initial findings from this research show that users may be interested in such systems, but full deployment of such novel technologies has not yet been completed. Moreover, prior research has not considered the specific constraints associated with health-related transportation.

There is a need for rural HCI research that investigates what transportation barriers vulnerable populations such as people with HIV face, and what facilitators allow them to overcome transportation barriers. This is critical since the financial models underlying existing technology-based solutions rely upon high population density and short distances between locations, which makes it financially difficult for rural drivers to participate. This work bridges existing gap by investigating the experiences and perspectives of rural dwelling people living with HIV and their case coordinators.

3 METHOD

3.1 Regional Focus

This research was conducted in a region comprised of 39 counties within a single state in the United States (US) Midwest. These counties have an average Rural-Urban Commuting Area (RUCA) code of 4.3, indicating that they are non-metropolitan areas, also known as “large rural” [11,67]. This region is primarily agricultural, with an average of 13.6% living in poverty, as compared with 11.8% in the US as a whole. There is a large number of people living with HIV in the area due to a serious outbreak linked to the opioid epidemic in the US. HIV care in the area is primarily provided via two specialist practices located in a large and a mid-sized city, respectively. In the study region, 26 counties are declared medically underserved for primary care. Residents of this region may also have limited Internet access [90]; 37 of 39 counties in the area have areas within them that lack provider of broadband Internet access. Of the 1,508 census tracts in this region, 129 (8.6%) are designated as having low access to food based on distance to the nearest grocery store.

3.2 Procedures

3.2.1 *Recruitment.* We recruited in two phases from May to July of 2020. The first phase consisted of the dissemination of recruitment material (i.e., physical and digital flyer, website ad, and social media post) with the help of an HIV support center located in the study region. The material was disseminated via the center’s social media accounts, an ad on their website, and via an internal newsletter. The material provided information about the aim of the research project and invited individuals who were living in rural areas, were living with HIV, and who were older than 18 to fill out an online pre-interview survey regarding their transportation needs and practices. In addition, we invited the staff of the HIV support center to participate in the study. The material contained a link to an online survey described below. In the second phase, we contacted survey respondents who indicated interest in participating in a follow-up phone interview[1]. We reviewed our consent form with each participant to explain how their data and identity would be protected. The first author then scheduled a date and time for a phone interview.

3.3 Data Collection

3.3.1 Pre-interview Online Survey. The online survey contained informed consent information, and questions about vehicle access (e.g., car, motorcycle, bike), and participants’ sharing of rides with others, for the purposes of travel to work, grocery stores, and healthcare appointments. For each block of questions, the survey included a prompt to remind participants that all questions were to be answered based on their travel experiences during the past year, which was prior to the COVID-19 pandemic. We also included a separate block of questions inquiring about how the pandemic had affected their travel experiences. The survey also contained questions about access to healthcare, disability and chronic conditions, access to technology, and demographics and took an average of 18 minutes to complete. We used a similar online survey for case coordinators at the HIV support center, minus questions regarding access to care, disability, and chronic conditions. At the end of the

[1] Initially the interviews were to be conducted in person at the HIV support center, but due to the Covid-19 pandemic, our team decided to conduct phone interviews to protect participants and researchers.

survey, participants indicated whether they wanted to enter a drawing for two $25 gift cards and whether they wanted to participate in a follow-up phone interview.

3.3.2 *Phone Interview.* The first author called participants and read a description of the study and informed consent information. After obtaining consent, the author conducted the interview using a semi-structured interview guide that contained questions regarding current transportation practices, challenges faced, and help from others for transportation. We also asked participants about the applicability of urban-based transportation models to their local contexts. Interviews lasted an average of 49.3min (SD=10.2) and were audio-recorded and transcribed verbatim for later analysis.

3.3.3 *Participants.* We conducted 31 surveys and 18 interviews with people living with HIV (22 surveys, 14 interviews) and their case coordinators (9 surveys, 4 interviews). Our sample size aligns with those reported in HCI research studies that have recruited people living with HIV in their procedures (e.g., [43,73]) and in interview data saturation guidelines [31]. Recruitment for HCI research of people living with highly stigmatized conditions is challenging, especially in rural areas where the impact of stigmatization is stronger (e.g., [85]). To make the most of the sample, we designed the data collection instrumentation to gather in-depth information regarding the participants' experiences of transportation access. Table 1 contains demographic information of participants. Each participant received a $25 USD electronic gift card sent to their email after the interview was completed.

3.4 Self-Disclosure and Ethical Considerations

We worked with a local HIV support center that acted as part of a community advisory committee to the project. The HIV support center staff provided feedback about the recruitment material, survey, and interview protocols used in this study. This HIV support center provides services to help people living with HIV in the state of [anonymized] by pairing people living with HIV (aka "the clients") with a case coordinator that helps them navigate their HIV care. Care coordination staff help to connect their clients to medical services (e.g., doctors, clinics) and remain in treatment. The first author has been volunteering at this HIV support center since 2017 to better understand how to approach this community with respect and empathy. Additionally, the sixth co-author has conducted community-based HIV research for 18 years. Ultimately, all co-authors share a commitment to foster co-creation of knowledge with participants and abide by ethical guidelines proposed for HCI research with stigmatized populations [40]. All procedures, recruitment material, and protocols received IRB approval at the first authors' affiliated university.

3.5 Data Analysis

All co-authors completed an iterative analysis involving both inductive and deductive approaches. Inductively, the team conducted open-coding analysis after an initial round of data familiarization [65]. Deductive approaches involved creating a codebook based on transportation models, barriers, and facilitators identified

Table 1. Demographics of Study Participants Living with HIV and Case Coordinators.

		People living with HIV Survey Respondents (n=22)	People living with HIV Interviewees (n=14)	Case Coordinator Survey Respondents (n=9)	Case Coordinator Interviewees (n=4)
Age (Mean, SD)		48 (12.6)	49 (12.8)	43 (13.4)	(45, 10.4)
Gender (#/%)	Female	4 (18.2%)	3 (21.4%)	7 (77.8%)	4 (100%)
	Male	18 (81.8%)	11 (78.6%)	2 (22.2%)	-
Race/Ethnicity (#/%) (multiple responses possible)	African American	2 (9.1%)	1 (7.2%)	-	-
	Latino or Hispanic	4 (18.2%)	3 (21.4%)	-	-
	White	17 (77.3%)	10 (71.4%)	9 (100%)	4 (100%)
Education Level (#/%) (highest level completed)	Grade 8 or less	1 (4.5%)	1 (7.1%)	-	-
	Grades 9 to 12, no diploma	2 (9.1%)	1 (7.1%)	-	-
	Some college	11 (50%)	7 (50%)	-	-
	Associate degree	3 (13.6%)	3 (21.4%)	-	-
	Bachelor's degree	5 (22.7%)	2 (14.3%)	7 (77.8%)	3 (75%)
	Graduate Degree			2 (22.2%)	1 (25%)
Monthly Income (#/%)	$0 - $1,000	13 (59.1%)	9 (64.3%)	-	-
	$1,001 - $2,000	7 (31.8%)	4 (28.6%)	1 (11.1%)	-
	$2,001 - $3,000	2 (9.1%)	1 (7.1%)	5 (55.6%)	2 (50%)
	$3,001 - $4,000	-	-	1 (11.1%)	1 (25%)
	$4,001 - $5,000	-	-	2 (22.2%)	1 (25%)
Employment Status (#/%) (multiple responses possible)	Working full-time (30 or more hours)	4 (18.2%)	2 (14.3%)	9 (100%)	4 (100%)
	Working part-time (< 30 hours)	2 (9.1%)	-	-	-
	Unemployed	4 (18.2%)	4 (28.6%)	-	-
	Retired	1 (4.5%)	1 (7.1%)	-	-
	Disabled	11 (50%)	7 (50%)	-	-
	Other - "Closed due to Covid"	1 (4.5%)	1 (7.1%)	-	-
Health Insurance (#/%) (multiple responses possible)	Medicare	9 (40.9%)	6 (42.9%)	-	-
	Medicaid	12 (54.5%)	7 (50%)	-	-
	Private health insurance	5 (22.7%)	2 (14.3%)	-	-
Access to Technology (#/%) (Yes responses)	Desktop computer	7 (31.8%)	5 (35.7%)	6 (66.7%)	3 (75%)
	Laptop computer	16 (72.7%)	12 (85.7%)	9 (100%)	4 (100%)
	Cell phone or smartphone	22 (100%)	14 (100%)	9 (100%)	4 (100%)
	PDA or other personal data device	2 (9.1%)	2 (14.3%)	2 (22.2%)	1 (25%)
	Tablet computer	5 (22.7%)	3 (21.4%)	5 (55.6%)	3 (75%)
	A game console	6 (27.3%)	4 (28.6%)	3 (33.3%)	1 (25%)
	A smartwatch	5 (22.7%)	3 (21.4%)	2 (22.2%)	-
	An activity tracker	2 (9.1%)	2 (14.3%)	5 (55.6%)	1 (25%)
Vehicle ownership (#/%)	a car, van, SUV, or truck	14 (63.6%)	9 (64.3%)	9 (100%)	4 (100%)
	a bicycle	2 (9.1%)	1 (7.1%)	2 (22.2%)	-

in [21]. During analyses, researchers met on a weekly basis to identify, revise, and group the inductive codes into emerging categories with the goal to identify experiences and perspectives that addressed the research questions. The authors discussed and revised codes by engaging in an iterative process of semantic level analysis, dialogue, and refinement. The open source software Taguette was used to facilitate a centralized and shared process of qualitative analysis.

4 FINDINGS

4.1 Characteristics of Participants

As Table 1 shows, the survey and interview respondents were demographically similar. A larger proportion of participants living with HIV were male than female, reflecting the demographics of the epidemic. In keeping with the demographics of the region, the majority of participants were white. Most participants with HIV were living on less than $2,000 per month, and a minority were employed. Just under two-thirds of participants with HIV had a car. By contrast, case coordinators were majority female, white, and employed full time. In this paper, the word 'participants' or 'interviewee' refers to study participants living with HIV who filled out the survey and who were also interviewed; we clearly state when we are referring to case coordinators or survey respondents only.[2]

4.2 RQ1: How do People Living with HIV in Rural Areas Travel to Healthcare Appointments, Grocery Stores and Employment?

Table 2. No. of interviewed participants (more than one response was possible), travel time, and frequency of trips to work, grocery store, and healthcare appointments from home per transportation model.
*The table shows current use of transportation modes at the time of the interview.

	Employment			Grocery Store			HIV Specialist Appts.		
Transportation Mode*	Participant (N)	Travel Time in min (avg, SD)	Times per Week (avg, SD)	Participant (N)	Travel Time in min (avg, SD)	Times per Month (avg, SD)	Participant (N)	Travel Time in min (avg, SD)	Times per Year (avg, SD)
Personal									
Driving	3 (21.4%)	18.3 (10.4)	5 (0)	10 (71.4%)	10.1 (5.6)	6.1 (4)	9 (64.3%)	50 (22.7)	2.3 (0.7)
Walking	1 (7.1%)	15 (0)	5 (0)	-	-	-	-	-	-
Biking	1 (7.1%)	30 (0)	5 (0)	-	-	-	-	-	-
Public									
Public Transit	-	-	-	1 (7.1%)	10 (0)	8 (0)	-	-	-
Paratransit	-	-	-	-	-	-	4 (28.5%)	46.2 (10.3)	2.7 (0.9)
Non-Profit	-	-	-	-	-	-	6 (42.9%)	42.5 (15.7)	2.1 (0.4)
Private									
Taxi	-	-	-	-	-	-	-	-	-
Ridesharing (Uber/Lyft)	-	-	-	-	-	-	-	-	-
Interpersonal									
Favors	-	-	-	6 (42.9%)	15 (5.4)	4.5 (4.6)	3 (21.4%)	56.6 (35.1)	2 (0)
Resource Pooling	-	-	-	-	-	-	-	-	-

Getting to Work. The majority of survey respondents (n=16, 72.7%) and interviewed participants (n=12, 85.7%) self-reported being unemployed, retired, or disabled (see Table 1). However, as indicated in Table 2, for interviewees who were still working (n=3, 21.4%), driving their own cars was the most common way to get to work. Two interviewed participants (14.3%) also mentioned using ridesharing services (i.e., Uber) to get to their work in the event that they experience mechanical problems with their own cars; however, this was very infrequent. One interviewed participant also mentioned walking or biking to get to work as his place of employment was located near his home. When asked how the COVID-19 pandemic had affected their travel to work, three survey respondents (13.6%) indicated that it had affected their travel to work because they were no

[2] In quotes we use the codes 'P' for interviewed participants, and 'PL' for interviewed case coordinators.

longer traveling to work at the time of survey completion. Two survey respondents (9%) indicated that it was more difficult to schedule rides and that it was necessary to wear masks.

Getting to the Grocery Store. To get to the grocery store, as Table 2 shows, the majority of interviewed participants drove themselves using their own cars (n=10, 71.4%) or obtained rides with their family members or close friends (n=6, 42.9%), which they coordinated via phone calls or text messages. All interviewees mentioned going to large supermarkets located off highways in the outskirts of their towns to buy a whole week's worth of groceries. Just one interviewed participant mentioned taking the bus, and another walking or biking, to the grocery store. See Table 2 for average travel times and trips per month per transportation mode. In general, walking and biking were not seen as desirable modes of transportation for groceries because:

"You're not going to walk home with a case of water...I'd have to make multiple trips back and forth, like one day I'd go get this, and then maybe a day or two later I would go back and get different things… And the same way with riding a bicycle...it's hard to carry a whole lot on a bicycle..." – P9.

Although none of the participants mentioned regularly using golf carts themselves for their transportation needs, a few participants had seen many other people living in their area drive their own golf carts to the grocery store. This was more feasible for short trips, and one interviewee mentioned older adults in particular using this method of transportation. A few participants showed interest in using this type of vehicle for groceries if they had access to them, since they could accommodate both short trips and grocery bag cargo. For instance, P5 explained,

"*[Golf carts are] mostly in town, which is just across the highway from me, it's not far at all, and there's a lot of them. You have to be careful of them because not all of them have a little safety flag on them...but I guess if I lived in town, I would maybe even want one myself...they've got a place in our society, so I guess I feel okay with them. People are staying closer to home. They're staying more center base and they're staying in smaller groups."* – P5.

P5 also said that golf carts are cost effective, and P1 argued that they have a low ecological footprint: "*You charge your battery, there's no trips to the gas station. They're low maintenance, low cost. For little short trips and short errands, you don't have to fire up your car, so it's cost effective too*." In addition, some people driving golf carts give rides to others that need to go to the grocery store. For instance, P11 said: "One of my neighbors saw me walking to the grocery store one day and gave me a ride, he was going somewhere...That's happened a couple of times." However, P5 explained some of the limits around use of golf carts,

"*I think it's against the law to have them on state roads and then some of the county roads are like my road, it's not really the safest in the world. … The roads are well well-paved...but people go too fast. The speed limit is 20 mph and they're going 55 and 60 on the road out here*." - P5.

Thus, although interviewee participants did not use golf carts themselves, it was interesting to find that this alternative means of personal transportation was popular amongst rural dwellers for trips to the grocery store.

When asked how the COVID-19 pandemic had affected their travel to the grocery store, seven survey respondents (31.8%) indicated that it had affected their travel to the grocery store. The reasons provided were that they traveled less frequently to the grocery store (n=3, 13.6%) at the time of survey completion. Five respondents (22.7%) also described wearing face masks and carrying hand sanitizer as they were scared of "catching Covid". One respondent stated that they went to the grocery store only for essentials and another respondent stated that it was more difficult to find rides for this purpose.

Getting to Healthcare. For interviewed participants, commuting to healthcare appointments with their HIV specialist doctors usually involved long trips out of town, to bigger towns or cities in the state. To get to healthcare appointments, as Table 2 shows, most interviewed participants drove themselves using their own cars (n=9, 64.3%) or relied on paratransit transportation paid for by insurers (n=3, 21.4%) as well as transportation provided by their case coordinators (n=6, 42.9%). Due to privacy and confidentiality concerns, when people living with HIV get rides to healthcare appointments, they typically prefer to be the only passenger in the vehicle. Notably, due to privacy laws, this was a requirement of transportation services provided by case coordinators. In fewer cases, they also reported family members or friends giving them rides (n=3, 21.4%). There was an overall average of 2.7 (SD=0.3) trips to HIV specialist care appointments across all transportation modes utilized (see Table 2 for more detail on average travel times and trips per year per transportation mode). Only one interviewee mentioned borrowing a friend's car when her car was not working.

When planning trips to healthcare appointments, often participants first asked for rides as favors from a small circle of family members (i.e., parents and siblings) and close friends. If their family members or friends could not provide a ride due to a schedule mismatch, participants then resorted to the paratransit transportation services provided by their medical insurance (e.g., Medicab, in which a medium-sized vehicle is occupied by the driver and a single passenger) or their case coordinators. All survey respondents and interviewed participants had some type of medical insurance (most were on Medicaid or Medicare, see Table 1). In order to use this paratransit, interviewees explained that they had to call their insurance to schedule a ride; this generally took a few minutes. Four interviewed participants (28.5%) reported using this type of transportation mode to go their HIV specialist healthcare appointments.

Only two interviewees (14.3%) mentioned using a door-to-door service provided by the public bus system that is tailored for rural dwellers (i.e., Rural Transit, Call-a-bus) to go to healthcare appointments, but this was for primary care. These services needed to be scheduled by phone ahead of time (i.e., three days, or a week in advance) and were provided on an individual basis. Payment for this service was by cash, at about $5 for a round trip per passenger. If the person scheduling the ride decided to travel with someone else, they would receive a discounted price for each additional passenger:

> "*You call and schedule it and then they pick you up and it's like a flat fee. So, I can travel then and go to the grocery store or run errands that I need to run or go into town. It's called Rural Transit and I'm not sure who...but Rural Transit is what we call it, and they operate in [anonymized] County and probably the surrounding counties. You call and schedule a ride through them. So, if I wanted to go to get my haircut one day or go to the eye doctor or something, I would call and say I have an appointment at two o'clock, and then they would probably pick me up at 1:30 and then for an extra dollar, then they will take you back home. it's a very minimal cost. I think it's like $5 to go round-trip. So, it's a great service for people who live out in the country and they need to go into town, but don't have a vehicle."* - P1.

Thus, to get to HIV specialist care, interviewees usually drove their own cars, or relied on paratransit transportation. They also asked for assistance from family members and their local case coordinators. The latter provide rides themselves or helped their clients find ways to get to healthcare appointments. In either case, interviewees explained that they prefer an individualized ride that provides privacy and confidentiality. When asked how the COVID-19 pandemic had affected their travel to healthcare appointments, nine survey respondents (40.9%) indicated that it had affected their travel to their healthcare appointments. The reasons were that they had canceled or postponed appointments because it was more difficult to find rides (n=2, 9%).

Two respondents (9%) stated that their appointments had been canceled and one respondent also indicated that they would only travel for emergency appointments. Finally, three survey respondents (13.6%) had had an online video appointment with an HIV specialist doctor or provider during the pandemic at the time of survey completion.

4.3 RQ2: What Role do Community-based and Healthcare Organizations Play in These Forms of Travel, if Any?

Case coordinators give rides to healthcare appointments. Apart from the transportation modes described earlier that allow participants to get to their healthcare appointments, they can also rely on their case coordinators as a "last line of defense." That is, when participants could not find a way to get to their healthcare appointments through usual methods (e.g., not finding someone who would give them a ride, not having enough money for gas or for the bus ticket, or when their Medicab ride did not show up), they contacted their case coordinators for help. In response, paid case coordinators gave them rides to their healthcare appointments using cars that they owned. To make use of this transportation service, participants typically called their case coordinators on the phone to schedule a ride. Through this service, on the day of the appointment, the case coordinator picked up the client from their home, took them to the appointment, waited for them at the doctor's office, and then drove the client back home. All participants liked this type of transportation service and were grateful to have access to it: "*[My case coordinator] has taken me to a few appointments]. I mean it's a great benefit to have. It's something I would've never expected, so to have it offered to me, that they can take me to places like that, is fantastic."* - P1.

Notably, the assistance of case coordinators was concentrated on healthcare access, with gaps in grocery store access or employment-related transportation not typically being fulfilled by this service. Thus, while case coordinators mentioned that they could give rides to grocery stores if needed, none described doing so.

Case coordinators arrange financial assistance for travel healthcare appointments. If the case coordinator was not available on the day and time of the appointment, case coordinators usually provided their clients with gas cards, bus passes, or taxi/Uber vouchers after approval based on their client's financial situation at the time. Such assistance may be available to both the person with HIV, and anyone else who might provide a ride to a healthcare appointment, but not to work or grocery stores. Case coordinators also help clients access medical insurance so that they can get access to paratransit transportation services.

Case coordinators problem-solve with clients about healthcare transportation needs. Case coordinators could also help their clients find alternatives, such as by asking them if they can find a friend who can give them a ride:

> "*We try to...help a client triage that so that they can get there another way. That's not always possible and if they're past due for labs, then we will go ahead and get them there and then for the next time start figuring out a different plan that is like, talking about do you have a friend that can take you, we can arrange a gas card for the friend to be able to take you to your appointment... friend or family member and then we might... we've used taxis in the past."* - PL1.

Other community-based organizations uninvolved in meeting transportation needs. No participant mentioned knowing of or having used transportation services from any other local community-based organization. Nevertheless, when we asked them if they would be interested in transportation services provided

by non-profit organizations or churches, such as through loaning cars. All interviewed participants said that they would be interested in having such type of service in case they needed it. Yet, one participant clarified that these organizations would have to be aligned with her beliefs. For example, P5 explains why she would not use transportation services provided by a church:

"*I suppose it would be something that would be nice to have, although I'm not a church goer so I wouldn't feel right in borrowing a church's vehicle if I'm not a member. I don't believe in organized religion, so… I would be more apt to take from a non-profit organization though. I'm surrounded by bible-thumpers in my community though so they would definitely go for the church one*." – P5.

Thus, it is important to consider the values and beliefs of riders as these may impact their decision regarding using or not a transportation mode available in their community. In addition, although case coordinators were not always able to provide rides to their clients themselves, they helped their clients by providing them with support and guidance for finding other transportation modes.

4.4 RQ3: What Facilitators and Barriers underlie these modes of travel to healthcare appointments, grocery stores, and employment?

4.4.1 Facilitators

Car Ownership. For participants, owning a car in a rural community facilitates reliable travel to distant places. Fourteen surveys participants 14 (63.6%), and nine interviewed participants (64.3%) reported owning cars, and all participants mentioned that driving was their preferred mode of transportation, which they saw as necessary for people in their area. For instance, P7 observed that,

"...if you go walking on the street and turn around to see the houses, all of them have more than 2 or 3 cars. They can be brand new or old. But that lets you know that the only way for people to move around here is by car. I mean there are no buses, taxis, or any other form of transportation service. Thus, if you don't have a car here, you couldn't survive." – P7. Similarly, another participant asserted that, "*It's almost impossible to live here without a car. Which is the problem with most small towns in the United States. We are basically set up completely for cars... There's no form of mass transit or public transit and if you don't have a car, you're basically pretty screwed*." – P11.

Having a Support Network in Place*.* Participants who had access to a network of family members (i.e., parents and siblings) and close friends could ask them for rides to get to the grocery store or their healthcare appointments if needed: "*I've got friends and family, if for instance, both vehicles were in the shop, there's several people that I can call and say "Hey, I need a ride*." - P10. For those who did not have such networks or could not always rely upon them, case coordinators were a source of transportation assistance. Case coordinators would also help their clients coordinate access to other forms of transportation to healthcare appointments.

Having Medical Insurance. People living with HIV who have medical insurance like Medicaid or Medicare can access transportation services that can pick them up from their homes and take them to their healthcare

appointments. It was common for participants to use this type of service to get to their healthcare appointments. However, medical insurance was not available for food- or employment-related trips.

Light reciprocity or no payment as compensation for rides. When seeking rides as favors from others, apart from paying the drivers with gas money, people also compensated riders with "light reciprocity," which included gestures such as paying for their lunch, exchanging rides in the near future, or doing chores around the house for them like weeding the yard, doing home repairs, and buying or splitting the cost of groceries. A case coordinator explains:

"I had a client who really likes to cook, and he lives in an apartment complex so he was like, 'Oh, I have a new neighbor who will drive me to the grocery store if I cook a couple of meals and give it to him.' So, yes. I have definitely heard of kind of a barter system and it's usually neighbors. It's usually some kind of extended neighbor that they're bartering with. I know another client who recently said, who wanted an Uber, but it was an appointment that was in Indy, which they get very...they're very expensive to do for an Uber and then said, 'Well, I have a friend who will do it if I can get a gas card for him, if you guys can help me with a gas card, and I can pay him the gas and he will take me there' so things like that." – PL3.

P7 also explained that he invites his friends for lunch after they have given him a ride to his healthcare appointment to show appreciation; this is another form of light reciprocity. He says:

"*When my friends give me rides to my healthcare appointment, it takes 2 hours for them to get here, and then there's another hour to the city. My healthcare appointment itself is another hour. So, we are talking about five hours total. Thus, the least I can do is invite them for lunch, don't you think? They do not expect I pay them back or anything, but I think it is necessary because it is a way of saying thank you and making sure I am not taking advantage of them*." – P7.

In some cases, no payment at all was requested or expected, especially for favors. For instance, participants who owned cars offered and gave rides to their friends and neighbors when they needed it. Typically, they did not expect any compensation, especially if they deemed their relationships to be too close for that type of exchange. However, they would accept the compensation if they really needed the money. P5 explains:

"*If I really needed the gas money, if I was low on funds and someone offered, I would say, 'I'm sorry, I have to take this from you, but we're going to go to the gas station, we're going to put it in the gas tank' and I would accept it. Otherwise if I had plenty of gas and I had money in my purse and I didn't need any extra money, it would be a favor and I wouldn't expect the person to give me anything for it.*" - P5.

Another participant explained that he would only offer any type of compensation if he knew the driver needed it. As he said:

"*Well there was one neighbor...one that's very well off. I usually didn't offer her anything, but...I had another neighbor that would sometimes take me to my healthcare appointment, and I would offer her money because I knew that she was maybe not as well off as our other neighbor*." - P3.

Confidential Modes of Transport. Participants preferred confidential transportation that offered individualized service. In particular, when going to healthcare appointments with others, participants preferred that those others be close family members due to a desire to keep information about their condition confidential. For instance, P9 explains that she would only take rides given by family members to get to her healthcare appointments: "*I sure wouldn't use anybody else [who is not family] to take me to my doctor's appointments.*

That's private, I just, no." – P9. Participants also valued the confidential and individualized transportation service provided by their medical insurance or by their case coordinators. These forms of transportation helped assure confidentiality by not allowing their clients to share their rides with people other than the drivers. Unlike with healthcare appointments, participants more often asked their friends to take them to work or to the grocery store, as these trips did not entail HIV status disclosure.

4.4.2 Barriers

Lack of Infrastructure & Safety. Personal modes of transportation like walking or biking were seldom used due to a lack of adequate infrastructure, and related safety concerns. In terms of infrastructure, participants mentioned that there is inadequate sidewalk access and lack of bike lanes on rural roads and highways, which make these methods of transportation difficult. For example, P1 explained,

> "*We live about two miles to the highway, and then maybe it'd, you know, be another three quarters of a mile or so into town. So, I've chosen not to attempt to walk that. I guess that I could, but it's not something I want to do. There are no sidewalks… If the roads were wider and not as narrow or if things were just more bike friendly, but it's in small rural towns like this, it's difficult to find that. So, living where I live, which is out in the country, you know you're on these little county roads that are not bike friendly, so there's lots of hills and curves. So, it's a little unnerving...I'll be nervous to be on the bike for that amount of time on those county roads*." - P1.

In addition to the infrastructural concerns, the behavior of drivers on rural roads could present safety concerns: *"[biking] is kind of scary because the cars don't necessarily treat you as an equal, so it can be scary.*" - P5.

Other safety concerns were related to other people, and participants who self-reported being women expressed more concern about their safety when walking or biking in rural areas due to such concerns. For instance, P14 argued that in spite of the lack of prior negative incidents, she was concerned that the physical conditions left her vulnerable:

> "*I would like to walk everywhere but that's not possible. I live in a rural area and everything is so far away and I feel that it could be dangerous. I never go out and walk, not even for a short walk. I feel it is dangerous because there are no people in the streets, the houses are so far away from each other, or located deep into a wooded area. So, I don't safe being a woman walking by myself. There are many trees, and yes sometimes the cars on the streets, but you never know who might be driving them*." – P14.

As previously mentioned, the speed at which drivers drove on roads was a safety concern. This was on rural roads, as well as highways. One participant expressed these concerns as follows:

> "*Getting a ride from a friend, which I prefer because they're on I-69 to get to my doctor's office, and it's just horrible. It's really fast and I'm not comfortable driving on it at all. I'm not even comfortable being a passenger on it*." - P5.

Physical Health and Disabilities. A few participants mentioned having medical conditions or physical disabilities that made them feel more afraid of biking. One said*: "I don't have the world's greatest balance anymore. So, I don't use a bicycle...the last time I got on a bicycle, I fell over, caused a big...I wound up having stitches in my eyebrow and a torn rotator cuff." - P4. Driving could also be frightening or anxiety-provoking due*

to participants' physical conditions. For example, they could be taking medications that make it dangerous for them to drive a vehicle on a highway. For instance, P1 said:

"*I don't prefer to drive because I get tired, so it's not always the safest thing for me to be on the road. I much prefer being a passenger in a car. Well, because I am on medication that makes me tired or drowsy. I have to really like, concentrate to be aware and alert. So especially at the end of the day, after I've worked all day. Going home might be difficult.*" - P1.

In addition, public transportation is challenging to use for those living with disabilities or those experiencing mental health conditions. This can be due to both physical inaccessibility and social challenges of this mode of transportation, as this case coordinator outlines,

"*[One of our clients] has a walker. He has tried to take like a 'BT Access' I think in the past. You have to schedule that in advance, and he has, that's just challenging for him to figure it out and navigate it sometimes. He's got some intellectual challenges, so that can be an issue*." – PL2.

Lack of Independence. The majority of participants felt that it was challenging to ask family members, friends, and their case coordinators for rides because of the lack of independence they feel and the difficulty of coordinating transportation and matching their schedules with that of others:

"*It's a challenge because we have to rely on other people to get us to and from appointments and market and food banks and doctor appointments and all that. So, I'm literally working off of someone else's schedule while trying to keep my schedule. It's a challenge*." – P2.

More importantly, participants feel that they may be imposing on others, bothering them, when requesting rides: "*When you ask them, you have to kind of think, well am I bothering them or what's their schedule like...that was a concern. If I was imposing or not*." – P3.

Temporal Matching. Participants mentioned that their schedules do not always match with the schedules of available transportation modes. For example, P1 mentioned using the bus to go to the grocery store and healthcare appointments on a regular basis, yet he also explained that the availability of public transportation is limited:

"*Rural Transit it's a great service for people who live out in the country and they need to go into town, but don't have a vehicle. [yet] this service doesn't run early in the mornings and it doesn't run late in the evenings, but there's a good, I think, five or six hours during the day that they do operate*." – P1.

Similarly, P2 complained of the complexity and time-consuming nature of travel to a grocery store:

"*I was able to catch a bus that would be like almost a 2 and a half, 3 hour wait. Because the bus would go downtown, then you'd have to wait like 15, 20 minutes for a different bus to take you that far out...And they stopped running at night, like 9:00 at night*." – P2.

Coordination Breakdowns. *Coordination of rides can be a complex process for both the private and interpersonal transportation models. We found that the main coordination problem is drivers not showing up after they had agreed to give a ride, or people being unavailable when a ride arrived. For instance, P2 explains such challenges in the context of travel to work:*

"*When I used to work for another company, a lot of us car-pooled. The person who drove had to make sure everybody was up at a certain time so they could come by and pick you up. They also worked with us*

too...let's say you were driving, and we had to be at work at eight o'clock. Well we had to pick up four other people on the way to work. That means you had to get up at least by 05:00 AM to make sure you had all your things ready and set. Then you picked up person number 1, then you went to number 2, 3, and 4. And 9 out of 10 times, let's say number 3 never called you and say 'hey, I'm not feeling well, I'm not going to work.' You still show up to their house, you're waiting 20 minutes for them to come out. And then everyone's late." – P2.

All participants who had used paratransit transportation complained of its unreliability, which also resulted from coordination breakdowns. For instance, case coordinators talked about clients who missed or rescheduled their appointments because the drivers of these services did not show up and failed to communicate this to their clients beforehand:

"*I guess whatever driver it's assigned to doesn't show up, or nobody picks it up. But they don't communicate that back, that 'Hey, we don't have somebody to come get you.' Like a client scheduled a ride or we schedule a ride on behalf of a client through the Medicaid transportation assistance and then we... everybody thinks that we're set and then the driver doesn't show up*." – PL1.

Given this unreliability, participants explained that they had to schedule pick-up times much earlier than their healthcare appointment times in order to arrive on time. P4 said:

"*...they worry about you being late, so instead of being late...one day Medicab came and there was a gentleman that drove all the way from <city name> to come and get me...he got to my doctor's appointment an hour and a half early and their office wasn't even open when I got there, so I had to wait outside*." – P4.

Lack of Knowledge of Availability of Transportation Services in the Area. We found that participants do not know whether public transportation or certain private services like Uber or insurance-provided transportation are available in their areas. This happens due to them not having used these transportation services in the past, and they may not have investigated them due to the lack of appeal of those services to them. For instance, a few participants were not sure whether services like Uber or Lyft were available in their towns, but if there were, they would still not use them because they did not like the idea of getting into a car with a stranger. In addition, a participant mentioned that he found out that his insurance provided transportation services only after he had to undergo dialysis treatment. Although the majority of participants reported not having taxi or ride-sharing services like Uber or Lyft in their area, many were actually not sure if they were available in their area*:*

"*I've never seen a Lyft or Uber around here in my town. Most people walk because it's a small town. It may take you 20 minutes to take you to walk from the grocery store to your house. You don't see too many people like even taking cabs. I haven't seen a yellow cab or even Uber or whatever in my town*." – P6.

Spatial Matching (Distance to Destinations). Overall, the median self-reported time to get to work, the grocery store and their healthcare appointment across all modes of transportation was 21.6 min (SD=9.3), 11.1 min (SD=6.3), and 48.2 min (SD=18.7), respectively. Longer distances to get to healthcare appointments restricted the types of transportation models participants used such that participants mainly resorted to driving and relying on medical insurance or case coordinator-provided transportation services. Longer distances also involve further spending on gas and car maintenance as participants needed to have their cars in good working order in order to travel on a highway for a length of time. Even for those participants who had a nearby local

grocery store within walking distance, they could not afford to buy groceries there as the price of things there would be much higher in comparison to prices at a bigger supermarket chain located further away:

"*The problem with going to the local grocery store is the cost. A pound of ground beef is $6.99. A dozen eggs is $3.50. A gallon of milk is $3.99, which is just about twice the price of what it is at the [bigger] grocery store in town*." – P11.

Stigma & Cultural Boundaries. Participants felt reluctant to ask for rides from friends to get to their healthcare appointment due to the stigma towards HIV. As mentioned, they preferred confidential services such as those from family, case coordinators, or medical insurance. Case coordinators also actively managed stigma in relation to the transportation services they provided by seeking to avoid association between their service and people with HIV. A case coordinator explains:

"My friends know what I do, but I always try to share with my friends...I work with people living with HIV and some people not living with HIV so that is always ambiguous hopefully to them someone's status...my friends have definitely seen me driving with people so I'm, like, 'I work at [anonymized], but I also work with people who don't live with HIV' so that if they see me with someone...they just wouldn't be able to know." - PL4*.*

Stigma concerning poverty and disability also affected transportation choices. A few participants mentioned feeling uncomfortable or embarrassed of using public transportation due to concerns that it was travel for poor people. Similarly, in the case of alternative means of transportation like golf carts, P1 mentioned that he would feel embarrassed to use one as these vehicles are often used by older adults who need aid going to the grocery store. He said:

"My mom asked me if I wanted a golf cart. Hmm I am not sure. I mean I've thought about it, but I don't really know. I guess I don't want to be seen driving a golf cart around town. I think it would be embarrassing or, I don't know somehow I would be self-conscious." - P1.

Lack of Interpersonal Trust. In general, participants did not like the idea of taking rides with strangers as they feared for their interpersonal safety. Accordingly, we found a generalized lack of interpersonal trust towards ridesharing or taxi services. Most participants (n=10, 71.4%), and all women (n=3, 21.4%), indicated that they would not feel comfortable riding with a stranger due to safety concerns:

"*I just find it weird. I guess it just goes against everything I've been told about getting in a car with a stranger...You've seen stuff on the news with Uber and things like that...I'm not afraid of people but at the same time, I don't really want to be in a car with someone that I don't know. Probably 99% of the time nothing would happen, but I just, I don't know*." – P9.

Trust was also mentioned in relation to the possibility of sharing vehicles such as cars. All participants explained that they would only loan their vehicles to people they know well. Case coordinators have heard many clients mention that they have an arrangement for borrowing a family member, friend or neighbor's car. Nevertheless, they would not feel comfortable loaning or borrowing their vehicles to strangers due to interpersonal trust and lack of accountability to care for the vehicle as desired. Two participants said:

"*...if I were sharing a car with you. I'd want to make sure that your ideas of like, for instance keeping the car maintained are the same as mine. I wouldn't want to feel like I was the one doing all of the work, or you were the one doing all the work....if you're sharing a car, then someone's got to be responsible for maintenance,*

and someone's got to be responsible for storage and parking. And so, then that's just a lot more responsibility." – P3.

"*Most of the people who live in [location] are drug addicts, so sharing a vehicle with another person, no. Not my idea of fun. No. Because let's say you did drugs and you left your shit in the car, and I get pulled over. It's not you going to jail, it's me. Because I'm driving the vehicle, and it's your crap in the car. Yeah, no*." - P2.

Cost & Affordability. Although the majority of the participants reported owning a car, oftentimes they could not afford to pay for gas or maintenance for that car. Additionally, the majority of participants reported not being able to afford ridesharing or taxi services if they were available in their areas due to the distances involved:

"In the areas where these models do exist, they are still too expensive for this population: "I refuse to pay for an Uber and screw the Lyft, no. I'm not paying $45 to have some young kid come to my house, pick me up, drive me off to another place that's like 15, 20 minutes away and end up paying them $200 for a cab ride. Are you kidding me?" - P2.

Thus, as described above, there are key facilitators and barriers that affect the ways in which participants travel to work, the grocery store, and healthcare appointments. Next, we summarize the answers to our research questions and discuss design implications for technology that could leverage the identified facilitators and address the barriers uncovered here.

5 DISCUSSION

Although more than one third of the participants did not own cars, those who did relied mostly on driving their own vehicles to get to work, the grocery store, and their healthcare appointments. Moreover, there was limited use of services such as ridesharing or public transportation to meet transportation needs for these purposes. This confirms prior research suggesting that rural reliance on cars is due to the lack of public and private transportation access. This is especially the case for vulnerable populations like people living with disabilities [9,35,46,70], those living in low-income areas [8,38,46] and people living with chronic conditions like HIV [48,63]. In addition to a lack of car ownership, the lack of infrastructure, long distance to destinations, physical health, schedule mismatches, and affordability were identified as key barriers both in the present work and previous literature.

Given that access to an automobile was not always consistent, we found that people living with HIV in rural areas access multiple types of transportation models, including relying on others to get rides. These findings align with prior research conducted with people living with HIV in rural areas where researchers reported that people living with HIV had "to weave together" different transportation options [63]. Our work further contributes to this line of research by providing a detailed description of facilitators and barriers experienced by people living with HIV when using the different types of transportation models in rural areas, which was largely missing from prior work.

In particular, the layered support network to which participants had access has not previously been explored in depth. In response to RQ2, we found that non-profit health organizations employ case coordinators who play a critical role in helping participants living with HIV navigate the various transportation models available to them. However, unlike in some urban areas, we did not find other types of nonprofits providing transportation services to rural people with HIV. Additionally, our findings newly suggest the presence of a neighborly altruism amongst

participants that have tightly-knit social networks; these allow them to leverage facilitators such as having the option to compensate transportation favors via light reciprocity or no payment at all, and by being able to ensure confidentiality about their condition while getting to their destinations. These findings align with, and extend, prior research that argues that people living in rural areas have access to more bonding social capital than people living in urban areas [25,32,86].

Table 3. Transportation Models used in Urban Areas [21] vs Our Findings in Rural Areas. U=Exists in Urban Area. R=Exists in Rural Area. *Occurs rarely.

Transportation Models		Work	Grocery Store	Healthcare Appt.
Personal	**Driving**	R & U	R & U	R & U
	Walking	U	U	U
	Biking	R & U	U	-
	Golf cart	-	R	-
Private	**Broker**	-	U	-
	Jitney	-	U	-
	Realtime Ridesharing	R* & U	U	R*
	Taxi	U	U	-
Public	**Paratransit**	-	U*	R & U
	Public Transit	U	U	U
	Non-profit	-	-	R
Interpersonal	**Favors**	R & U	R & U	R & U
	Resource Pooling	R*	U	U

As Table 3 shows, transportation methods identified only in the context of this rural study include use of golf carts for groceries, case coordinators for healthcare appointments, and for two participants, carpooling for employment. By contrast, urban modes of transport not found in our rural study area include walking and public transit (for jobs, grocery stores, or healthcare appointments), biking to grocery stores, use of brokers or jitneys for groceries, and use of taxis for work and grocery stores. Resource pooling was also used in urban areas for grocery stores and healthcare appointments, but not in rural areas. Together, these differences can be explained by known differences between rural and urban areas, including physical infrastructure (e.g., lack of sidewalks), faster speeds of driving [45], longer distances, lower population density (leading to deserted areas in which to walk), and fewer available services in rural areas. The unique context of HIV, with the availability of case coordinators to facilitate care linkage, also explains an observed difference.

Some observed barriers and facilitators also differ between rural and urban areas. Concerns about independence were more acute in this population than in prior urban work, potentially reflecting rural cultural values [26]. Lack of knowledge regarding the existence of transportation models in their communities was also observed more in rural than urban areas; this may be due to the lesser availability of community-specific media in US rural areas. Another key facilitator in rural areas but not in urban research is the generalized sense of altruism expressed between community members. Barriers that were similar between rural and urban areas included affordability of transportation and trust towards strangers who might provide services such as real-time ridesharing. In the next subsection, we provide design implications for technology to mitigate key barriers while leveraging key facilitators for people living with HIV in rural areas.

Design Implications. As explained in our literature review, HCI research has mainly focused on the design or use of technology that could help people living in rural areas get connected with others for rides (e.g., [24,47]) or track the location of a public bus (e.g., [1,2,52]). However, our findings show that public transportation is

often not available, and ridesharing services may not be a good fit for our population if this service is not provided by members of strong social networks. Furthermore, there is scant HCI research that has explored the design of technology that could allow users to locate different types of transportation models at any given time depending on their location (e.g., [77]). Recent research explored the ways in which vulnerable populations used different transportation modes in urban areas to go to work, the grocery store, and healthcare appointments identifying facilitators and barriers [18,21]. Yet, there is no HCI research that has proposed technologies to assist with transportation access for people living with HIV in rural areas taking into account all of the transportation models currently in use. In this sense, we suggest the exploration of technology that would integrate the transportation models discussed in this paper, and in particular those models that are being used more often by this vulnerable population in question. Accordingly, we contribute the following design implications:

Delivery of Contextualized Information Including Facilitators and Barriers. Participants were not always sure about what transportation models were available in their areas. They did not always know whether or not there was a public transit or ridesharing system available in their town. Furthermore, they did not have information about the potential barriers that they may face for particular trips (e.g., bad road conditions, no access to sidewalks, high cost), or the facilitators that they could take advantage of (e.g., assistance from family, friends, case coordinator) when using a particular transportation mode. Hence, technology could deliver information regarding transportation models available in the area as has been proposed in previous research [77], but it should include alternative and local transportation means that people use in the area (e.g., use of golf carts). This information would aid users in coordinating the various modes of transportation available to them at any given time. This data could be generated by crowdsource-based methods like the one proposed in [89] where stakeholders (I.e., bus drivers, riders) of a public transit system are the ones reporting about the transportation barriers (i.e., transportation disruptions) from their mobile phones. Similarly, [64] employs the same concept where people can alert others from their phones about street and sidewalk conditions.

From Rideshare to Favor-share. Ridesharing services were not used by our participants due to lack of trust in the system and high cost, especially given distance. Thus, transportation models based on favor exchange should be further explored for this population. For instance, The Generalized Favor-based model proposed by [21] consists of allowing people to volunteer to be drivers and provide rides to people that need them in exchange for rides or other resources. In a similar vein, we envision technologies being used by people needing transportation (the riders) as well as for those who are able to provide transportation services like family members, friends, and case coordinators from non-profit and health organizations. The design of this technology could integrate a reputation system in order to increase trust amongst riders and drivers as suggested in [18]. Additionally, it has been well established in the literature that HIV-related stigma can hinder access to proper medical care, as individuals fear disclosing that they live with HIV to others for fear of social rejection [50,62,74]. Thus, technologies designed for people living with HIV should take into account the effects of HIV-related stigma in their decisions when selecting a transportation mode. For example, the reputation mechanisms could adopt features described in order to also be able to rate potential drivers based on how likely they are to react to them due to HIV-related stigma. Alternatively, methods such as use of “secret shoppers” [5] trained to rate the accessibility of transportation services for people with HIV might help to increase personal trust. Another approach might be to recruit family members of people with HIV to form a network of drivers for people with HIV in a given county, or larger region.

The system could have three main frontend user interfaces depending on the type of user. The frontend user interface for the rider could collect personal information including budget, vehicle ownership, physical health, and availability for travel. Preferences regarding use of transportation models to go to work, the grocery store, or healthcare appointments would also be stored via the rider's interface. The frontend user interface for family, friends, and case coordinators would allow them to store availability of time to give rides and type of compensation required, including options indicative of light reciprocity. Furthermore, the case coordinator's frontend user interface would also allow them to see transportation modes available to the rider, and information about facilitators and barriers related to the rider and type of trip. The system could then automatically match riders with the different transportation models that would best fit the facilitators and barriers related to the trip explained, or the case coordinators could complete this process manually. Additionally, in the case of healthcare appointments, the system could also determine if alternative solutions exist so that frequent travel is less necessary. For example, there is an ongoing project in Europe known as the EmERGE Project [30] that could allow people living with HIV to access their clinical data or do brief consultations with their HIV specialists remotely via a mobile application.

To recruit drivers and build trust, the system could be linked to a timebanking system similar to hOurworld1 in order to help riders be linked to trusted members of the community who are willing to help with transportation services in exchange for other services. The timebanking metaphor facilitates reciprocity in a community by allowing people to use time dollars for exchange of services (e.g., given a ride, cooking, etc.) among members of the community based on how much time they have invested in those services [6,10]. Timebanking-based sociotechnical systems have been already studied in HCI and they have shown to have the potential to leverage altruism and light reciprocity especially amongst members of a tight and supportive community [6,71]. To promote generalizability of our findings, we invite researchers and practitioners to further explore the design of favor-based and crowdsourced-based sociotechnical systems that could leverage the resources of rural communities whose members rely on people and nonprofit organizations that they trust to cover their transportation needs. Furthermore, our findings and design implications could be applied and further explored with people living with HIV outside of the US where lack of transportation access is also a major barrier to proper care (e.g., [22,51]). Our findings could also be applied to other populations in need of specialty health care (e.g., cancer, mental health). Indeed, previous related research with these groups living in rural areas (e.g., [9,17,87]) has highlighted similar barriers in transportation access such as long travel distances, lack of social support, disability, affordability, and a lack of adequate infrastructure.

In future work, we plan to conduct participatory design workshops with people living with HIV in rural areas in order to produce prototypes of a coordination system like that outlined herein. In particular, we want to explore the perspectives of transportation providers and explore further the effects of the pandemic on travel experiences. These workshops could include elicitation artifacts that would promote discussion around the transportation models as well as the facilitators and barriers identified and discussed in this paper. To maintain social distancing requirements necessary to prevent the spread of COVID-19, we are considering sending physical materials to participants prior to synchronous sessions via phone or Zoom as suggested in Harrington and Dillahunt's case study of remote speculative co-design among Black young adults [33]. We could also use the Asynchronous Remote Communities (ARC) method which a method that has been used successfully to conduct HCI research remotely with people living with HIV [41,42]. Ultimately, with this research agenda, our main goal is to design and develop technology that could facilitate vulnerable populations to get to places that

are critical for their health and that would take into account the different stakeholders' perspectives (e.g., family members, friends, and case coordinators) so that the sociotechnical interventions can help address barriers while at the same time leveraging existing facilitators and being aligned with their values.

6 LIMITATIONS

Our study has the following limitations. First, all study participants living with HIV were already connected to services provided by case coordinators working at the HIV support center at the time of conducting this study. Thus, the perspectives of those living with HIV and who are not linked to care are not represented. Second, the notion of rurality may be a relative aspect to define as stated in [32]. We relied on the HIV support center and its network within the study counties to help us recruit rural dwellers living with HIV. Participants also referred to their towns as small or rural towns in their interviews. Additionally, we verified zip codes provided via the online survey in order to screen participants and determine whether they were living in rural areas in the state. Third, HIV is a condition for which care linkage services are available, but this is not necessarily the case for other chronic conditions such as diabetes, cardiovascular disease, or mental illness. Therefore, findings may not be representative of other conditions, and more research is needed to establish transportation practices among other groups.

7 CONCLUSION

Our study identified key transportation models used, and facilitators and barriers experienced by rural-dwelling people living with HIV. These differ in important ways from underserved and vulnerable urban populations. Yet, more work is needed. If we are to design sociotechnical interventions to aid in transportation access, it is critical that the needs and perspectives of vulnerable populations such as people with HIV are addressed by technologies designed with and for them. We encourage HCI researchers and practitioners to expand their work on transportation to rural areas while taking into account the contributions presented in this work. We believe that it is possible for the promises of current transportation technology to yet be designed with needs of rural dwellers at the center.

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