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Exploring RV-dwelling American Nomads' Experiences When Seeking Healthcare

by

Ruth Tretter

A dissertation

submitted in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy in the School of Nursing, College of Health

Idaho State University

Spring 2023

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Committee Approval

To the Graduate Faculty,

The members of the committee appointed to examine the dissertation of Ruth Tretter find it satisfactory and recommend that it be accepted.

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RE: Study Number IRB-FY2022-233 : Exploring RV-dwelling American Nomads' Experiences When Seeking Healthcare

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Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

Dedication

This work is dedicated to my partner in life and adventure, Tim Jacobson. Thank you for making sure that we never ran out of electricity, water, or propane, and for fixing everything that broke, especially when the thing that broke was me. You made this adventure fun!

It is also dedicated to my mother, Ellen Marie Tretter, who was brave enough to share my first RV adventure with me, even when we had no heat, and I killed the battery so the alarms wouldn't stop alarming. Who would have guessed in that first freezing parking lot that our adventure would lead me here?

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List of Abbreviations

COVID	coronavirus disease of 2019
CPR	cardiopulmonary resuscitation
ER	emergency room
IRB	institutional review board
LCFAH	Levesque's Conceptual Framework of Access to Healthcare
ODPHP	Office of Disease Prevention and Health Promotion
PCP	primary care provider
PI	principal investigator
RV	recreational vehicle
RVer	someone who travels in a recreational vehicle
RVFAN	recreational vehicle-dwelling fulltime American nomad
RVIA	Recreational Vehicle Industry Association
SUV	sports utility vehicle
U.S.	United States of America
VA	Veterans Affairs

Exploring RV-dwelling American Nomads' Experiences When Seeking Healthcare

Dissertation Abstract - Idaho State University (2023)

Purpose: The purpose of this study was to explore the experiences of RV-dwelling full-time American nomads when seeking healthcare in the U.S. and to identify barriers and facilitators of access to care.

Background: Up to a million or more Americans, live while traveling full-time in recreational vehicles (RVs). Some health policies are based on assumptions of stationary residency. Little attention in the literature has been devoted to the healthcare experiences of Americans who are geographically mobile.

Methods: The exploratory, qualitative design was informed by interpretive description. Levesque's Conceptual Model of Access to Healthcare was used to generate questions for the interview guide. The principal investigator lived in an RV and traveled to a variety of campgrounds in several states to post recruitment flyers. Interviews were recorded and transcribed verbatim. Thematic analysis was conducted with a phronetic iterative approach using Atlas.ti software. Participants included American adults who lived for more than six months of the year in an RV while traveling to different regions of the U.S. Participants were located in a variety of campgrounds in several states including Oregon, Wyoming, Colorado, New Mexico, Texas, and Arizona.

Results: Twenty-five RV-dwelling nomads participated in semi-structured interviews. Three overarching themes described the experiences of RVers: overwhelming logistics, don't need healthcare, and orchestrating a web of care. Some of the barriers identified included difficulty vetting healthcare resources in unfamiliar locations, caregivers' lack of understanding of the

nomadic lifestyle, limited resources in rural areas, and rules limiting care and payment for care by state. Some of the facilitators identified included caregiver collaboration, telehealth, national chains with shared records, information and support from other RVers, and self-advocacy.

Discussion: RV-dwelling nomads are an understudied population that face complexity and barriers to healthcare access related to seeking care in unfamiliar locations, misunderstandings about their lifestyle, and policies that prevent the portability of healthcare across state lines. More research is needed to determine the most effective solutions to improve healthcare access for RV-dwelling nomads. In addition, the impact of healthcare policy decisions on people who are geographically mobile should be considered.

Key Words: recreational vehicle, healthcare access, nomad, healthcare experience, Levesque's Conceptual Model of Access to Health Care, United States of America, lifestyle mobility

Chapter I: Introduction

Many Americans have adopted a nomadic lifestyle and live in vehicles (Bruder, 2018; Long, 2018). The culture of recreational vehicle dwellers (RVers) has been documented by historians, anthropologists, and sociologists but little attention has been devoted to their health. RVers are a diverse group, ranging in age from birth to death and from impoverished to wealthy. Although their demographics are varied, RV nomads are united by fellowship within a neo-tribe that defines its identity through lifestyle mobility. This study will focus on the healthcare of full-time nomadic RVers in America.

Healthcare delivery in the U.S. is predicated on the assumption that consumers have a stationary address. This may impact RVers healthcare access and experiences. Patients are asked to document physical addresses when they register for services and this information may be used to confirm their identity. Healthy People is a national public health initiative from the U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion [ODPHP] (ODPHP, 2021). Each decade, Healthy People sets specific goals to improve the health and well-being of the nation. These common goals facilitate the collaboration of the multiple stakeholders that work to improve public health. Achievements of the initiative have included reductions in heart disease and cancer, improvements in preventative care, and reductions in the prevalence of risks to health such as smoking and high cholesterol. Healthy People 2030 aims to improve healthcare access, including increasing the percentage of Americans who have established care with a primary care provider (PCP) (ODPHP, n.d.-a.).

The PCP relationship has been associated with better communication and trust, a greater likelihood of receiving appropriate care, and lower all-cause mortality (Agency for Healthcare Research and Quality, 2021; ODPHP, n.d). People without a primary care provider are more

likely to be hospitalized, to delay preventative care, and to receive more costly care in emergency departments (Starfield et al., 2005). Every 10 additional primary care physicians per 100,000 people have been associated with an increase in life expectancy of 51.5 days (Basu et al., 2019). Nomadic mobility may make it difficult to establish a relationship with a PCP. Some providers require an in-person visit each year to continue to qualify for PCP services (Torrey, 2020). Many professional licensing boards restrict healthcare professionals from providing remote care to patients who are traveling in a state where they are not licensed (Maheu, 2021). Inconsistency in professional licensing means that providers may be permitted to do a task (i.e. a registered nurse recommending over-the-counter medication by telephone) in their home state but prohibited from doing the same task in another state. Additionally, variations in telehealth training and experience impact the quality of remote care. Determining what can be safely treated using remote technology is subjective. Chike-Harris et al. (2021) reported that telehealth education in physician, physician assistant, and NP curricula was inconsistent in volume and content. Providers who felt less confident providing telehealth services were more likely to refer patients for face-to-face care (Varley et al., 2016). Seeking care in multiple locations without shared medical records may result in fragmented care. In addition to barriers to obtaining local or remote primary care, payor policies may also create barriers for mobile people.

Policies prohibiting reimbursement for telehealth services may discourage PCPs from providing care remotely. Restrictions on telehealth reimbursement in the U.S. have been loosened during the coronavirus disease of 2019 (COVID) pandemic but whether this will continue into the post-pandemic era remains to be seen (Weigel, 2020). Many American insurance policies limit healthcare benefits to provision of emergency care when policy holders are out of their “home” state (Norris, 2022). Norris (2021) noted that definitions of “emergency

care" are variable and provided examples of insurance companies who billed patients for emergency room visits after diagnoses determined that their conditions were not emergent. Some insurers in the U.S. will only pay for prescription refills when they are ordered through mail order pharmacies or they may reimburse the patient at a lower rate. Pharmacies may be difficult to contact to make alternate arrangements or may be reluctant to transfer available refills for pick up by nomads in distant stores (Chamberlain, 2019). Since nomads spend most of their time traveling, these payor policies may prevent them from accessing or paying for preventative or follow-up care where and when they need it. Policies that make care harder to access for certain populations could be construed as discriminatory.

While some RVers have documented their personal healthcare experiences on social media, little research examining the healthcare experiences of this population exists. Highly mobile people may experience unique barriers and facilitators to healthcare access in the context of U.S. health policy. This study will address a gap in the knowledge of public health in the United States by exploring the health seeking experiences of RVers. The remainder of this chapter will provide a brief overview of the literature to illustrate the purpose and significance of the study. The research questions will be stated and assumptions, limitations, and delimitations will be reported.

Definitions

Recreational vehicle (RV): "Any readily mobile vehicle or vehicle attachment which is both road-worthy and constructed to provide shelter in support of camping-style activities" (Burel, 2017, p. 134).

RVer: Someone who operates a recreational vehicle. This term includes vacationers as well as those who live in RVs.

Full timer: People who live in RVs all year rather than in a stationary residence (Counts & Counts, 2001). Full timers are often nomadic.

Serious RVer: People who live in RVs more than six months of the year.

Nomad: A nomad is a person without a stationary residence whose life routine includes traveling from place to place with the seasons (Marchi, 2010).

RV-dwelling Full-time American Nomads (RVFANs): Americans who embrace lifestyle mobility, spending most of the year traveling while living in a recreational vehicle.

Seasonal migrators: People with a fixed movement pattern who alternate between multiple stationary residences, i.e. snowbirds (Counts & Counts, 2001).

Lifestyle mobility: A way of life characterized by ongoing semi-permanent moves of various durations to new locations (Cohen et al., 2015).

Healthcare access: the interface between the characteristics of consumers that enable them to initiate care and the characteristics of health services and providers (Levesque et al., 2013).

Healthcare disparities: Differences in treatment that cannot be explained by differences in health needs or patient preferences (Artiga et al., 2020).

Background of the Problem

Incidence

RV-dwelling nomads evolved with the widespread use of the automobile (Counts & Counts, 2001). Official census forms do not include an option for mobile residency and the U.S. Census Bureau noted that nomads are difficult to count (America Counts Staff, 2020). While some RVers own property, many derive addresses for official paperwork from friends or relatives, use temporary addresses such as campgrounds, or hire a mail forwarding company to establish an address for them (Counts & Counts, 2001; Loring, 2021). Estimates of RVFAN

numbers range from hundreds of thousands to millions (Counts & Counts, 2001; Long, 2018). A report published by the RV Industry Association (RVIA) stated that 11.2 million households owned RVs, with at least 616,000 people living in their RVs for at least half of the year (RVIA, 2021). This report was based on purchases of factory-built RVs, hence, it excludes RVFANs who build their own vehicle conversions, such as members of the #Vanlife movement. Failure to accurately count nomads portends a failure to appropriately care for nomads (Randall, 2015).

A story passed down in the RV community describes the interaction of a group of RVers who encountered a group of census takers. It was reported that no category on the census accurately depicted their nomadic lifestyle so the RVers were recorded as homeless (Counts & Counts, 2001). Although the RVers counted moved on, funding for the homeless was increased in the area where they were camped that day. In fiscal year 2015, $675 billion dollars were allocated to 132 federal programs based on data from the U.S. census (Hotchkiss & Phelan, 2017). Although they are difficult to count, RVFANs constitute a significant portion of the U.S. population whose numbers could impact public health statistics and the allocation of resources.

Lifestyle mobility

Full-time nomads are differentiated from migrants, tourists, and other RV dwellers by lifestyle mobility. Lifestyle mobility is a lifeway encompassing ongoing semi-permanent moves of varying durations (Cohen et al., 2015). Nomads perpetually “move on” instead of visiting and then “moving back.” While snowbirds and other seasonal migrants alternate predictably between established homes, full-time RV nomads follow less predictable routes composed of “fluid, ongoing and multi-transitional” movements (Cohen et al., 2015, p. 161). While tourists travel for defined periods and then return home, nomads are at home while traveling. While some RV dwellers move from one parking spot to the next within a confined locality, RV nomads travel

through North America. Such movement is imbued with meaning and defines a nomad's individual and collective identity (Cohen et al., 2015). Figure 1, which Cohen et al. (2015) adapted from Bell & Ward (2000), illustrates the differences between temporary mobility (tourism or seasonal migration), permanent migration, and lifestyle mobility. RVFANs lifeways may result in barriers to health and healthcare access which are as unique as they are.

Culture

Hardy et al. (2013) describe RVers as a neo-tribe. Neo-tribes are described as communities of individuals from different walks of life who bond through a shared activity (Hardy et al., 2013). Campgrounds provide the context for the shared rituals of the RV lifestyle and RVers use a unique shared vocabulary to describe their activities. Fellowship in the RV community attracts many to the lifestyle and support from members of the neo-tribe has been cited as a strength in times of crisis (Counts & Counts, 2001; Hardy et al., 2013).

Discrimination is a social determinant of health that refers to unequal treatment based on stereotypes (Davis, 2020). RVers have reported that settled communities hold negative stereotypes about them (Counts & Counts, 2001; Hardy, 2013). Outsiders assume that RVers are "homeless and cheap; they violate the consumer ethic; they threaten community and 'family values' and they are trailer trash and slobs" (Counts & Counts, 2001, p. 91). While economic devastation pushes some into vehicle residency (Pruss & Cheng, 2020), not all who live in vehicles are mobile. Many RVers use vehicle-dwelling to facilitate lifestyle mobility because they feel happier and healthier after adopting a mobile lifestyle. In contrast to these stereotypes, RVers have described themselves as "independent, sharing, caring, resourceful, self-sufficient" and the "embodiment of the American dream of freedom and independence" (Counts & Counts,

Figure 1

Comparison of Lifestyle Mobility to Temporary Mobility and Permanent Migration

Definition	Temporary Mobility	Lifestyle Mobility	Permanent Migration
	Non-permanent moves of varying duration	On-going semi-permanent moves of varying durations	Permanent change of usual residence
Key Concepts			
Usual Residence	Less centrality	Multiple moorings	Integral concept
Return	May involve a return 'home'	May involve a return (to) 'home(s)'	No intention to return
Belonging	Generally fixed to one location	Not fixed to anyone (or more) location	Fixed to one or two locations
Key Dimensions			
Duration	Varying duration of stay	Varying durations of stay	Lasting relocation
Frequency	Generally a repetitive event	Multi-transitional and on-going	Single transition
Seasonality	Large seasonal variation	Some seasonal variation	Minor seasonal variation
Temporality	Occurs at a specific point during the life-course	On-going throughout the life-course	Occurs at a specific point during the life-course, a one-off event

Note. From "Lifestyle Mobilities: The Crossroads of Travel, Leisure and Migration," by S. A. Cohen, T. Duncan, and M. Thulemark, 2015, *Mobilities*, 10(1), p. 159 (www.tandfonline.com). Copyright 2018 by Taylor & Francis. Reprinted with permission.

2001, pp. 94, 59). The existence of negative stereotypes about nomads and RV living places RVers at risk for discrimination. Individual and institutional discrimination can have negative impacts on mental health, physical health, and healthcare access (Davis, 2020).

Nomad Health

Little is known about the health of full-time RV nomads. Counts & Counts (2001) conducted ethnographic research between 1990 and 1998 to explore RVing as an alternative lifestyle for retirees. They interviewed RVers and conducted a survey. Most of the survey respondents were members of the Escapees RV club. Eighty-six percent of survey respondents were "full timers" or "serious RVers" who traveled most of the year in their RVs. Ninety-two percent rated their health as good or excellent for their age. However, Counts & Counts (2001) noted that they tended to downplay serious medical issues. Twenty-five percent professed that their health had improved after they started traveling, with seventy-four percent of those attributing the change to decreased stress. Eight percent stated what their health had worsened, with fifty-seven percent of those attributing the change to aging and twenty-nine percent attributing it to a poor diet and lack of exercise. Most respondents to this survey (81%) were between the ages of 55 and 75 (Counts & Counts, 2001, p. 267).

Researchers have suggested that full-time RV travel may result in healthier aging due to the lifestyle's increased physical and social activity (Counts & Counts, 2001; Haskell, 2013). These authors have drawn links between studies reporting that healthier aging is associated with increased physical, mental, and social activity, and reports from RVers who state they are more physically, mentally, and socially active. A level of mental alertness and physical mobility is required to drive and maintain a mobile home. Although it is possible that the increased activity involved with the RVing lifestyle may slow the decline of aging, aging often results in a return to sedentary living. Counts & Counts (2001) described finding a home base as the second stage of the RV life cycle. In this stage, RVers purchase or rent space where they can park their RV long-term. They gradually spend more time at their home base and less time traveling or may become

snowbirds, alternating between seasonal residential locations. Since little attention has been devoted to studying specific healthcare experiences in this population, it is impossible to determine whether the transition to this second stage could be hastened by limitations in healthcare access during a stage in life when more care is needed.

Little research exploring RVFAN's healthcare experiences was available. The available research suggested that RVers may be underinsured, may forgo needed care, and may experience care fragmentation. Counts & Counts (2001, p. 282) reported that twelve percent of RVers surveyed were uninsured. Among the forty-three percent who admitted to having a bothersome physical condition, only twenty-seven percent had seen a physician in the past year (Counts & Counts, 2001, p. 281). Health emergencies could occur in unfamiliar places where the location, type, and quality of healthcare facilities are unknown (Haskell, 2013). Carnival workers are often RV-dwelling nomads and their children have been found to experience duplication of care as a result of seeking care at multiple sites (Kilanowski & Ryan-Wenger, 2007).

In countries where more research has been done on the health of nomadic populations, disparities in healthcare between nomadic and sedentary populations have been well documented. Healthcare disparities experienced by nomads in other countries included individual and institutional discrimination, care fragmentation, and a lack of resources to facilitate the provision of healthcare at rural health facilities (Ali et al., 2019; Aziz et al., 2015; Calma et al., 2018; Erdenee et al., 2017; Gammino et al., 2020; McFadden et al., 2018; Raven, 2015). The abundance of research documenting disparities in the healthcare of nomads in other countries demonstrated the importance of understanding the healthcare experiences of American nomads.

Significance of the Study

Public health goals

The United Nations has issued a call to action, outlining 17 sustainable development goals to improve lives worldwide by the year 2030 (United Nations [UN], n.d.). One of these goals is achieving worldwide universal health coverage (UHC). The World Health Organization (WHO) is the agency of the United Nations charged with this task. The WHO defines universal health coverage as "all people have access to the health services that they need, when and where they need them, without financial hardship" (WHO, n.d., para. 1). Healthy People 2030 has set goals to improve healthcare access in the U.S.

Nomad groups globally have been declared vulnerable due to discrimination from settled majority populations and the lack of representation in policy making (Marchi, 2010). They have been described as hard-to-reach because their frequent relocation and lack of residential address results in challenges providing and coordinating care (Ozawa et al., 2019). RVFANs have been described as "marginalized" communities due to the stigma attached to nomadism and RV living (Counts & Counts, 2001, p. 89). The lack of representation in government or healthcare policy decisions may result in healthcare delivery that does not meet the needs of nomads. To meet public health goals, it is necessary to identify and eliminate disparities in mobile populations' healthcare.

Disparities

Healthcare disparities are differences in treatment not explained by patient needs or preferences (Artiga et al., 2020). They may be associated with socioeconomic or environmental disadvantages. The constitution of the World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease of

infirmity" (2006, p. 1). It states that, "the enjoyment of the highest attainable standard of health is a fundamental right of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, 2006, p. 1). Organization of healthcare delivery may create disparities when it makes obtaining services harder for certain populations. Organizational factors that interfere with nomad's abilities to attain their highest level of health are a violation of their human rights.

Prior research on the healthcare experiences of nomadic RVers in America is very limited. As a marginalized population, RVers are likely to face disparities in healthcare access. RVers often dwell in rural areas. Rural healthcare facilities are under-resourced, which may impact the type and quality of care that they provide (Butkus et al., 2020; Schuller et al., 2019). RVers are at risk for discrimination based on negative stereotypes about nomads and RV dwellers. Providers who have not acknowledged nor adapted care plans to lifestyle mobility may put RV nomads at risk for sub-optimal health outcomes. For example, Ozawa (2019) noted that nomadic movement in Africa interfered with the completion of vaccination series. A savvy healthcare provider could engage the nomad to create a plan of care situated in mobility by arranging to have subsequent vaccine doses given at sites along the nomad's route. Increased knowledge about RV nomads' interactions with healthcare providers is essential to prevent healthcare disparities by enabling care planners to plan services that are accessible and acceptable to adherents of lifestyle mobility.

Statement of the Problem

Ideally, healthcare planning should involve collaboration between the provider and the patient to design plans of care that are feasible and acceptable within the context of the patient's lifestyle, care preferences, and resources. In current practice, patients are often assumed to be

stationary. The full impact of lifestyle mobility on RV nomads' healthcare experiences and their ability to access healthcare is unknown. Healthcare professionals who neglect to consider the nomadic lifestyle may be less effective in their efforts to support and improve nomad health. Developing knowledge about the healthcare experiences of RV nomads could result in more effective care being provided to this population. Increased attention within the healthcare community to the health of mobile populations could further progress towards meeting the public health goals set by the WHO and Healthy People 2030.

Purpose of the Study

The purpose of this study is to understand the experiences of RV-dwelling nomads when seeking healthcare in America. The current knowledge about the healthcare experiences of RV nomads is too limited to provide direction for researchers that hope to improve health services. An in-depth understanding of RV nomad experiences is needed to support the design of future comparative or interventional studies with this population. In practice, this knowledge has the potential to enable healthcare practitioners to design interventions that are more effective for RV nomads. It could also enable healthcare planners to consider the needs of nomad populations when structuring public health programs. Including mobile populations in health planning could improve public health in America.

Research Questions

1. What are the experiences of RV-dwelling full-time American nomads (RVFANs) when seeking healthcare in the United States?
2. What are the barriers to healthcare access for RVFANs in the United States?
3. What are the facilitators to healthcare access for RVFANs in the United States?

Assumptions

1. The researcher will be able to locate RVFANs and they will agree to participate in the study.
2. Participants will answer questions truthfully.

Delimitations

1. Research participants will include Americans who live in RVs while practicing lifestyle mobility for more than 6 months of the year. It will exclude snowbirds, permanent migrants, unhoused people living in stationary vehicles, and tourists.
2. The study will be limited to descriptions of the lived experiences of RVFANs. No interventions will be implemented. No chart review will be completed.

Limitations

RVers have expressed distrust of government and other empowered establishments such as the health system. As a hidden population, they have reported concerns about the outcomes that may result from the publication of their lifestyle (Counts & Counts, 2001). Some RVers have withdrawn from the healthcare system entirely, preferring self-reliance through a healthy diet, exercise, and herbal remedies (Counts & Counts, 2001). Participants may view a highly educated healthcare professional as a representative of the establishment which they have chosen to avoid. It may be difficult to gain sufficient trust to facilitate honest and open communication.

As the future of the COVID pandemic is uncertain, the researcher may face barriers to conducting face-to-face interviews with RVers. Many RVers use technology to work remotely. Conducting interviews online may increase the availability of RVers to interview, however, Davies et al. (2020) note that distanced communication can have a negative impact on

relationship building. Online communication requires a different skill set than in-person communication.

Summary

Since the healthcare system was designed for stationary populations, lifestyle mobility may create challenges to healthcare access. Little research has been done to explore the healthcare experiences of RV-dwelling nomads in America. This study will generate knowledge about RVers' experiences when navigating the healthcare system. This chapter has introduced the concepts of the study.

Chapter II: Review of the Literature

This section will provide more depth on the concepts that were introduced in chapter one. First, the search strategy will be reported. Then the history of nomads and the culture of RV-dwelling nomads in America will be explored in more depth. Next goals for healthcare access in America will be discussed. The conceptual framework will be described, then literature describing the barriers and facilitators to healthcare access for nomadic populations will be organized using the dimensions of the framework. Finally, the findings of existing literature will be synthesized to identify gaps in knowledge.

Search Strategy

A comprehensive search of the literature was completed. Multiple databases were searched, including OneSearch, CINAHL Complete, ProQuest, and Google Scholar. OneSearch is a search tool which combines multiple databases and scholarly resources. Beginning search terms included nomad or gypsy or RVing or recreational vehicle or "RVer" or full timer or vanlife or vehicle-dweller AND health. No articles published between 2015 to 2021 that examined the health of RV-dwelling American nomads were found. The search for information on American nomads was deepened by extending the date range through 2000. A single ethnography focused on RVers was found with a few pages dedicated to health (Counts & Counts, 2001). Several articles that described the culture of full-time RVers were also retained.

Many studies were found on the health of nomads in other countries. Since information on the healthcare access of American nomads was sparse, additional sources were retained when they focused on healthcare access for nomadic populations in any country. Nomadic people may experience common challenges when interacting with healthcare services in stationary communities. Limiting terms were added to improve the specificity of the search. These included

healthcare or health care or health services or health facilities and access or experience or approachable or acceptable or available or affordable or appropriate. References of retained articles were reviewed to identify seminal sources.

Foundation

Nomads

Humans existed as nomads before the invention of farming facilitated the sustenance of settled populations. Nevertheless, settled populations have marked nomads as distant 'others' and viewed them alternately as threats to order or as heroes of freedom and adventure (Engebrigtsen, 2017). Nomadic movements were considered as challenges to state control and private land ownership (Salazar & Smart, 2011). As a result, nomadic populations around the world have been subjected to persecution and forced settlement (Engebrigtsen, 2017). Persecution of nomadic groups intensified with the formation of nation-states and industrialization in the 19th and 20th centuries.

While some use the term 'nomad' to refer specifically to pastoralists, others define 'nomads' as inclusive of any group that chooses a mobile lifestyle instead of a stationary home (Carlsen Häggrot, 2018). Pastoralists are nomadic groups who travel to find fresh pasture for their livestock (Gammino et al., 2020). Hunter-gatherer nomads travel to hunt wild game and to gather naturally occurring foods and materials from their environments and peripatetic nomads travel to provide services or supplies to settled populations (Carlsen Häggrot, 2018). Some nomads are born into cultures of nomadism, while others adopt nomadic mobility as adults.

Technological advancements have created new kinds of nomads. Digital nomads sell goods and services online to customers in remote locations (Olga, 2020). Since their work is location independent, they choose their travel locations based upon personal preferences which

may include consideration of economic, environmental, social, and political conditions. Geographic arbitrage describes the practice of residing in locations with a lower cost of living, while earning higher rates of pay from remote customers residing in places with stronger economies (Mancinelli, 2020). Some nomads live in countries with weaker economies, while selling their work to consumers in countries with stronger economies. Other digital nomads hold jobs in cities with high costs of living and wages, while living in less expensive rural and remote areas. Location independent nomads may also be retired or unemployed. Although the lifestyles of nomads vary, the value they share is mobility.

RVers in America

Recreational vehicles (RVs) are vehicles which have been equipped to accommodate food preparation, bathing, toileting, and sleeping. RVs have been built and enjoyed in America since the use of automobiles became widespread in the 1920s (Counts & Counts, 2001). Previous research has noted cultural differences in RV groups based on travel patterns. RVs serve as short-term housing for some such as tourists and seasonal migrants (i.e. snowbirds). They serve as long-term homes for others. Some RV dwellers are stationary, using their RVs as substitutes for site-built homes (Pruss & Cheng, 2020). “Full timers” combine RV living with nomadic mobility (Counts & Counts, 2001, p. 48). They include peripatetic nomads, digital nomads, artists, and those who are retired or unemployed. The failure to differentiate study findings by the level of mobility of RVers has led to conflating groups with different behaviors and resources. For example, some studies have labeled all people who travel to southern locations in the winter as snowbirds, though they could be tourists or nomads (i.e., Al-Haque et al., 2015). In the following literature review the groups will be labeled as the authors have labeled them.

Hardy et al. (2013) described recreational vehicle users (RVers) as a neo-tribe. Neo-tribes are populations from diverse backgrounds who form emotional connections through shared lifestyles, goods, scenes, activities, and vocabulary. The specialized goods and services required for RV travel provide common subjects of conversation for neo-tribe members. Campgrounds, overnight parking spots, and online social clubs are the shared scenes where RVers meet and discuss their travel experiences using a vocabulary which is unique to the activities of RVing. Examples of shared activities in the RVers neo-tribe include caravans, happy hours, and rallies. Caravans describe groups of RVers who travel planned routes together, happy hours describe campground evenings when RVers gather outside to share stories about their days, and rallies are large gatherings where RVers from around the country meet to share fellowship, food, information, and resources. Companionship within the RV neo-tribe is a perk which draws people into the RV lifestyle and encourages members to stay (Hardy, 2013).

Several subtribes have been delineated within the larger RV neo-tribe (Hardy et al., 2013). Many RVers use their RVs for vacation weekends and holidays but full timers travel for most of the year. Counts & Counts (2001) described RVers who have no stationary residence as "full timers." They defined "serious RVers" as those who spend more than six months a year living away from home in their RV. Since both groups spend most of the year living in their RV, they are likely to be traveling when a health need arises and may experience health disparities resulting from lifestyle mobility.

Full timers and serious RVers are diverse groups representing all stages of life. Although many associate RV living with retirement, the numbers of working age RVers traveling with children are growing (Dahl, 2020). Some RVers are wealthy while others live below the poverty line. Many full timers and serious RVers change locations weekly, while others prefer daily

movement, and some stay a month or longer in one spot. Some RVers are planners, reserving spots months in advance while others travel spontaneously (Counts & Counts, 2001). RVers may park their homes in campgrounds with amenities, on public land without services (boondocking), in city parking (stealth camping), or outside the residences of friends or family members (mooch docking). Some travel following the weather, while others plan travel around contract work, family or public events, sporting interests, or other attractions. Despite the group's diversity, full-time travel unites them.

Full timers are distinguished from other RV dwellers by lifestyle mobility. Cohen et al. (2015) describe lifestyle mobility as a way of life characterized by perpetual semi-permanent moves of varying durations. Movement composes a meaningful element of identity for adherents of lifestyle mobility. While snowbirds alternate between multiple stationary destinations, they do so in a predictable seasonal pattern structured around a plan to return home (Haskell, 2013). While tourists may visit destinations for varying lengths of time, their plans are also structured around a return to home. While economic devastation may push unhoused people into RV residency (Pruss & Cheng, 2020), they may choose campsites within a single community. Full timers adopt vehicle residency to facilitate their mobility because lifestyle mobility aligns with their chosen values (Counts & Counts, 2001). Full timers choose to make their home on the road. In contrast to other RV dwellers, a full timer's identity is defined by their mobility.

Shared cultural values and experiences bind neo-tribe members together (Hardy et al., 2013). RVers seek self-actualization through the adoption of an alternative lifestyle. Nomads reject the values which settled populations use to mark success, such as accumulation of material goods. In their place, RVers promote values of freedom, independence, and adventure. Accumulation of experiences is prioritized over accumulation of property. While their alternative

lifestyle marginalizes RVers from mainstream society, it increases social interaction with like-minded individuals and results in bonding within the neo-tribe (Hardy et al., 2013). Unfortunately, the rift in values between RVers and settled populations could result in differential treatment by healthcare professionals.

Healthcare Access in the U.S.

HealthyPeople 2030 defines access to health services as "the timely use of personal health services to achieve the best health outcomes" (ODPHP, n.d.-a.). Broad aims for improving healthcare access in the U.S. include improving the proportion of adults who have access to medical care, insurance, prescription drugs, and telehealth; increasing the proportion of adults who receive high-quality primary care; and increasing the proportion of adults who receive recommended preventative services. The most common barriers to healthcare for the general population include cost, lack of insurance or inadequate insurance, lack of availability of healthcare services or providers, and lack of culturally congruent care.

Healthcare Disparities in the U.S.

Social determinants of health describe living conditions that impact health outcomes (Agency for Healthcare Research and Quality, 2020). Differences in social determinants of health between groups result in healthcare disparities when they make it more difficult for some groups to access the resources they need to achieve optimum health. Discrimination is a social determinant of health which has been associated with disparities in mental health, physical health, and healthcare access (Davis, 2020). It can occur at the individual level or at the institutional level. Individual discrimination describes the differential treatment of people or groups based on their race, religion, sexual orientation, age, weight status, or social class (Davis, 2020). An example of individual discrimination would be a healthcare provider who does not

provide an equivalent level of communication and care to a patient because of negative stereotypes about their lifestyle (McFadden et al., 2018). Institutional discrimination refers to laws or policies which intentionally or unintentionally make services harder to access for certain groups (Davis, 2020). An example of institutional discrimination could be a health insurance policy that only provides payment for health services consumed in the state of domicile. This could be construed as institutional discrimination because it would make healthcare services harder to access for nomadic people who spend most of the year traveling outside of their domicile state. Both individual and institutional discrimination can lead to disparities in health.

At the request of congress, the Agency for Healthcare Research and Quality publishes an annual report addressing disparities in 205 health metrics among vulnerable populations (Agency for Healthcare Research and Quality, 2020). Progress in reducing disparities is monitored and reported. In the 2019 National Healthcare Quality and Disparities Report, vulnerable groups were identified based on race, ethnicity, insurance status, income level, and location of residence. The section of the report that focused on residence location divided the population by levels of urban development. The mobility of populations is not discussed. Although many Americans are nomadic, nomadism has not been addressed by these national public health initiatives.

Theoretical Framework

Levesque's Conceptual Framework of Access to Healthcare (LCFAH) will be used to generate interview prompts and to frame the themes identified from data analysis. Researchers who were interviewed after using LCFAH described it as the most comprehensive framework to address the phenomenon of healthcare access or as an improvement from previously used frameworks (Cu et al., 2021). To develop the framework, Levesque et al. (2013) completed an extensive review of literature on healthcare access. Eleven of the most frequently cited

conceptualizations of healthcare access published between 1971 and 2008 were analyzed and factors significant to healthcare access were synthesized to create the comprehensive conceptual framework. Since little is known about the barriers and the facilitators to healthcare access for American nomads, the breadth of this framework will be essential to categorize the variety of themes that are likely to emerge from descriptions of the healthcare experiences of a diverse population.

Levesque's conceptual framework of access to care provides a patient-centered approach for the study of populations. The outcome measures of a conceptual framework guide researchers to their conclusions about the sufficiency of healthcare access. Some models for exploring healthcare access, such as Andersen's behavioral model of health services use, measure success through the utilization of healthcare services (Cu et al., 2021). This is a provider-centered approach. Declining to use a specific health service may not represent a lack of access to healthcare. Despite adequate opportunity, the population may determine that another service is more suited to their needs. Use of an equally effective, alternative service represents freedom of choice rather than a lack of access. In contrast, LCFAH measures successful access through consumer health outcomes, satisfaction, and the economic impact on the consumer (Levesque et al., 2013). These measures address the fulfillment of the consumer's need rather than promoting the use of a specific health service. For example, in a study of access to breast health services, breast cancer survival rates would provide a more meaningful measure of success for the patient than the number of clinic appointments.

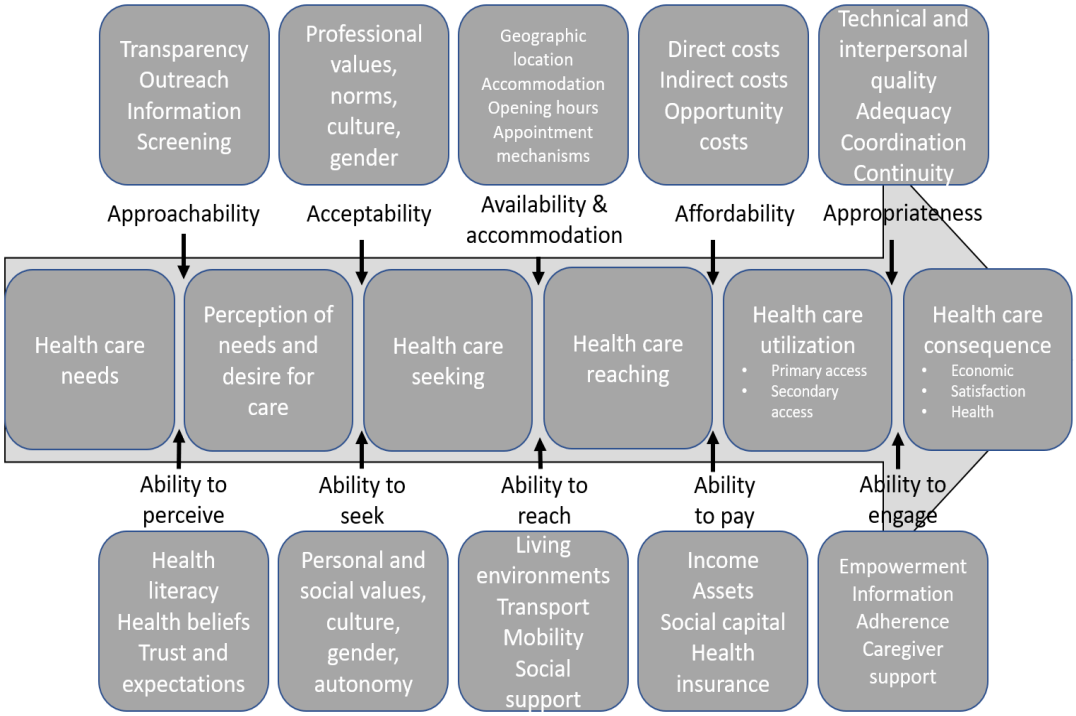
Levesque et al. (2013) define healthcare access as the interface between the characteristics of consumer populations which enable them to initiate care and the characteristics of available health services and providers. It is not sufficient to make healthcare services

available. For a successful interface between supply and demand, providers must make the services that are available known to consumers and consumers must believe that the services will satisfy their needs. The culture of healthcare providers and institutions must make consumers feel comfortable with the care provided and the culture of consumers must enable them to access care. Services must be offered at locations that patients can reach, and they must be available during days and times when patients can come. Consumers must have transportation and social support to allow time for the health visit. Services must be affordable for their target populations and consumers must have the resources to pay for them. Services must be of a sufficient quality to meet the consumers' needs and consumers must be empowered to participate (Levesque et al., 2013). LCFAH assumes that successful access to care depends on alignment of all these variables. Levesque's conceptual framework is displayed in Figure 2. The inwardly pointing arrows illustrate correlating supply-side and demand-side dimensions of healthcare access.

Several researchers have cited the inclusion of both sides of the healthcare interaction as a strength of Levesque's framework (Cu et al., 2021). This specificity facilitates the development of interventions to enhance facilitators or reduce barriers on both the supply side of the care equation (i.e., providers and healthcare institutions), as well as the demand side (i.e., patients and communities). Supply side dimensions of access were defined as the approachability, acceptability, availability and accommodation, affordability, and appropriateness of healthcare services (Levesque et al., 2013). Demand side dimensions of access were defined as the consumer abilities: to perceive, to seek, to reach, to pay for, and to engage in healthcare services

Figure 2

A Conceptual Framework of Access to Healthcare



Note. From "Patient-centred Access to Healthcare: Conceptualising Access at the Interface of Health Systems and Populations," by J. F. Levesque, M. F. Harris, and G. Russell, 2013, International Journal for Equity in Health, 12(1), p. 5 (http://www.equityhealthj.com/content/12/1/18). CC BY 2.0.

(Levesque et al., 2013). Supply side and demand side dimensions of healthcare access were described as closely linked and interactive. In the model (Figure 2), the boxes adjacent to each healthcare dimension provide examples of social determinants of health that have been aligned with that dimension. Factors identified within each dimension may be defined as barriers or facilitators to access depending on their impact on the care equation. The population and context of the study determine which factors are relevant to the healthcare interaction being examined.

Many researchers have used the model to categorize themes identified in their qualitative data using the dimensions that provide the closest conceptual fit (Cu et al., 2021).

In addition to a comprehensive view of the healthcare interface, Levesque's framework spans the entire healthcare access continuum. The access continuum is defined as "the possibility to identify healthcare needs, to seek healthcare services, to reach the healthcare resources, to obtain or use healthcare services, and to actually be offered services appropriate to the needs for care" (Levesque et al., 2013, pp. 4). It is represented by the center arrow of the model and illustrates the movement from the start to the end of the episode of healthcare access (see Figure 2). This includes not only the primary contact for services, but also access to follow up care. The framework is appropriate to assess healthcare experiences from the onset of healthcare needs through to the outcomes of services provided.

Levesque's conceptual framework of access to care can be applied to research at different levels of practice. The supply side dimensions are general enough to be used for assessment of the accessibility of healthcare systems, institutions, organizations, or providers (Levesque et al., 2013). The demand side dimensions are general enough to be used for assessment of the abilities of populations, communities, families, or individuals (Levesque et al., 2013). The concepts and relational statements proposed by LCFAH are logical and applicable to this study.

Levesque's conceptual framework of access to care has been successfully used in dozens of studies in populations around the world since its publication in 2013 (Cu et al., 2021). Most often, the framework has been used to develop data collection tools or to analyze research data. It has been used to generate or analyze data in quantitative, qualitative, and mixed methods studies (Cu et al., 2021). It has also been used to analyze data abstracted from literature reviews (Casebolt, 2020; Rahman et al., 2019). While most researchers reported that the framework was

easy to use, some have reported difficulty determining which dimensions align most closely with the themes they have identified inductively in their data (Cu et al., 2021). This may be a consequence of the anticipated overlapping and interaction of the dimensions of access and may reflect the complexity of the concept of healthcare access. To address this challenge, the researchers suggested keeping a copy of the original framework nearby during analyses.

Cu et al. (2021) suggested that an additional dimension of time could be added to the model to address time spent waiting or traveling when seeking care. The directives of the original framework recommended that the categorization of time-related themes should depend on the impact to the patient (Levesque et al., 2013). For example, time as an inconvenience would be categorized under availability and accommodation, time as an economic cost would be categorized under affordability, and time as a measure of care urgency would be categorized under appropriateness. This study will apply the dimensions of access as originally described by Levesque et al. (2013). The significance of delays is situational and the categorization of time-related themes under dimensions according to their impact is a more patient-centered approach. For example, a thirty minute delay in initiating cardiopulmonary resuscitation (CPR) has a different relevance than a thirty-minute wait for a routine exam. If a separate time dimension were added, these would be categorized under the same dimension. Using the current framework the CPR delay would be categorized as a barrier to appropriate care while the delay for the routine visit would be categorized as a barrier to accommodation. A holistic view of healthcare access requires consideration of all dimensions and their interactions (Cu et al., 2021) Adding another dimension for time would make the categorization of themes simpler but it would decrease the significance of their categorization.

The importance of equity in healthcare access inspired the development of the LCFAH. Levesque's conceptual framework of access to care has been used to assess equity for vulnerable populations (Anderson et al., 2021; Oga-Omenka et al., 2020). Achieving equity in healthcare is one of the goals of Healthy People 2030 (ODPHP, n.d.-b.). This study aims to identify barriers and facilitators to healthcare access for American nomads by exploring the experiences of nomads. The findings may illuminate inequities in healthcare access experienced by RV nomads. Analysis framed with LCFAH will facilitate the analysis of themes that emerge at any level in the spectrum of care from individual health to public health and at any point in the timeline of care from the identification of a need to follow-up.

This study will be predominantly exploratory. Collins & Stockton (2018) note that theory is present in most qualitative research although its use may not be explicit. They advocate for clearer descriptions of the use of theory in qualitative research. The first research question in this study addresses participants' healthcare experiences. Participants were asked to freely describe their recent healthcare experiences. The overarching experiences of recreational vehicle-dwelling full-time American nomads (RVFANs) were described outside of LCFAH since they involved the interaction of multiple model dimensions.

The subsequent research questions address barriers and facilitators to healthcare access. LCFAH contributed a general description of factors that were relevant to healthcare access in other populations and concepts that were useful to organize the data related to healthcare access barriers and facilitators (Collins & Stockton, 2018). Organization of barriers and facilitators to healthcare access using labels familiar to the public health community will provide a connection to the larger body of knowledge about healthcare access in other populations and contexts. The framework was also used to illuminate barriers and facilitators to healthcare access that may not

have been mentioned spontaneously (Collins & Stockton, 2018). The latter portion of the interview guide was populated with questions inspired by the dimensions of healthcare access described in the model.

Although this part of the study has descriptive elements, the researcher was alert to avoid confirmatory bias through overreliance on LCFAH (Collins & Stockton, 2018; Thorne et al., 2004). Since very little information is available about barriers and facilitators to healthcare access in the context of nomadic mobility in the United States, the relevance of the specific factors in LCFAH to this context have not been confirmed. It is also possible that new factors may be identified that are specific to the nomadic context. In conclusion, the LCFAH was appropriate for use in this predominantly exploratory study about the health experiences of American nomads because of its philosophical approach towards equity and the comprehensive perspective it engendered. However, the researcher avoided overreliance on the conceptual framework to preserve the exploratory nature of the study.

Nomad Barriers and Facilitators to Access

The dimensions of Levesque's conceptual framework of access to healthcare will be used to organize findings of the literature review related to the barriers and facilitators to healthcare access experienced by nomads. The linked supply and demand dimensions will be analyzed conjointly. Finally, the findings are synthesized and gaps in the literature are discussed.

Approachability and ability to perceive

Approachability is a supply-side dimension of access that refers to the consumer's knowledge that healthcare services exist which are accessible to them and will address their needs (Levesque et al., 2013). Some strategies to improve approachability include community outreach and advertising (Levesque et al., 2013). Peripatetic nomads in Europe and retired

nomads in Australia reported difficulty in locating healthcare services (Calma et al., 2018; McFadden et al., 2018). These were barriers to the approachability of healthcare when viewed through the lens of LCFAH. The outreach efforts of the service providers were insufficient to enable nomads in the area to find them.

The ability to perceive is the correlating demand-side dimension that refers to consumer beliefs regarding the need for care. Perception can be influenced by health literacy and beliefs, expectations of care and consumer's level of trust in healthcare services (Levesque et al., 2013). Poor health literacy has been reported in peripatetic and pastoral nomads in Africa, Asia, and Europe (Ali et al., 2019; Gammino et al., 2020; McFadden et al., 2018). Pastoral nomads in Africa reported reluctance to approach healthcare institutions due to the perception that facilities would not address their needs (Gammino et al., 2020). European peripatetic nomads worried that their children might be taken from them as a result of approaching the conventional healthcare system and preferred to seek care from community healers (McFadden et al., 2018).

Acceptability and ability to seek

Acceptability is the supply-side dimension that refers to cultural and social factors of healthcare institutions and healthcare professionals which determine the consumer's level of comfort in accessing services (Levesque et al., 2013). This dimension includes individual and institutional discrimination. Individual discrimination against nomads was reported by pastoral and peripatetic nomads in Asia, Africa, and Europe (Ali et al., 2019; Aziz et al., 2015; Gammino et al., 2020). Widespread discrimination against the peripatetic Roma in Europe stimulated the United Nations to declare 2005 to 2015 "the decade of Roma inclusion" (Sándor et al., 2017). Other cultural attributes of healthcare institutions could result in patients deeming them unacceptable. For example, healthcare workers may not speak the language that patients feel

most comfortable communicating in (Aziz et al., 2015; McFadden et al., 2018). Patients may deem services to be unacceptable if they are not comfortable being cared for by healthcare workers from a different sex, race, or religion (Aziz et al., 2015). In addition to the attributes of healthcare providers, facilities may have policies that exclude certain groups.

Institutional discrimination was reported by nomads in Asia and Europe, where care facilities required official documents not possessed by nomads, required proof of living at a stationary address for six months to qualify for services, or requested fees for services from nomads that were provided for free to the majority population (Aziz et al., 2015; McFadden et al., 2018). Discrimination may be intentional or unintentional (Davis, 2020). For example, charging nomads fees for services that are free for most people was likely to be an intentional act of discrimination. On the other hand, the policy that required official identification to register for services may not have been intended to disenfranchise nomads. It is likely that nomads were not included or considered when the structures of healthcare service provision were designed, so the policy was unintentionally discriminatory.

The correlating demand side dimension to acceptability is ability to seek. Ability to seek refers to cultural and social factors of consumers which impact their capacity to obtain care (Levesque et al., 2013). Examples of this include conditions which impact personal autonomy. Several nomadic populations reported that the requirement for women to travel with a chaperone was a barrier to accessing care, as were prohibitions on women making healthcare decisions (Ali et al., 2019; Aziz et al., 2015; Gammino et al., 2020; McFadden et al., 2018). Some nomad groups viewed seeking care as a sign of weakness (Ali et al., 2019). Forced evictions from camp sites formed another barrier to seeking care (McFadden et al., 2018).

Availability, Accommodation, and Ability to Reach

The supply side dimension of availability refers to the location and number of healthcare services and their environmental contexts (Levesque et al., 2013). Accommodation refers to the times and modalities of services that are available. Assessment of this dimension also includes consideration of the qualifications of providers who are available, and the sufficiency of available equipment (Levesque et al., 2013).

To participate in the U.S. financial and political systems, American nomads must record the address of a fixed domicile. They employ various strategies to secure addresses, including using the addresses of friends or relatives they visit, listing addresses of properties that they reside in temporarily, or hiring mail forwarding services to establish addresses for them (Loring, 2021). Due to a blend of legal factors including favorable tax laws, insurance options, and requirements for physical presence, Florida, Texas, and South Dakota are popular places for nomads to establish their domicile addresses (Adams, 2020). Billions of dollars are distributed to federal health and social programs based on census data (Hotchkiss & Phelan, 2017). Population counts are used to determine eligibility for federal programs, to determine the amounts that will be distributed to different locations, and to monitor program performance (Hotchkiss & Phelan, 2017). Failure to count nomads and track their travel patterns may result in some health facilities being over-resourced while others are under-resourced. Governments in Africa and Europe have reported difficulty in appropriating healthcare services to nomads since they are not included in census counts and the locations of their camps are not mapped (Gammino et al., 2020; McFadden et al., 2018). Healthcare professionals in rural Australia reported that the unpredicted arrival of Grey Nomads strained the resources available in rural facilities (Raven, 2015). In the southern United States, Al-Haque et al. (2015) examined health visit data in veterans and noted

large seasonal variations in demand at healthcare facilities. They recommended adjusting staffing models based on seasonal demand fluctuations to preserve the quality of care.

Nomads often camp in rural and remote locations. Pastoral, peripatetic, and Grey Nomads reported that the rural facilities they accessed provided limited services, were less likely to have access to online medical records, did not have sufficient supplies, and that the providers that worked there were poorly educated or unqualified (Ali et al., 2019; Aziz et al., 2015; Calma et al., 2018; Erdenee et al., 2017; Gammino et al., 2020). Distance to care was reported as a barrier and mobile healthcare workers refused to travel to nomad camps in some places (Ali et al., 2019; Gammino et al., 2020; McFadden et al., 2018). Other barriers in accommodation included inflexible service delivery systems, difficulty obtaining appointments, and waiting times (McFadden et al., 2018). A reported facilitator of access was the availability of community healers (Ali et al., 2019; Gammino et al., 2020).

The ability to reach is a demand-side dimension of access that refers to the consumer's resources for travel to healthcare facilities and the flexibility they have leave work (Levesque et al., 2013). Barriers to travel reported by nomads included lack of transportation modalities, poor roads, difficult terrains, and extreme weather conditions (Ali et al., 2019; Erdenee et al., 2017; Gammino et al., 2020). Pastoral nomads in Africa and Asia also reported armed conflict as a barrier to travel (Ali et al., 2019; Gammino et al., 2020). Use of technology such as global positioning system satellites and cellular phones were reported as a facilitator to reaching care by pastoral nomads in Africa and Asia (Ali et al., 2019; Gammino et al., 2020), while the need to use informational technology to reach care was reported as a barrier by peripatetic nomads in Europe (McFadden et al., 2018). Community support facilitated reaching care for pastoral nomads in Africa and Asia (Ali et al., 2019).

Affordability and ability to pay

Affordability is a supply-side dimension of healthcare access. It refers to the cost of services and any costs that are incurred because of seeking healthcare (Levesque et al., 2013). This includes lost income because of time away from work. Nomads reported that resources to facilitate payment for healthcare services and transportation were lacking (Ali et al., 2019; Aziz et al., 2015; Gammino et al., 2020). Barriers to access also resulted from the cost of missed work (Aziz et al., 2015; Gammino et al., 2020) and the cost of telephone use (McFadden et al., 2018).

Ability to pay is the corresponding demand side dimension. This is defined as the consumer's ability to raise the funds to pay for healthcare and the incidental expenses associating with seeking care without sacrificing life's necessities (Levesque et al., 2013). McFadden et al. (2018) reported that lack of insurance was a barrier to access for European nomads. In 2001, Counts & Counts reported that 12.2% of American RVers lacked insurance (p. 282).

Some RVers in America depend on support from the RV community to make care more affordable. The Caring Affordable Respite Experience (C.A.R.E.) facility is a non-profit facility that helps RVers who are unable to care for themselves due to short-term or long-term disability (Caring Affordable Respite Experience, 2021). RVers pay to park their homes at the facility when they need assistance with their activities of daily living such as housekeeping, RV maintenance, and meal preparation. Volunteers from the RV community provide services and costs are kept low through donations. When their independence has been restored, these RVers may return to traveling. They may then provide support to other neo-tribe members during their own times of need.

Appropriateness and ability to engage

Appropriateness is a supply-side dimension of healthcare access. It refers to the quality of services provided and how well they fit the needs of the consumer (Levesque et al., 2013). Aspects of appropriateness can include the timeliness of services and how long the provider spends with the patient. It can include technical and interpersonal quality measures and measures of care coordination and continuity. Due to barriers in primary care access, nomads often access care at multiple sites. Fragmentation of care has been reported as a barrier to appropriateness of care (Calma et al., 2018; Gammino et al., 2020; McFadden et al., 2018). Fragmentation of care was exacerbated by a lack of shared medical records. A facilitator of appropriateness was reported to be carrying a medical summary and discussing travel with the primary care provider prior to leaving (Calma et al., 2018). Lack of culturally congruent care was another barrier to appropriateness reported by nomads (Gammino et al., 2020; McFadden et al., 2018).

The demand side dimension correlating with appropriateness is the ability to engage. This refers to patients' capacity to participate in decision making and treatment (Levesque et al., 2013). Motivation and empowerment are important elements of engagement. Illustrating the overlapping access dimensions in LCFAH, poor health literacy can be categorized as a barrier under either the ability to perceive dimension (when examining identification of care need), or the ability to engage dimension (when examining healthcare use) depending on the point along the continuum of care that is being examined (Cu et al., 2021). Ali et al. (2019) and Marchi (2010) noted that lack of political advocacy was a barrier to nomad engagement in their healthcare. Aziz et al. (2015) noted that supportive relationships between members of lower castes and between women of upper and lower castes facilitated engagement in healthcare for peripatetic and pastoral nomads in Pakistan.

Synthesis and Gaps

Neo-tribes of recreational vehicle-dwelling American nomads have existed in America since the 1920s. Although the numbers of full-time nomads are substantial and growing (Dahl, 2020), many in the majority population remain unfamiliar with nomadic RV-dwelling as a personal lifestyle choice. American nomads are a socioeconomically diverse group who are connected through their mobility-based lifestyle. Improving access to healthcare has been identified as a public health priority by Healthy People 2030. Despite this, population mobility has not been addressed in national public health initiatives. The lack of knowledge of the health experiences of nomadic Americans represents a significant gap in the knowledge of public health in America. The lack of understanding of the healthcare experiences of mobile populations in America could result in decreased effectiveness of healthcare interventions with this population and stunted progress towards public health goals. The lack of documentation of barriers and facilitators to healthcare access for RVFANs precludes research to improve care.

Disparities in healthcare access have been documented in nomadic populations in Africa, Asia, Australia, and Europe. The most documented barriers to healthcare access in nomadic populations included poor health literacy, individual discrimination, institutional discrimination, lack of documentation in census numbers, lack of resources at rural facilities, distance to care with transportation challenges, cost, and fragmentation of care caused by receiving care at multiple sites. The commonalities noted between culturally divergent and geographically distant nomadic groups indicate that these barriers may be features of the nomadic lifestyle.

The available data describing the health experiences of American nomads was sparse and out of date. Advancements in technology and changes to the healthcare system over the past twenty years have likely had a significant impact on the demographics of the population and on

their experiences with the healthcare system. The dearth of research available on the health of RV-dwelling American nomads indicated that a predominantly exploratory approach to research was appropriate. Levesque's Conceptual Framework of Access to Healthcare was useful to categorize the themes that were identified regarding barriers and facilitators to healthcare access in the context of nomadic mobility and current health policy in the U.S.

Summary

Nomads have a right to equitable healthcare access (Marchi, 2010). Unfortunately, nomads are often unrepresented in the decision-making processes of healthcare planners (Marchi, 2010). Mobility status is not documented in the U.S. census nor in U.S. healthcare databases, making it difficult to compare nomadic populations' health metrics with those of the general population. Disparities must be identified before they can be addressed.

Lack of knowledge about American nomads' barriers and facilitators to accessing healthcare has implications for population health, U.S. public health, and the allocation and utilization of health resources. More information is needed about full timers' experiences when interacting with healthcare providers and the strategies they use to overcome institutional barriers to mobility predominant in U.S. healthcare delivery models. To assure that RVers do not face negative health outcomes, it is imperative that the American medical community become familiar with this subtribe. Healthcare professionals have an obligation to provide culturally congruent care. Culturally congruent care for nomads means that their mobility must be acknowledged and accommodated when planning healthcare services. Undertaking research to increase knowledge about American nomads' interactions with healthcare providers is the first step to facilitating change.

Chapter III: Methodology

To provide culturally congruent care for nomads in America, there is a critical need to understand the healthcare experiences of recreational vehicle-dwelling full-time American nomads (RVFANs) and the factors that impact their access to healthcare. The purpose of this study was to explore the healthcare experiences of recreational vehicle-dwelling full-time American nomads and to identify factors that are barriers or facilitators to healthcare access for this population. This chapter will explain the methodology and research design that was used to answer the research questions. The target population, sampling strategy, and data collection tools and strategies will be described. Finally, ethical considerations will be explored.

Research Questions

1. What are the experiences of RVFANs when seeking healthcare in the United States?
2. What are the barriers to healthcare access for RVFANs?
3. What are facilitators to healthcare access for RVFANs?

Healthcare experiences and healthcare access are complex, socially constructed phenomena. The research questions explored the impact of the nomadic RV dweller's culture and lifestyle on healthcare access and experiences. To answer the research questions, semi-structured interviews were conducted with RVFANs. The outcomes of this research included descriptions of the healthcare experiences of American nomads. In addition, Levesque's conceptual framework (see Figure 2) was used to categorize the barriers and facilitators to care. It is hoped that these will be useful tools for healthcare professionals and policy planners who are entrusted with improving public health, population health, and the health of individual nomads.

Methodology

Exploratory research design is the appropriate approach when little is known about the phenomenon of interest (Brink & Wood, 1998). The goals of exploratory research are to identify and describe problems. These goals align with the study's aims. Exploratory designs are flexible to allow researchers to adapt their line of inquiry as new knowledge illuminates the most pertinent areas for discovery (Brink & Wood, 1998). Qualitative data collection facilitates exploration.

Qualitative methodology is well suited to exploratory research involving marginalized populations since it allows participants, who do not share the hegemonic discourse of the majority, to explain their experiences using their own words (Webber-Ritchey et al., 2021). The available literature on the health of RV-dwelling American nomads was sparse and outdated. In the past twenty years significant changes have occurred such as the implementation of the Affordable Care Act and the increased adoption of technology to promote remote work and telehealth. It is hoped that the base of knowledge provided by this study will support future descriptive, comparative, and interventional studies.

A variety of methodologies have been developed that employ qualitative data to achieve different goals. This study was value-based. Thorne explains, "nursing always and inherently requires knowledge about patterns and themes within people in general so that it can better inform the care of the unique and distinct individual" (2016, p. 28). In keeping with this pragmatic philosophy, interpretive description was used to frame the study.

This nursing methodology employs elements of phenomenology, ethnography, and grounded theory, but encourages adaptation to maintain focus on the goal of generating practical knowledge for clinical healthcare applications (Luciani et al., 2019; Thorne, 1997). For example,

while phenomenology aims to encapsulate the existential essence of an experience, interpretive description aims to describe experiences within the context of healthcare to help clinicians to relate more effectively to their patients (Thorne, 2016). Phenomenology recommends bracketing to prevent the researcher's previous knowledge from contaminating the interpretation of the phenomenon. In contrast, interpretive description casts doubt on the ability of the clinician researcher to 'unknow' the known and instead recommends situating discovery within the context of previous clinical knowledge (Thorne, 1997). Ethnography aims to document the worldview of a group through cultural immersion, while interpretive description aims to describe how culture influences health and healthcare (Thorne, 2016). Grounded theory recommends avoiding the use of previous theory to avoid the influence of preconceived notions on inductive analysis (Tracy, 2020). In contrast, interpretive description recommends an iterative approach to data analysis that maintains awareness of existing theory while accepting that emerging data may alter theoretical assumptions (Thorne et al., 2004). While phenomenology, ethnography, and grounded theory recommend strict methodological adherence, interpretive description recommends pragmatic application of methods with respect to the needs of the discipline and the resources available (Thorne, 2016).

Target Population

The study included adult participants who spend more than six months of the year living in a recreational vehicle while moving from place to place in the U.S. It did not include tourists, snowbirds, sunbirds, seasonal migrants, or stationary people who live in RVs. These travel patterns were excluded because they may be more suited to obtaining healthcare through the predominant primary care model. To distinguish the study population from RV dwellers with other lifestyles, the population was referred to as recreational vehicle-dwelling full-time

American nomads (RVFANs). Mobility is fundamental to the identity of nomads and impacts most facets of their lives, including their use of healthcare services. Participants were included if they had been a nomad for at least a year. Both full timers and serious RVers as defined by Counts & Counts (2001) were included. Since both groups spend most of their time traveling, they are likely to be away from their home base when health issues arise. Studying RVFANs as a distinct population will facilitate the development of interventions that address the unique needs of full-time travelers. Although Counts & Counts (2001) included a significant number of Canadian nomads in their ethnography, access to Canadian healthcare altered their experiences. This study was limited to American nomads to facilitate the focus on healthcare access factors specific to health policy in the U.S.

Sample and Recruitment

RVFANs are a hidden and hard-to-reach population (Hardy & Gretzel, 2011). Previous researchers observed a mistrust of institutions associated with reluctance to participate in survey research (Counts & Counts, 2001). Counts & Counts (2001) stressed the importance of community immersion to gain trust and collected much of their data in campground laundromats. Researchers have suggested the use of multiple recruitment strategies when studying vulnerable and hidden populations (Fête et al., 2019; Langer et al., 2021).

A combination of convenience and purposive sampling strategies were employed. Convenience sampling involves including the participants that are most readily available (Polit & Beck, 2017). Purposive sampling involves selecting participants who are most likely to have characteristics or experience that will contribute to the knowledge gap (Polit & Beck, 2017). To investigate experiences that occur at the interface between nomadic mobility and U.S. health policy, criterion sampling was used. Criterion sampling is a purposive strategy that limits the

sample to participants that meet established criteria (Polit & Beck, 2017). This sample included only American RV dwellers that spend most of the year traveling. RV dwellers that were not nomadic were excluded.

Recruitment strategies that have proven effective with marginalized populations included partnering with community leaders, using communication modes and materials that are culturally acceptable, arranging study activities at times and places that are convenient for participants, and offering meaningful incentives (Langer et al., 2021). The primary recruitment strategies for this study included contacting RVFANs known to the researcher, posting flyers, maintaining a researcher presence at campsites, and snowball sampling. If more participants were needed after employing these strategies, the researcher planned to post the flyer on social media.

The context of this study was nomadic mobility in the United States. RVFANs travel throughout North America and create their home wherever they are at. The location where they are camped may not be the location where they seek healthcare, they could seek care at any point along their route. Haskell (2013) recommended avoiding snowbirds by going to northern sites in the summer to find full time RVers. One couple they interviewed in Newfoundland reported spending winters in California, New Mexico, Arizona, and Texas. In the summer they traveled to Montana, Colorado, South Dakota, Michigan, or New England. Parentin (2006) advised that popular summer spots for RVers include Hendersonville, NC and Sioux Falls, SD. Popular winter spots identified were Naples, FL, Mission, TX, and Quartzite, AZ. In contrast to the north-south routes of snowbirds, Haskell (2013, p. 140) described the travel patterns of full-time RVers as a “great circular cycle that constantly expands to the fringes of North America.” The principal investigator spoke with two members of the RV community to enquire about the best route to meet full-time RVers. They both advised that the greatest concentrations of RVers

during the winter months could be found in Arizona, Texas, and Florida. They stressed the importance of maintaining a flexible travel itinerary. For example, if the air quality is poor during the fire season, nomads may go east. If it is cold, they go south and if it is warm, they go north. While gathering data for their ethnography on RVers, Counts & Counts (1992; 2001) interacted with RVers in British Columbia, Nevada, Arizona, California, and Texas. Although they covered a large geographical area, contextual descriptions focused on campgrounds, campground facilities, RVs and the items placed in campsites to decorate their temporary homes. Geographical location was rarely mentioned.

Campsites are nodes where RVers gather and share fellowship (Hardy et al., 2013). To recruit participants with diverse healthcare experiences, flyers were posted in a variety of campgrounds ranging from free public land to expensive RV resorts. Permission was obtained from campground management prior to posting flyers on private property. The researcher visited two sites known for hosting large numbers of RVers in Arizona and Texas. RVFANs change their travel patterns based on a variety of factors such as weather conditions and current events (Counts & Counts, 2001). Additional study site selections were based on recommendations from RVers, mobile applications that are popular with RVers such as Campendium, availability, and financial resources. Due to the unpredictable travel patterns of the target population, the investigator maintained a flexible itinerary that was responsive to weather events when choosing recruitment sites.

Hardy et al. (2013) described two rituals that provided convenient and comfortable opportunities for RVers to be introduced to the study. At “happy hour”, RVers take walks around campgrounds and introduce themselves to their neighbors (Hardy et al., 2013, p. 56). Campfires serve as an informal invitation to visit. RV rallies are venues where RVers gather for social and

educational purposes (Hardy et al., 2013). The researcher traveled to RV campsites and socialized with RVers. A gas fireplace was placed in the campsite with empty chairs arranged nearby to encourage visitors. She also attended an RV rally. To prevent a feeling of home intrusion, the researcher did not knock on camper doors or enter others' campsites uninvited.

Snowball sampling involves asking participants to refer other participants. It is a successful strategy for enlarging the sample in hidden populations (Tracy, 2020). Snowball sampling may limit transferability by producing a homogenous sample when participants recommend others who are like themselves (Tracy, 2020). For maximum variation, the researcher asked participants to refer RVFANs that may have had different healthcare experiences than themselves (Polit & Beck, 2017). As knowledge is gained during qualitative interviews, areas requiring further inquiry will be illuminated and will guide the selection of subsequent participants (Thorne, 2016). Participants were asked to refer others from demographic groups that were underrepresented in the sample. If sufficient participants were not found using flyers and snowball sampling, social media was planned to enlarge the sample.

Social media is an important networking tool for RV dwellers who maintain relationships despite geographical distance (Hardy et al., 2012). However, relying on social media as the only method of sample recruitment could have resulted in gaps in knowledge about RVFANs who are less technologically savvy. If more participants were needed after several months of recruitment using flyers, the researcher planned to post the recruitment flyer on her personal LinkedIn and Facebook pages. In addition, she planned to ask the editors of RVtravel.com and the Escapees RV club to include the recruitment flyer in their email newsletters (Escapees, 2021). Thorne (2016) noted the importance of a flexible sampling strategy that is responsive to knowledge as it

is generated. In this study, a sufficient sample size was obtained using in person methods, so the backup strategy to use social media was not needed.

Sample Size

Interpretive description aims to gather enough data to describe the phenomena to the extent that the information produced will be relevant to clinical application (Thorne, 2016). Interpretive description methodology acknowledges that diverse patients may present infinite variations of experience so it may be impossible to achieve true theoretical saturation. Thorne (2016) recommended that the sample should be added to and expanded until the researcher has determined that sufficient data has been analyzed to provide useful information for clinical practice. The product of an interpretive description study should include the identification of patterns and themes that have been organized into a professional narrative that will improve the understanding of the phenomena for healthcare professionals. Although interpretive description recommends avoiding claims of theoretical saturation, obtaining useful information remains dependent on the identification of recurrent themes and patterns. As such, the standards of saturation provided useful estimates for the target size of the sample.

In a study to evaluate the number of participants needed to achieve theoretical saturation, Guest et al. (2006) interviewed sixty participants from two countries. Although twelve participants were needed to achieve comprehensive theoretical saturation, only six were required to identify the most abstract and general concepts. The authors noted that larger samples may be needed depending upon the heterogeneity of the sample and other contextual factors. Hagaman & Wutich (2017) used a different method to evaluate the number of participants needed to reach saturation. They examined cross-cultural themes across four research sites. They recommended that twenty to forty interviews may be needed to identify metathemes in heterogenous

populations. RVFANs share some cultural practices and beliefs but represent diverse socioeconomic strata. The researcher aimed to interview a minimum of fifteen RVFANs. To accomplish the goals of the study, the researcher estimated that up to thirty interviewees might be needed.

The goal of maximal variation sampling in this study is not to describe every barrier or facilitator that nomads may experience, but rather to determine which common factors are reported by RVFANs across various demographic strata (Thorne, 2016). Availability of resources places unavoidable bounds on study design (Thorne, 2016). The principal investigator anticipated that she had the resources to conduct approximately thirty interviews. Tracy et al. (2020) estimated that fifteen hours of analysis are required for each interview, thus thirty interviews could require 450 hours of analysis. The principal investigator conducted interviews until sufficient analysis of concepts was achieved to make a useful contribution to the nursing literature (Tracy, 2020; Thorne, 2016).

Incentives are important to recruitment of vulnerable populations (Langer et al., 2021). For this study, participants were offered a ten dollar Starbuck's gift card. Starbuck's was chosen because of the large number of stores nationwide and because they sell a variety of beverages and food items that accommodate dietary restrictions.

Data Collection and Management

At campsites the researcher discussed the study informally with people who showed interest. The recruitment flyers contained the email and telephone number of the principal investigator (PI) and she responded to inquiries. To facilitate scheduling, contact information for volunteers was recorded in an encrypted excel spreadsheet. First, the PI confirmed eligibility. If the volunteer was eligible to participate, the investigator asked them to identify the dates, times,

and interview venues that would be most comfortable and convenient for them. Couples were encouraged to consider their comfort with sharing health information prior to deciding whether to attend the interviews together or separately (Bjørnholt & Farstad, 2014; Norlyk et al., 2015). Most of the interviews were conducted outdoors in campgrounds or public parks. Three interviews were conducted inside RVs, two were conducted in parking lots, and one was conducted in a senior center. Interviews were conducted between September 2022 and January 2023, in Arizona, Colorado, Texas, Oregon, New Mexico, and Wyoming. Data collection ceased when sufficient data had been gathered to make a meaningful contribution to the nursing literature.

The PI conducted twenty-two interviews. First, the consent information was reviewed and participants were given the opportunity to ask questions. Verbal consent was obtained. Participants were given the option to retain a copy of the consent. The semi-structured interviews were recorded using a purpose-built audio recording device. The interviews were transcribed using Otter.ai application (Otter.ai, n.d.). The transcripts were compared to the audio recordings to verify accuracy. After the accuracy of each transcription was verified, the recordings were deleted. The transcripts were identified with a participant number and stored in ATLAS.ti software (Atlas.ti, 2019). The data will be stored for three years and then deleted.

Data Sources

Semi-structured interviews

Interviews were semi-structured to empower participants by allowing them to focus on the elements of their healthcare experiences that were most meaningful to them. The interview guides included informed consent, rapport building information, and close-ended and generative questions (Tracy, 2020). Follow up questions clarified the narrative of the participant and were

drawn from the analysis of data already collected. The interview guide was approved by the institutional review board (IRB). As knowledge was gathered, interview prompts were adapted to focus on concepts that required further clarification (Thorne, 2016). This strategy promoted efficiency in refining the relevant concepts.

Member checking for this study was completed concurrent to data collection (Polit & Beck, 2017). Parentin (2006) attempted more formal member checks with RVers by offering to supply RVers with interview transcripts at a later date. All the participants declined. Parentin (2006) interpreted this as an illustration of their desire to preserve their freedom from obligations and their preference for more personal forms of communication. In this study, the researcher reviewed her preliminary impressions of the barriers or facilitators to healthcare access that had been expressed by the participants at the end of each interview and asked the participants to confirm or clarify her impressions. While this may not have been as effective as member checking of the final analysis, it aligned with the previously identified preferences of RVers and reduced the risk of a breach to confidentiality that would be introduced by storing contact information linked to interview transcripts. The interview questions specific to the research questions are listed below. See Appendix A for the complete interview guide which includes additional eligibility and demographic questions.

- Take a few minutes to reflect on a time in the past couple of years when you needed healthcare. Can you walk me through your experience?
- (Follow up questions to explore factors mentioned by interviewee that could represent barriers to access. Follow up questions on factors that could represent facilitators to access. Consider the dimensions of Levesque's Conceptual Framework of Access to Healthcare.)

- Appropriateness: How would you describe the quality of the health services that were offered?
- Engage: How did the healthcare providers involve you in making decisions about your treatment?
- How do you think this experience was different than it may have been if you had not been traveling?
- Perceive: Do you trust the healthcare system?
- Acceptability: If healthcare were designed specifically for RV-dwelling nomads, how would it be different?
- Acceptability: What assumptions do you think healthcare professionals make when they learn that you are nomadic and live in an RV?
- Pay: What kind of insurance do you have?
- Perceive: Do you have any long-term health conditions that you manage while traveling?
- Approachability, to seek: Who do you reach out to first for questions about your health or healthcare?
- Do you have a primary care provider?
- Availability & accommodation: If so, does your primary care provider offer remote consultations by telephone or online?
- Appropriateness: Does your primary care provider help you to coordinate care that you receive in other places?
- Affordability: Are there times when you have skipped healthcare visits or prescriptions due to cost?

- Affordability: Have there been times when your insurance did not pay for services that you expected they would pay for?
- What information do you think healthcare professionals need to provide the best care to nomads?
- What information would you like to share with new nomads to help them obtain the best healthcare?
- Member checking: It sounds like … helps you to obtain healthcare. It sounds like … makes it more difficult to obtain healthcare. Is my understanding correct?
- Is there anything you would like to share with me that we have not talked about yet?
- Do you know of any other RV-dwelling full-time nomads who may be interested in participating in this study?
- I would like to speak to nomads who have had diverse experiences with healthcare. Is there anyone you could recommend that might have had a different experience?
- How would this person be most comfortable being contacted?
- Do you think they would they prefer it if you reached out to them or should I?
- Thank you for taking time out of your day to participate in this study. To compensate you for your time I would like to give you a 10$ gift card for Starbuck's. The information you have provided will remain confidential.

Trustworthiness of Qualitative Data

Knowledge must be trustworthy to be useful for application in clinical practice (Thorne, 2016). Several researchers have developed frameworks describing strategies to evaluate quality in qualitative research (Polit & Beck, 2017). Lincoln & Guba (1985, as cited in Polit & Beck, 2017) used the term "trustworthiness" to refer to the quality of qualitative data. Specific

measures of trustworthiness include credibility, dependability, confirmability, transferability, and authenticity. To enhance trustworthiness, this study employed reflexive journaling, recording and verbatim transcription of interviews, triangulation of space and person, member checking, and peer review.

Reflexive journaling

In qualitative research, the researcher is the instrument that analyzes participant responses and converts them into themes. Reflexive journaling improves the credibility and authenticity of data (Polit & Beck, 2017). It involves the researcher keeping a journal to reflect on thoughts about the phenomenon and to consider how her assumptions may influence the research and how the research may influence her assumptions. A paper journal was kept close to the researcher for reflection in naturalistic settings which promoted journaling at times when thoughts about the research arose unexpectedly. The researcher made journal entries at least weekly, and after each interview. To illuminate the context of the RVing lifestyle, the investigator lived and traveled in an RV during the data collection period. Journal observations included reflections on the researcher's perceptions of the RVing lifestyle and her interactions with RVers (Polit & Beck, 2017). She explored potential biases based on her values and previous experiences and considered how RVFANs' perceptions may have differed based on their unique perspectives. She documented her thoughts on the progress of the study and methodological issues. The researcher considered whether changes to interview prompts were needed and reflected on the goals of subsequent sampling. Reflexive journaling supported the analysis of the interview data (Polit & Beck, 2017). The journal data was not explicitly included in the analysis of themes but was used to enhance the ability of the researcher to understand and translate the experiences reported by RVFANs (Emerson et al., 2011).

Interview techniques

The extent of the transferability of findings is a judgement made by the reader based on comparison of the research context with the context of their question (Polit & Beck, 2017). Transferability of findings was limited by the exploratory nature of the study and by nonprobability sampling. The study results may be transferable to some RVFANs, but RVFANs are a diverse group. The goal of interpretive description is to identify common themes that may be considered when caring for unique individuals (Thorne, 2016). Although common themes were identified, participants' experiences varied. Readers should avoid making assumptions about individuals.

Dependability describes whether another researcher using the same method would obtain a similar result with similar participants and context (Polit & Beck, 2017). It can be a challenge to achieve dependability when meanings are co-constructed by the participant and the researcher as instrument. Credibility describes the level of confidence in the accuracy of the findings. Member checking was used to improve the dependability and credibility of the data (Polit & Beck, 2017). Credibility was also enhanced by recording and accurate transcription of interviews.

Space and Person Triangulation

Triangulation also improves dependability and credibility by comparing data obtained from different sources (Polit & Beck, 2017). This study employed space and person triangulation. Space triangulation involves the collection of data in different areas (Polit & Beck, 2017). Person triangulation involves the collection of data from different socioeconomic backgrounds to evaluate the consistency or divergence of experience in different contexts (Polit & Beck, 2017). Cultural differences have been noted between RVers with different types or

brands of RVs and campgrounds with different characteristics have been found to attract certain RV types (Hardy et al., 2013; Haskell, 2013). Haskell (2013) surmised that RV types and brands may be indicative of socioeconomic differences. Socioeconomic differences have also been aligned with differences in healthcare (Agency for Healthcare Research and Quality, 2021). To facilitate space and person triangulation, recruitment for this study took place in different types of campgrounds ranging from free public land to luxury RV resorts in several states.

Peer Debriefing

Peer debriefing enhances the confirmability of findings (Polit & Beck, 2017). Confirmability describes the potential for two researchers to reach similar conclusions. The principal investigator met with an experienced qualitative investigator on two occasions to review the coding scheme. The second investigator was asked for feedback on the appropriateness of the coding scheme. Developing themes and personal biases were discussed. The second investigator provided suggestions to enhance the analysis.

Data Analysis

The interview transcripts were analyzed using ATLAS.ti software (ATLAS.ti, 2019). A phronetic iterative approach was employed (Tracy, 2020). In this approach data collection and data analysis are concurrent (Tracy, 2020). Deductive and inductive reasoning are used. The combination of inductive and deductive analysis aligns with the goals of interpretive description (Thorne, 2016).

Phronetic iterative analysis includes multiple rounds of coding. A codebook was developed and repeatedly updated and memos were used to enhance analysis. During the first cycle of coding, codes were identified inductively with consideration of “what” was happening in the data (Tracy, 2020, pp. 219). In second cycle coding, the investigator considered theoretical

concepts to determine “how” and “why” the information was important while organizing the codes into more abstract themes. Barriers or facilitators to care were clustered using the concepts of Levesque’s conceptual framework (Levesque et al., 2013).

Ethical Considerations

Ethical approval was obtained from the Idaho State University institutional review board (IRB) prior to beginning the study. Consent procedures respected participants by honoring their autonomy and privacy. All participants were advised that participation was voluntary and confidential. In addition, they were advised that they could skip any questions that they would prefer not to answer and that they could withdraw from the study at any time prior to data analysis. Data management procedures were discussed. The researcher did not have close relationships with any of the participants. Participants that were referred to the researcher by their friends or family were informed that their choice of participation would remain confidential. Consent was verbal to prevent revealing participants’ identity through recording their signature on a consent form.

Reporting procedures will promote beneficence. The data collection methods posed a very low risk of harm to participants. RVFANs have reported that there is a stigma associated with RV-dwelling. To avoid exacerbating existing stigma, the study reports will avoid using stigmatizing language. The researcher will promote beneficence by preparing materials for the distribution of findings that are appropriate for academic, professional, and RVFAN audiences. Although the participants may not derive a direct benefit from participation, it is hoped that the knowledge generated will ultimately be used to improve the healthcare of RVFANs. Broad dissemination of results will ensure that the time that participants have devoted to study participation is more likely to produce benefits for the RVFAN community.

Summary

This chapter reported the study design and described the rationale for design decisions. To review, the exploratory study used a qualitative methodology informed by interpretive description. Qualitative data was selected to provide rich descriptions of the phenomena from the perspective of those who experience it without etic content limitations imposed by researcher-developed surveys. Multiple strategies for recruitment were used to secure a sufficient sample size in this marginalized population (Langer et al., 2021). Data was analyzed using phronetic iterative analysis to merge existing theoretical knowledge with emerging inductive knowledge supplied by participants. Reporting will be motivated by the concept of beneficence with the goal of making the knowledge available to participants as well as to academics and healthcare professionals. Ethical issues have been considered and addressed.

Chapter IV: Results

The purpose of this study was to learn about the healthcare experiences of recreational vehicle-dwelling full-time American nomads (RVFANs) and to identify barriers and facilitators to healthcare access in this population. The research questions included: what are the experiences of RVFANs when seeking healthcare in the U.S., what are the barriers to healthcare access for RVFANs, and what are the facilitators to healthcare access for RVFANs. The investigator identified answers to these questions by analyzing qualitative data from semi-structured interviews with RVFANs using Atlas.ti software. In this chapter, the sample and the results of the analysis will be described. Quotations from the participants are labeled with a participant number. When couples were interviewed together, 'f' reflects statements of the female partner and 'm' reflects statements of the male partner. To preserve the confidentiality of participants, age ranges are used including young adults (under age 40), middle-aged (40 to 64 years), or older adult (over age 65). The specificity of place names is limited to state.

Sample Description

Volunteers were included when they met the inclusion criteria. Twenty-five RVFANs participated in semi-structured interviews. Participants represented diverse socioeconomic backgrounds and were predominantly female (72%). The ages of participants ranged from 35 to 81, with a median age of 59. Thirteen participants were married and traveled with their spouses, the sample included five couple dyads, and one couple traveled with a minor grandchild. Twelve participants traveled alone. Fifteen participants traveled with pets. The majority of the sample had college degrees (84%). At the time of the interview, thirteen participants were retired or disabled and seven were employed for financial gain. Five participants were not employed at the time of the interview, but their spouses were employed (n = 2), they were volunteering for

charitable organizations (n = 2), or were in a career transition (n = 1). Five participants reported that they owned stationary residences, the others did not. See Table 1 for detailed demographics of the sample.

Health status varied in the sample, though all participants were independent in self-care. Eighteen participants reported managing chronic health conditions on the road. Two of these participants did not have primary care providers despite reporting COPD, diabetes, mental health issues, and chronic pain. Eighteen participants had primary care providers and some maintained relationships with specialists in mental health, endocrinology, pulmonology, cardiology, neurology, gastroenterology, and a few less common specialties. Sixteen participants had public health insurance, seven participants had private health insurance, and two participants had no insurance. Ten participants combined multiple insurance policies. Participants chose their states of domicile for various reasons, for some participants healthcare and insurance options available in that state were a deciding factor. Some participants reported an unclear domicile (n = 4); while others were domiciled in Nevada (n = 5), Texas (n = 5), California (n = 3), Arizona (n = 2), Colorado (n = 2), Nebraska (n = 1), Oregon (n = 1), Wisconsin (n = 1), and Wyoming (n = 1). Fourteen of the twenty-one participants that reported their state of domicile were outside of that state at the time of the interview.

Participants' experience with full-time traveling ranged from 1 to 15 years, with a median of 3 years. Participants described their travel patterns as fluid; some took months or years away from traveling and then returned to the lifestyle. Most of the participants described spending weeks in each location, while some preferred to change locations after several days and others preferred to stay in each location for a month or more. The vehicles that were adapted for living ranged from self-converted sports utility vehicles (SUVs) to factory-built fifth wheel trailers, that

were 8 to 40 feet in length. One participant with a fifth wheel also traveled with an additional vehicle, storage trailer, and boat. The ages of the recreational vehicles that were disclosed ranged from 2 years to 57 years, with a median age of 12 years. Interviewees gave several reasons for choosing different sizes of rigs. Many stated that they chose smaller rigs because they facilitated a greater choice of campgrounds due to their ability to travel on rougher roads and fit into smaller campsites. Interviewees also noted that smaller rigs achieved better fuel efficiency and they appreciated the simplicity and durability of amenities. They explained that jugs of water are less likely to leak, cause damages, and need repairs than RV plumbing systems. Participants with smaller rigs tended to move more often. The reasons interviewees gave for choosing larger rigs included having more space and having the options of amenities similar to those in houses, for example, larger RVs were more likely to have washing machines. Some participants chose older rigs to save money, while others reported that they kept older rigs because of emotional attachment to the rig, or because they favored the aesthetic of the older rig.

Most participants reported visiting a variety of campsites, but ten participants preferred campsites with hookups to water and electricity while fifteen participants preferred boondocking on public land. Reasons given for camping in RV parks included the convenience of having hookups, the potential for longer stays, and the perception of increased safety due to the proximity of fellow RVers that could help if a problem arose. Reasons given for boondocking included saving money, feeling closer to nature, and having more space and privacy. The investigator noted from observation that people who appeared less affluent were unlikely to be encountered at expensive RV parks, while people who appeared more affluent were encountered at all types of campgrounds. Free and budget campgrounds hosted the greatest apparent socioeconomic diversity. The investigator spent 41 days in free campsites, 51 days in budget

campgrounds (less than 35$ per night), 21 days in mid-range campgrounds (35 to 60$ per night), and 41 days in expensive campgrounds (more than 60$ per night). Campgrounds included BLM land, fairgrounds, city, county, and state parks, and private RV parks. At the time of the interviews, participants were camped in free (n = 2), budget (n = 6), midrange (n = 2), or expensive (n = 6) sites; or were attendees at an RV rally (n = 9).

Table 1

Sample Demographics/Descriptive Characteristics

Participants	Total	25
Gender	Female	18
	Male	7
Age	Young adult, < 40	1
	Middle age, 41 to 64	15
	Older adult, > = 65	9
Companions	Alone	12
	Couple	13
	Pets	15
Education	High school	4
	Undergraduate degree	17
	Graduate degree	4
Employment	Employed	3
	Self-employed	4
	Retired or disabled	13
	Not employed	5
Property owner	Yes	5
	No	20
Chronic medical condition	Yes	18
	No	7
Primary care provider	Yes	18
	No	7
Insurance	Employer-sponsored	3
	Privately purchased	4
	Public	16
	Multiple policies	10
	None	2
Years of travel	1 to 2 years	11
	3 to 5 years	8
	6 to 15 years	6
RV type	Fifth Wheel/ Class C	6
	Travel Trailer	9
	Bus/ Class B/ Van	6
	Minivan/SUV	4
RV age	< 10 years	9
	> 10 years	9
	Not reported	7
Campground preferences	Hookups	10
	Boondocking	15

Research Question 1:

What are the experiences of RVFANs when seeking healthcare in U.S.?

In response to this question, three overarching themes were identified that described the processes RVFANs used to access healthcare, the sentiments engendered by their interactions with healthcare, and the ways that their healthcare experiences subsequently influenced their motivation to obtain care. These themes included: overwhelming logistics, don't need healthcare, and orchestrating a web of care. Participants described multiple barriers that increased stress when accessing healthcare such as difficulty finding caregivers that they trusted in unfamiliar areas, caregivers' inability or reluctance to accommodate the nomadic lifestyle, and unpredictable variations in the availability, quality, cost of services. They also described multiple factors that facilitated positive healthcare experiences such as self-advocacy, maintaining collaborative relationships with providers that they trusted, and using national chains of providers to maintain continuity of care across distance. Combinations of barriers and facilitators to healthcare access contributed to participants' overall healthcare experiences. Some participants explained that the complexity of accessing healthcare on the road was overwhelming. They were unable to predict the outcomes of their logistical choices (i.e. location, timing, and source of healthcare access) on their health and finances. Sometimes participants decided that they did not need healthcare and disengaged from the healthcare system when frustrated with barriers to care or disappointed with the quality of care they had received. Other participants energetically described the strategies they had developed to engage with the healthcare system by orchestrating a web of care that combined accessing services from local and distant providers according to their needs. These overarching themes are described in more

detail below. The specific barriers and facilitators to healthcare access will be described in further detail in the subsequent section.

Overwhelming Logistics

Many participants described feeling overwhelmed with the complexity of decision-making that was required to make choices about accessing healthcare while traveling. The complexity of the logistics was increased when choosing between variable services in unfamiliar locations and in the context of changing routes of travel. Nomads vetted providers each time a care need arose to decide whether seeking care with a local provider, using telehealth, or postponing care until the next location would be likely to produce the best outcomes on their health and finances. Decision-making was described as a multi-step process in which several types of information were considered, such as the urgency of symptoms, the types of services needed, the types of services offered by local or distant providers, the quality of those services, and their anticipated cost. Accurate information was sometimes difficult or impossible to find. After using the information available to estimate which services would be most appropriate for their needs, they tried to obtain an appointment. Often participants described the time they had spent vetting providers as wasted because they were informed that the providers they selected did not see new patients, did not see patients with their type of insurance, or did not have an appointment available until after they planned to leave the area. Inability to obtain an appointment reset them to the beginning of the cycle, reconsidering where, when, and from whom to obtain healthcare. Their need for care was weighed against their willingness to begin the process again, assessing the services available from the next provider or location. Several participants reported that this process was time-consuming and overwhelming and tempted them

to postpone dealing with health issues. Elements of the participants' experiences will be illustrated by quotations.

The following exchange illustrates how the complexity of determining the most effective way to access healthcare while traveling led one participant to procrastinate dealing with health issues. P4f and her spouse were a fit and fashionable middle-aged couple who rented out their stationary residence and started an online business to facilitate their nomadic lifestyle. They spent most of their time on public lands and relocated every week or two. P4f explained that she had an aversion to seeking healthcare based on negative previous experiences. She spoke for several minutes about how the additional complexity required to arrange healthcare on the road had led her to procrastinate dealing with health concerns. She also returned to the topic later in the interview:

> Sometimes it just feels really overwhelming because there's so many logistics (…) if it's going to be longer term care, what are the implications of that? How would that look? (...) It's hard to think about that whole process of selecting a doctor and knowing how to vet one, it's already really hard. And then you add all of the logistics [of travel], and it's just a little overwhelming. (…) Like how long would I need to be there (…) no doctor is going to be able to see me within any sort of timeframe, so why bother? Because, like, how do we plan our lives around that? (…) Trying to figure out like, where am I going to be? Who's going to be the doctor of that place? How many places do I have to call to make that appointment? (…) When you're traveling and having all of the barriers you already have. (…) How do I even navigate and find that right person?

She dreaded the process of information-finding and decision-making, expected that appointments would not be available within her stay limit at the campsite, and feared unpredictable

consequences of care such as being stuck in place for a prolonged time for follow up. She admitted that her overwhelming dread of the logistics of seeking care while traveling contributed to neglecting care such as preventative cancer screenings, having a tooth pulled, and the investigation of pelvic pain. P3, an eloquent young adult living in a van, described feeling overwhelmed after making multiple phone calls and being repeatedly transferred to different representatives in the search for an effective insurance policy. He commented on the complexity of healthcare, "the fact is, healthcare is still labyrinthian." In the end, he opted to go without.

The excerpt below illustrates how delays in care seeking could result from inability to locate information. P19 was a middle-aged business owner who traveled independently in a self-built van conversion. She had a chronic illness and returned to her medical base every six months for a scheduled infusion. She prided herself on her organizational skills and would have preferred to identify the best plan to access healthcare in another location in the event of an exacerbation of her illness. Despite reaching out to her insurance provider, she was not able to find the information about cost that she needed to form a plan:

> If I were to get an MS [multiple sclerosis] flare, I would have pills that I'm supposed to take. And then I probably would have to go in for steroid treatment to some, you know, random hospital. I don't know what that would cost. I tried to find out what that would cost (…) I asked the people I'm supposed to ask. They couldn't figure it out. And I got frustrated. And I was like, well, we'll deal with it when it happens.

Overwhelmed by her unsuccessful attempt to find the logistical information that she needed to plan, she gave up and opted to hope that she would not have an exacerbation. She also reported that she had delayed seeking care for coronavirus disease of 2019 (COVID) for six weeks due to uncertainty about the cost of accessing care 2400 miles from her medical base. When asked how

her experience would have been different if she would have been at her medical base she explained, “I would have gone in immediately with the COVID. Instead, I like bought the thing that tests the oxygen in your blood (…) delivered to my van. (…) I was like, no, I’m gonna hold off.” She was at risk for severe COVID due to the immunosuppressive effects of her medication. She reported that she was ill for six weeks, but experienced a full recovery.

Choosing services could feel overwhelming when variation in the quality, availability, cost, and culture of healthcare services from site to site and provider to provider made the outcomes of care unpredictable. Participants expressed confusion when they used the same process to access healthcare but obtained different results at different sites. Often the sources of the variation were not known, which increased the uncertainty of decision-making. Rules and regulations sometimes interfered with access and were different in content or interpretation from site to site. P2, an elderly retired educator who traveled independently, emphatically reported her concern about variation in the quality of care between two clinics which was illustrated by different rules and attitudes regarding COVID:

> [at previous clinic] before you even got to the doctors, they took your temperature, they ask you questions (…) it’s posted you gotta wear a mask, they were trying to follow the protocols. In this office, I walked in and the lady behind the counter was (…) a little hostile toward me. I had a mask on, she did not. Nobody had a mask on. And then this woman comes in with kids, and they’re yelling, and like this [motioned close to face]. And she could tell, the gal that was interviewing me, that I was getting really uncomfortable. And she said, “we don’t wear masks here. If you don’t like it, you may leave. I will cancel your appointment, and you may leave.”

She was at a high risk of severe illness due to her age, but her concern about the risk of infection resulted in her appointment being cancelled. She reported that she would avoid seeking care in that state in the future and postponed her visit until she was in another state, about 1000 miles away, where she felt more comfortable with the quality of care. P13m, a middle-aged man who had a remote job in internet technology, had routine blood work done in a new state using the same laboratory chain and insurance provider that he regularly used. He was confused when the cost was different than usual and wondered whether the correct specimens had been drawn:

> So this is the hassle, so I got to call my doctor to figure out, to make sure I got the right labs drawn, because it's 50-60$ over, and it's Florida, and maybe they charge more for those. I don't know.

P7 had about nine years of experience managing chronic health conditions while traveling around the U.S. with her spouse in a van. When asked how they chose which locations to travel to, she explained how variation in the quality of care in different regions influenced their route of travel:

> That's one of the reasons why we only come here for the summer and not the winter. (…) The healthcare is not very good. The veterinary care is not good. And it's weird, because they have good healthcare and veterinary care in Florida, and they also have good veterinary care and healthcare in California.

She reported that concern about the limited availability and quality of healthcare in the rural region where her domicile was located was a factor in her decision to be a nomad. This couple's response to concern about healthcare quality in rural areas was to limit the amount of time that they lived there. Nomads perceived that the location they chose to seek care could affect their health and financial outcomes, but their routes were sometimes unpredictable.

Changes to nomad's routes of travel added complexity to decision-making. Routes were subject to change due to circumstances out of their control such as weather, campground availability, or events. Route changes could have social, health, and financial repercussions. Changing the route to wait for an appointment could mean missing out on a work contract or a family event. Route changes could also result in missing appointments that had been planned. Accessing care in a different state could affect insurance coverage for the visit. Deciding how to access healthcare as a nomad meant weighing the perceived urgency of the need for healthcare against perceptions of the resources available in each location, during the time frames that they expected to be there. P5, an older woman traveling with a dog, explained that it was difficult to plan for a prescription refill when she was not sure where she would be or what pharmacies were available:

> Right now, I'm down to a week's worth of my Verapamil, and I'm like, okay, who do I have to fill this? And where do I pick it up? Do I get this filled here, or do I wait until I get to the next spot? It'll depend on if I stay another couple of days, we'll see.

She had filled out an online form to request refills of all her medications the previous week, in "Timbuktu, Iowa, (…) I don't know where it was. One of the four Walmart's I stayed at last week." The pharmacy only refilled one medication without explaining why. This was time-consuming because it forced her to repeat the work of identifying a pharmacy along her route and transferring her prescriptions. She was overwhelmed by the thought of planning this again because she anticipated that her route might change due to family events. P21, a middle-aged veteran traveling in a van, reported that obtaining refills of her blood pressure medication could feel overwhelming because she was required to make an appointment to establish care with a

new provider wherever she wanted the refill. This was difficult when route changes due to unanticipated events made it impossible for her to keep her appointments:

> A few years ago, when we're doing all the riotin', it's like I'm headed to St. Louis. They have a great VA [Veterans Affairs]. People are rioting in the streets; we're not going to St. Louis. So that was my VA appointment and everything. It's like, time to miss that one. I've had to change plans a lot on that. If you're in Florida, and you're all set up to go to your doctor to get your Losartan, and it's like, here comes a hurricane. Yeah, then you got to wait another couple of weeks for another appointment instead of just getting the medication.

Her ability to change her route protected her from dangerous events, but the requirement for a face-to-face appointment to obtain her prescription refill could have affected her health. The difficulty finding information and the complexity of making decisions about when, where, from whom, and at what price to obtain healthcare sometimes overwhelmed RVFANs and influenced them to avoid interacting with the healthcare system, while other times they dedicated an extraordinary amount of time, effort, and money to identify and obtain the care they needed.

Don't Need Healthcare

Several participants questioned their need for healthcare services. They explained that they could prevent illness more effectively through lifestyle management, explained that their health was improved by travel, or described previous negative experiences or barriers to healthcare access that influenced their perceptions of the need for services. A common response, when RVers were asked how they access healthcare on the road was, "don't get sick." This was often followed by descriptions of the behaviors that nomads used to preempt the need for healthcare by preventing illness, such as eating a healthy diet, exercising, and attending to mental

health. They felt that medical culture was focused on the treatment of symptoms rather than the prevention of illness or the identification of its source and were concerned that profit motives sometimes superseded caregivers' interest in health outcomes. P20, a slim middle-aged property-owner, rented out her home when she retired from truck driving and moved into her SUV after removing the rear seat to accommodate a twin-sized bed. She enjoyed changing scenery and camping on public lands. She explained that she reduced her need for healthcare by eating organic food and exercising regularly. She ordered soy milk on Amazon when she could not find it in rural areas and ate little meat since she had limited access to electricity and storing meat in her ice chest was inconvenient. She walked 10,000 steps a day and lifted weights when she was near a gym. When asked what information healthcare providers needed to care for nomads, P20 advised that providers should educate themselves on nutrition:

> They should educate themselves so they can educate their nomadic patients on ways to eat healthy on the road, besides eating chips and hotdogs from 7/11. (…) Have they ever asked me what kind of diet I have? No, nobody ever does.

She reported that she had a physical and cancer screenings recently, but she did not plan to continue with them. She believed that the lifestyle measures she took to prevent illness were more relevant to her health than visits to healthcare providers would be.

Some participants described traveling as one of the lifestyle changes that reduced their needs for healthcare and improved their mental health. They reported being exposed to fewer contagious illnesses, or reducing the symptoms of chronic conditions by moving to avoid inclement weather. P5, an older retired woman, described how traveling improved her mental health:

> I had a *lot* of depression. So, it's another reason I'm on the road, to try and get out, and it's really helped a lot. Not working, and not having that big, huge five-bedroom house with the yard and everything to take care of, and it's falling apart. You know, life is better. (…) In Michigan, it's so dark and cloudy, and you know, there's never any sunshine in the winter, and it's just gloomy, and I would always go into a deep depression every winter. So, I did not have that last winter (…) I got through it pretty well.

She cited several aspects of the nomadic lifestyle that improved her mental health including decreased responsibility, increased socialization, and increased exposure to sunshine. P4f explained that their transition to the nomadic lifestyle had reduced their exposure to contagious illnesses, "we have less contact with people so you don't get sick very often. (…) Have either of us been sick this whole time? I don't think we've had a single illness in the two years that we've been out here." Their remote work environment and life on public lands reduced the amount of time they spent indoors with other people. They had not been sick despite traveling during the COVID pandemic.

Some participants adopted healthier lifestyles after encountering barriers to healthcare access. P15 was an overweight middle-aged woman who traveled with her spouse and grandson. She did not have a primary care provider and went for years without health insurance before recently qualifying for disability. When asked whether she had ever skipped healthcare due to cost, P15 volunteered that lifestyle changes and traveling to avoid inclement weather had reduced her need for medications for her mental health and her asthma:

> When I first went out on the road I was taking 17 medications a day, I now take one and only if I absolutely, positively need it. Now, part of that is that I have improved my mental health, which eliminated six of those drugs. And the other part of that is, I'm not

> smoking nearly as much, so my lungs are significantly better. I'm not in the high humidity, I'm not in the super cold, I'm not in the bronchitis sort of weather which is what triggers my asthma.

When prompted for clarification of the reason that she stopped taking her medications, she described barriers to obtaining them:

> When I first got out here, I skipped them for cost. And because I couldn't like, I can't get my Ohio prescription in Texas. I can't get my Ohio prescription in Arizona. If it is in any way a controlled substance, and all psych meds are, you can't get 'em.

Due to difficulty paying for her medications and after realizing that regulations prohibited the transfer of her prescriptions across state lines, she made lifestyle changes to reduce her need for them and weaned herself off. Similarly, P17, a working disabled woman traveling in an SUV, reported that she could not afford the medication she had been prescribed for her fibromyalgia but due to lifestyle changes she no longer needed it, "I was also living in a climate that was really bad for fibromyalgia. So it was a bummer then, but I don't miss it now." In this excerpt, she described several attributes of her lifestyle that prevented exacerbations, "the flexibility, low stress, being out in nature, staying away from inclement weather, like the desert is a really good environment for my fibromyalgia." These participants reported that their nomadic lifestyle helped them to cope with barriers to healthcare access by decreasing their needs for healthcare.

Some participants questioned their need for healthcare after describing negative healthcare experiences. They questioned whether accessing medical services would improve their health. P3, was a young van-dweller who described a series of visits to urgent care for symptoms he felt were inappropriately assigned to anxiety. He reported that he had eliminated his symptoms and reduced his needs for healthcare through lifestyle changes, "your diet, your

exercise, your sunshine, your water, your fresh air (…) your rest (…) your spiritual well being." After being unable to find an insurance policy that would meet his needs while traveling, he pondered, "Do I even need to spend money on that kind of stuff? You know, I mean, I'm 35, I'm healthy." P6, a bohemian appearing van-dweller who had been traveling for about nine years, reported visits to a rural ER for symptoms, which he felt, were brushed off by providers. He underwent changes to his diet and exercise regimen and his symptoms resolved, "They didn't know, so I figure fuck, I better take care of myself and just do this and get myself better. You know, they're not worried about me. So that's what I did." When asked what new nomads should do to get healthcare on the road, he recommended adopting a healthy lifestyle to avoid needing healthcare:

> Diet, just eat a good diet. Take care of yourself and stay healthy. If you've got some serious issues, you probably shouldn't be on the road. You'd want to stay at home and find a doctor you trust. On the road, sometimes you're just a passerby (…) because I'm a passerby, I'm not going to put the effort into it. They've showed me enough.

He felt that the providers in the rural hospital had not taken his concern seriously so he could not rely on them. It was up to him to improve his health.

Thus, the sentiment, 'don't need healthcare', did not necessarily reflect the passive attribute of a healthy body. Sometimes not needing healthcare reflected active lifestyle management to avoid healthcare needs that enabled participants to live without services that were not accessible or not effective. While some participants questioned their need for healthcare; participants who felt that healthcare was essential expended extraordinary effort to obtain it by orchestrating a web of care.

Orchestrating a Web of Care

This theme describes the actions of participants who identified their needs for healthcare and energetically worked to maintain quality and continuity of care by orchestrating a web of connections between local and distant healthcare resources. Nomads' webs of care ranged from simple to complex. Many interviewees emphasized the first step of accessing healthcare was to become an expert in their own health so that they could identify the care they needed and find ways to arrange it along their intended route of travel. When asked what new nomads should do to get good healthcare on the road, a common response was "you've got to be your own advocate" (P8). P17, who had survived a rare type of cancer, explained how being knowledgeable about her illness helped her to collaborate with providers:

> Become that expert on your own illness so that you can advocate for yourself. (…) I knew that I wasn't going to be able to walk into any doctor's office or even any oncologist office and have them know what I was talking about. So I had to become like an expert on my own illness so that I could tell them (…) this is what it is, this is what it does. (…) I think it's all about advocating for yourself and knowing your physical and mental health, and listening to your body.

Being an expert in her illness allowed her to educate her caregivers about what she needed and what she should avoid. P12, an older retired healthcare professional, moved into a Class B RV after the death of her spouse and had managed healthcare issues while traveling over the past five years. She advised:

> Don't put off your healthcare. You know, just like everything else that we do. Figure out how to do it and then get it done. You know, because what might be a minor healthcare concern today could be something much greater if you just let it go.

The transition to nomadic living has a learning curve and participants reported it could take several months to develop strategies to live well. In the above excerpt, P12 described learning to access healthcare on the road as one of many nomadic lifestyle adaptations ("everything else that we do"). Becoming an expert in one's health needs was a prerequisite to orchestrating a web of care.

For many nomads, the web of care they orchestrated was simple, consisting of a medical home with a primary care provider and specialists in one location that they made routine visits to and connected to via telehealth for needs on the road. Some participants preferred having a smaller web of care for the simplicity. P19 admitted that she was likely to avoid care if the process of accessing healthcare was too inconvenient. Here, she described how technology allowed her to have one point of access for care, despite her distance from her providers, "So getting care while traveling with them, even though it's an HMO [health maintenance organization], it kept it simple. I have one place to go for my healthcare, I go to kp.org, or I go on my app." If the issue could not be addressed remotely, they visited local walk-in clinics or emergency rooms. Most participants relied on national pharmacy chains such as Walmart and CVS to obtain prescription refills because they had many locations and could transfer prescriptions electronically from store to store. A few participants had the results of routine laboratory tests sent to their providers from distant locations by using chain laboratories such as LabCorp and Quest Diagnostics. Although his primary care doctor was in California, P13m was able to get his routine laboratory specimens drawn in Florida, "LabCorp is around the country. So interestingly enough, when I went to the dermatologist, I noticed that there was a LabCorp right there. And I thought, well, I'll go get my labs drawn while I'm here." He remarked on the convenience of having standing orders for his laboratory tests so that he could have them drawn

anywhere. Sometimes webs of care were limited in size by state-bound insurance coverage. Although P19 appreciated the simplicity of having her care in one place, she also reported that it was not convenient to drive to her domicile state every six months for care. However, her insurance only covered her infusions in her domicile state:

> I just have to drive all the way across the country (…) For me specifically, it would be *really* helpful if I could get my treatment that I have to get every six months, it doesn't have to be everywhere, but at least get the regions.

While some nomads tried to maintain relationships with providers in a single location, others maintained provider relationships in two or more locations.

Some nomads who spent significant amounts of time in two parts of the country expanded their webs of care to maintain provider networks in two areas. One participant who routinely visited family in Washington and Nebraska maintained primary care providers and specialists in both states. Another participant had primary care providers in Wisconsin and New Mexico, with specialists split between the two states. A third participant had a primary care provider in Idaho and a primary care provider and specialists in Arizona who she kept updated on her health.

Nomads who had been traveling for longer periods, or who had more complex care needs tended to develop more intricate webs of care. They focused on maintaining relationships with providers that they trusted and visited them in-person or via telehealth when it was feasible. If they were not able to access their preferred providers, they had past experiences with alternate providers that they kept in mind for future health needs in those regions. P7, who had lived in a van for nine years, estimated that there were about ten different providers in three states that she might access face-to-face or via telehealth depending on her location, her symptoms, and their

available services. P14, a middle-aged woman with chronic health issues, had sought healthcare in many states, “so many states that I can tell you about the different medical in multiple states,” but she focused on two providers that she trusted, a primary care provider in Nevada, and a specialist in Colorado. P12, an active older woman, had a primary care provider and specialists in California who she maintained relationships with via telehealth, but she visited dentists in many states for frequent cleanings, “because I travel a lot in the West I’ve gotten to know some people throughout the western states that I can go back to that I’ve liked and so I’m willing to go back to.” She also visited chiropractors every six weeks, using a national chain of providers that treated her as an established patient at any branch:

> There’s this organization called The Joint Chiropractics, and they’re all over the U.S. (…) what I like about it is it used to be anytime I went and saw a new chiropractor, I had to pay the 150 bucks to go in as a new patient. And with this my record is available to every chiropractor that’s part of The Joint (. …) I only had to pay $29 a visit.

Orchestrating a complex web of care required a significant investment of time and effort. P1f, an engaged older woman, described her strategy to help her spouse find a facility to get his laboratory specimens drawn in advance of their trip to their medical base for follow-up:

> He’s got a list to call tomorrow and see if we can get somewhere here because this will be the first time we’ve gone out of LabCorp, just our primary lab. So we’re gonna call around [town] and see if we can get someone and see if they’ll do it. We don’t even know if they’ll do it and send it to [doctor].

Having the specimens drawn in advance of his appointment would facilitate the review of the results during his visit and reduce the amount of time they would be stuck in that town. Nomads valued providers, facilities, or national chains of providers where they had positive experiences

and accessible medical records. Participants reported that webs of care helped them to access care on the road but that they required knowledge, time, and effort to orchestrate. Webs of care appeared to expand in size with years of travel or complexity of care, or were sometimes limited in size by choice, or by barriers to healthcare portability.

Research Questions 2 & 3:

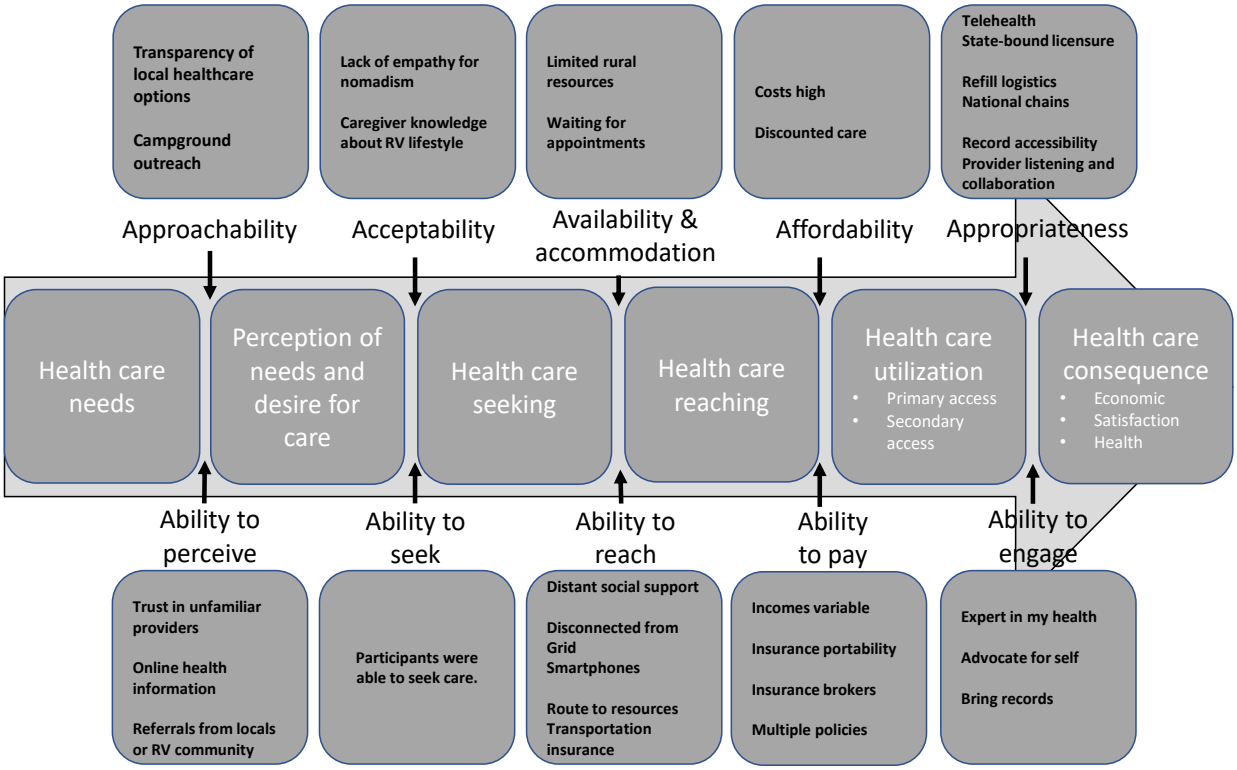
What are the barriers to healthcare access for RVFANs?

What are the facilitators to healthcare access for RVFANs?

Participants identified specific barriers and facilitators to healthcare access that correlated with nine of the constructs of LCMAH. The data to answer research questions two and three were organized using the concepts of the model. The first concept in each heading reflects attributes of healthcare services, while the second concept reflects the abilities of consumers. When barriers and facilitators are linked together, i.e. the presence or absence of a factor, they are discussed together. Figure 3 is an adaptation of Levesque's Conceptual Model of Access to Healthcare that displays the barriers and facilitators pertinent to RVFANs.

Figure 3

RVFAN's Barriers and Facilitators to Healthcare Access



Note. Adapted from "Patient-centred Access to Healthcare: Conceptualising Access at the Interface of Health Systems and Populations," by J. F. Levesque, M. F. Harris, and G. Russell, 2013, International Journal for Equity in Health, 12(1), p. 5 (http://www.equityhealthj.com/content/12/1/18). CC BY 2.0.

Approachability & Ability to Perceive

Many RVFANs reported difficulty finding and vetting healthcare services, particularly when needs arose in unfamiliar areas. A common barrier to approachability was difficulty finding sufficient information about local healthcare services to guide decision-making. A facilitator to approachability was information outreach that targeted campgrounds. A barrier to the ability to perceive that healthcare services would meet the needs of nomads was difficulty

trusting unfamiliar providers. Facilitators to trusting new providers included online information and referrals from local residents or other RVers. These barriers and facilitators are described in more detail below.

Barrier: Transparency of Local Healthcare Options

After determining the need for healthcare, many RVFANs used the internet to assess local healthcare options or asked local residents or fellow RVers for recommendations. Participants reported that choosing healthcare services in unfamiliar areas could be time consuming and frustrating. P15, a woman with COPD, noted, "finding a doctor in a town you don't know is a demon." When choosing facilities and providers, participants tried to assess whether the facilities were likely to offer the services that they needed (i.e. x-ray), how much their visit would cost, and what their follow-up recommendation would be. Many clinics limited appointments to established patients, people with specific insurances, or patients with referrals (i.e. specialty clinics). Participants made multiple phone calls because the information they needed was not readily accessible. Sometimes the information they found was incorrect, or the people they spoke to were not helpful. P13f, a married middle-aged woman, described making multiple phone calls to arrange healthcare visits and explained how the comportment of the clinic staff who answered the telephone influenced her experience:

> It is the thought of setting it up that is a little stressful. Yeah, making the calls and not knowing what you're gonna get or who you're gonna be talking to, like the first one not being super polite… like, "I gotta do this again." You know, "I gotta call again." Scary, you know, like "here we go."

When she used a list provided by her insurance company to find provider she noted, "either some of them weren't even at the office, or they were doing something totally different, you know,

some specialized kind of- it was not accurate at *all*, and it was just, it was like a worthless list basically." The process was time-consuming and frustrating.

Barrier: Trusting Unfamiliar Providers

Several participants noted that it was stressful trusting providers with their health when they were meeting for the first time and did not have any experience with the quality of care that they provided. P22, a middle-aged writer who had been traveling for four years, described how seeking healthcare might have been different if she had not been traveling:

> It would have been more comfortable, because I didn't have to meet a new healthcare provider every time and decide whether I trusted them or not, because I don't trust them at all. They're just human beings, and they're fallible like we are and some of them take their job really seriously and are really freaking good at it. And some of them really shouldn't even be doing that. And I don't just jump in and say "oh, you're a doctor, I'll do whatever you tell me." No, uh uh, I will not.

She did not have a primary care provider and had been postponing dealing with health issues during her years of travel. P7 orchestrated a wide web of care, but also reported anxiety seeking care from unfamiliar providers of uncertain quality, "Sometimes it's kind of scary not knowing the provider, you know? I mean, goin' in there cold turkey. You don't know if they're good or what. I mean I have to trust my insurance." Upon first meeting, she relied on her insurance company to assess the quality of care given by the providers that they recommended.

Although a few participants reported that they did trust the healthcare system, the majority cited concerns about the culture of medicine as a barrier to trusting unfamiliar providers. Participants were concerned that profit motives might supersede concern about patient welfare, or that expensive medications and exams might be ordered in place of less invasive

options such as lifestyle change. When asked if she trusted the healthcare system, P5 explained her concern about profit motives by describing how the likely futile treatment of her loved ones seemed to be based on what their insurance would pay for:

> I went through it with my dad and went through it with my significant other (…) they were both on their way out and they just kept throwing every test at them and they both had good insurance, you know [chuckled]. Every test in the book, 75 specialists coming in, I mean, the guy's got a brain injury (…) leave him alone [laughs] (…) let's cut Joe in on this, let him come in and get his share.

Some participants believed that individual providers had altruistic motives, but that they might be prevented from caring for patients in the way that they would like to because of the business motives of organizations. P2, a retired educator with experience writing grants for a healthcare organization, reported her impressions about the conflicts between profit and altruistic motives in healthcare after working in a clinic:

> They're not in it to provide healthcare for the people, they're in it to make money. That was a problem in our practice that the CEO [chief executive officer] kept pushing the doctors, you've got to see more patients (…) and the really good doctors that wanted to spend time with their patients got really upset about that.

She later described how she had been referred to multiple specialists after establishing care with a primary care provider in a second state and, with a cynical tone, commented on the business plan of that health system. She accepted some of the referrals but ignored others because she had existing positive relationships with specialists in the first state. Demonstrating trust in individual providers accompanied by mistrust of the system, P18 reflected a common sentiment when she explained that she was lucky to have established trusting relationships with *her* doctors:

> I'm very grateful that I found these two doctors that I trust. I trust them, the healthcare system, no. And the system in general, absolutely not. Because it's tying the hands of even all the doctors and the nurses that work so hard and really care. They can't do their jobs. Yeah, because I can see where sometimes doctors, it feels like they want to treat their patients in certain ways and they just can't, because of the system that they're stuck in.

Concerns about trusting unfamiliar providers and the healthcare system in general were mentioned when participants considered whether to seek care in unfamiliar locations.

Facilitators: Trusted Information Sources

RVFANs used multiple strategies to overcome the barriers of lack of transparency of facilities and trust in new providers. All the participants described comfort with using information technology for various purposes such as choosing travel routes, communicating with loved ones, and locating campgrounds and other resources in the areas they traveled to. They reported using health websites to assess their symptoms and make decisions about their need for care. In addition, they used online reviews to assess the quality of local providers and facilities. P13m, a man who worked in internet technology, described using online reviews to vet healthcare professionals, "that's been surprisingly effective in finding good (…) I'm a skeptical person by nature, but it did seem like a lot of the reviews have led us to good people." He raved about the dermatologist and dentist that he had found using online reviews.

Several participants noted that connecting with the RV community in person or through social or print media helped them to cope with the challenges of the RV lifestyle, including learning how to manage health conditions while traveling. P22, a gregarious woman who had

been traveling for four years, explained how she relied on her fellow travelers for provider referrals and other information:

> If you don't have a relative out here, they are the friends that you're gonna get referrals from. Absolutely, I mean, everything I've learned out here has been because I asked somebody I was camping with, and if they didn't know, they knew someone who did or they knew where I could go to ask.

P17 planned her route to attend events organized by an organization of RVers and explained how information from other community members helped her learn to manage her health on the road:

> Finding community was a big, a big change for me in terms of like, maintaining my mental health. And then also meeting other people who are also dealing with chronic illnesses and, you know, seeing different ways different people manage it, and then also just knowing that I'm very much not alone in that way.

Observing how other RVers managed chronic illness in the context of geographic mobility provided her with strategies for managing her own health, influencing her ability to perceive of healthcare resources and her ability to engage with them.

One participant reported accessing information about local healthcare resources at libraries, senior centers, and recreation centers. A few RVers noted that information about local healthcare resources was included in the flyers handed out by campgrounds when checking in, and two RVers noted that they had met their primary care provider at a health fair hosted at an RV park. Several participants also suggested that information about local health resources *should* be distributed at RV parks. Trusted information sources facilitated RVFANs' ability to perceive care and also facilitated their ability to engage in care.

Acceptability & Ability to Seek

A barrier to the acceptability of healthcare services was caregiver's lack of empathy for nomadism. Caregiver's who were more familiar with the lifestyle were more acceptable to participants. Although caregiver's familiarity of nomadism could make healthcare services more or less acceptable, participants did not report inability to seek care.

Barrier: Lack of Empathy for Nomadism

Cambridge Dictionary defined empathy as "the ability to share someone else's feelings or experiences by imagining what it would be like to be in that person's situation" (2023). Participants reported that they had to explain their lifestyle multiple times and that some caregivers could not seem to comprehend the information. Caregivers tended to assume that they were homeless and refer them to social services, or that they were on vacation having fun. The following quotes illustrate caregivers' difficulty comprehending the nomadic lifestyle. P18 was a middle aged woman who wore drapey, colorful clothing, and lived in a converted school bus. On a windy day in a public park, she described how difficult it was to convince caregivers that she was traveling, but not on vacation:

> I feel like they just don't get it. Like I feel like they go blank, like they don't understand. Like, and they just, like it totally short circuits and just doesn't compute (…). Just assuming that you're always going to be there, and they don't understand why you wouldn't always be here. "I'm a nomad." "[office staff] So you're not going to be here?" "No, I move around. I'm going to Arizona." "[office staff] So you're going to Arizona for like a week, or?" "No, I said April." That is kind of how the conversation goes.

P16 was an older woman who sometimes stayed with her children but spent most of the year traveling across the country in a minivan to see interesting sites or visit people. She described her

travels in terms of general directions; south, or west, or up the coast. Sometimes she worked contracts; she described work experiences at farm and at a national park. Her route was different every year. She reported that her caregivers were familiar with the concept of snowbirds, but explained that nomads were not the same:

> My primary care made a comment to the nurse that I'm a snowbird. So they have a concept of people that are going out of state for a period of time and they see other providers, you know, so then you have to deal with that situation in a different way. But a snowbird is not the same as a nomad. (…) I mean they go south for the winter, but I think that's more of the people go and park their RV in some RV park and they stay somewhere for a few months, or they have a condo or something.

Her route of travel was more variable than a snowbird, and she spent more time in unfamiliar locations. P8 was an older married man who had chronic conditions that he managed through a web of providers focused on two main locations. However, most of the year he was traveling in other regions, so he accessed local healthcare for urgent symptoms. He reported that providers assumed he was out having fun and he sometimes spent more time explaining his lifestyle to clinicians than he did addressing his healthcare concerns:

> Most that I run into (…) "oh, that must be really fun to do." Because they really have no clue what life is like out there. It's like being a truck driver, same thing. You know, it looks very glamorous, and interesting, but there's a lot of other things that aren't quite the same. And I think if they had a better understanding of what the lifestyle was for *most* people, it would be a little easier to deal with. I usually end up spending, talking more about our lifestyle than I do about my medical.

Although he enjoyed traveling, he was not on vacation. He ran a charitable organization and reported that daily life was composed of better or worse days in an RV just as it would have been in a house. The lack of understanding sometimes made it difficult to obtain cooperation from caregivers to adapt plans of care to fit their lifestyle. The caregivers were unable to imagine what it might be like to be in the nomad's situation.

This section includes quotes from nomads who reported that they were not homeless, even though they were houseless. P22 moved into an RV and began traveling after a divorce. Her living expenses were reduced, so she was able to do work that she enjoyed but did not pay as much as her corporate position had. When asked what information healthcare providers need to provide the best care to nomads, she explained that nomads were not homeless:

> I think it would really help them to get familiar with this life and understand that we're not a bunch of psychotic, drug-addled people. There's a lot of us who just never wanted to live like a lot of people live. I think they need to understand that a lot of us are out here for economic reasons, and to not judge us because of that. I do feel very judged by people because of that. (…) They need to stop looking at us like we're all a bunch of, you know, basically homeless squatters. Our homes just have wheels, and we have legitimate lives. And we have jobs, and we have goals, and everything that sticks and bricks people have. And so I think they need to do a better job of understanding how we live and not being judgey towards us. Like, you know, well if you would just go sit in one place you could get this care. Well, I don't want my ailments to determine how I live my life, you know?

She moved into the RV with the goal of trying the lifestyle for five years; after four years she reported that she was happier as a nomad and did not plan to return to living in a house. P17 lived in an SUV and worked with a charitable organization. She reported concern that resources

that are attached to homelessness may not be accessible to RVFANs who could benefit from them because they do not consider themselves homeless and are not seeking traditional housing:

> I think just the main thing would be just that nomads aren't homeless and aren't looking for homelessness services. Yeah, I think that's probably the main thing (…) maybe there might be services that people who are nomads could benefit from that are often coupled with social work and like trying to put people back into conventional housing. So uncoupling those things.

These quotes illustrated that RV-dwelling nomads may not consider themselves homeless, even if they had low incomes. They did not want to be associated with the stereotypes of homelessness and did not desire stationary residences.

The assumption that RVFANs were on vacation, i.e. a short trip, also presented barriers to care because it was sometimes accompanied by the assumption that care could be deferred because the patient would be returning home to their regular provider soon. Participants were concerned that providers might not be as invested in their care when the relationship was short-term. Within the culture of medicine, it is typical to refer certain requests to primary care providers, such as medication refills, or assessment of non-emergent symptoms. This was frustrating to participants who did not maintain relationships with primary care providers, or who were seeking care locally because their primary care providers were distant. The following quotes illustrate participants who felt brushed off, or that the caregivers were not listening when they explained their situation. P8 researched his healthcare options thoroughly and took pride in his ability to make the most appropriate choices for care. He was frustrated when office staff tried to defer his needs to his distant primary care provider:

> A lot of people kind of, mainly the nurses, or the office assistants, "[incredulous tone] you don't have a primary? "[sarcastic tone] No, I'm traveling." "[sarcastic tone] *Oh, okay*." It's just beyond their comprehension that I wouldn't have a primary. So, or if I have one, yeah, she's in New Mexico. Okay. "So when did you see her last and what'd she say?" You get all those kind of things. Well, okay, yeah, it has a bearing, but "I need to talk with *you* now."

P4m was a middle-aged endurance athlete who did not have an established primary care provider and described the resistance of a caregiver to provide prescriptions for him during a physical:

> I was like, I only have expired EpiPens, because I have food allergies, and I didn't have an inhaler. So I'm like asking this doctor while I'm getting the Department of Transportation physical. Like, "hey can I get these prescriptions?" And he's like, "why?" He's like, you know, "go go see your doctor at home." (…) I feel like I'm trying to pull one over on them when I was like, "I need an inhaler man."

His wife displayed heightened emotion when the topic arose, slumping back in her seat, raising her face to the sky, and raising her voice:

> That like, 'go see your doctor' phrase. It's such a conversation shut-down moment, where it's like, I think your mind just goes kind of like, 'I guess I'm just screwed, like, what am I supposed to do? I don't have a doctor. I feel like we should be better surrounding that (…) more like, 'do you have a doctor that you can,' you know?

P15 traveled with her spouse who worked as a mechanic. She did not have a primary care provider or insurance when she experienced an exacerbation of her COPD. She delayed care until she felt her life was in danger. Her emergency room caregivers repeatedly told her to follow up with her doctor after she had advised them that she did not have one:

> I told them while I was at the hospital, that I live in my RV. I'm not from here, I don't have doctors. They kept saying follow up with your doctor, and I'm like "dude, that's just not gonna happen."

She had two follow-up visits in the emergency room which took the couple three years to pay off. Feeling brushed off in the past influenced participants' beliefs about the value of seeking healthcare. Participants reported that lack of understanding about the RV lifestyle was something that they encountered sporadically, but it could affect interactions with caregivers at any level from office staff to licensed providers.

Several participants reported that they encountered no assumptions from caregivers regarding their lifestyle. They felt that their providers treated them the same as they would anyone else. Some participants posited factors that they felt influenced the likelihood of encountering assumptions including the age of the caregiver, the age and appearance of the patient, the patient's attitude when talking about their lifestyle, the insurance status of the patient, or the engagement of the patient in their healthcare. While he waited at a picnic table for his laundry to dry, P3 philosophized that nomadism was one of multiple attributes that strangers used to assess an individual's social status:

> The less healthy you are, the less attractive you are, the older you are, the less rich you are, I hate to say it, but any other those affect how you're treated across the board in society. (…) With the nomadic lifestyle, you're already kind of on the fringe, because that's not normal. So that's a tick box. But there are aspects of your life that can overcome that. If you're charismatic, if you're wealthy, if you're beautiful, then the nomadic lifestyle becomes glamorous.

He felt fortunate that he had not experienced negative assumptions from caregivers and attributed that to his youth, his charm, and his good looks. Experience with the RV lifestyle was the most commonly suggested influence on provider perceptions.

Facilitator: Caregiver Knowledge of the Nomadic Lifestyle

Providers that had experience with the RV lifestyle were described as "getting it" and being more understanding and accommodating. P13f traveled with her spouse who worked in internet technology. They enjoyed civilization so they usually camped in RV parks in urban areas with full hookups, fast internet, and laundry facilities. She described the difference in the response to her lifestyle between two providers, the first who made an erroneous assumption, and the second who had a nomadic acquaintance:

> He assumed that I'm just sitting, driving all the time in a truck, I think. That's how I felt, maybe he made me feel kinda- but yeah, the other one, no he was really, "oh, I just met another lady. She's gotten an Airstream doing the same thing." (…) So he was kind of a little bit more open.

She looked uncomfortable when she discussed the first provider's assumption and reported that she did not feel that the amount of time she spent sitting had increased after adopting the nomadic lifestyle. P22 appreciated being treated like any other person when she went to a clinic in a part of the country where living in RVs was ordinary, "It's not something that's weird, or out of the ordinary. I mean, most people there live in a home, you know, a sticks and bricks, but it's not at all odd for them." P18 had encountered social stigma when she moved into a bus, but was grateful that she had found a general practitioner that understood her lifestyle:

> Yeah, and the GP offers telehealth. And she's, she's just wonderful. She just *gets it* [emphasis added]. She's down to earth. She's friendly. She works with me. She listens to me, like she's like, yeah, I hope I never lose her.

Caregivers who were familiar with the lifestyle were described as more likely to provide telehealth, adjust appointments to accommodate travel plans, or to provide prescriptions for larger quantities of medications to prevent their patients from running out on the road.

Availability and Accommodation & Ability to Reach

Barriers to availability and accommodation included limited healthcare resources in rural areas, and concern about the consequences of waiting for appointments. Participants reported challenges reaching healthcare such as being distant from social support and lacking a street address. Facilitators to reaching healthcare included the use of smartphones, transportation insurance, and the ability of some participants to adapt their route of travel to areas where more resources were present. These barriers and facilitators will be supported with quotations below.

Barrier: Limited Rural Resources

Most participants spent at least half of their time camping in rural areas. Although participants reported some positive experiences accessing care in rural areas, more often they described long wait times for services and concerns about the quality of care in rural facilities. One participant reported that a rural emergency room provider wanted to admit her to the hospital for atrial fibrillation, but the nearest available hospital bed was in a city two hours away. She went home to the rural RV park instead. Her spouse had been waiting for a month for physical therapy to treat a back injury. P16, a single older adult, was working in a national park when she experienced a new onset of leg swelling. She described her visit to a remote clinic:

> They weren't really able to help me out. They were more like a Band-Aid place. You know when someone says, "well, we could send you into town and get a chest x-ray to see if you're having congestive heart failure." I laughed and said "well if you're going to do that, I'm going home. I'm not going to find out in the middle of nowhere, with doctors I don't know, that I have congestive heart failure. Then how are we going to deal with that?"

Instead of driving to the next town for a chest x-ray, she drove to her medical base where she could seek care from her primary care provider. Several participants voiced concern that providers in rural facilities were not up to date or did not have access to the latest equipment. P8 reported that locals in the rural area where he was camped preferred to drive to more metropolitan areas to obtain care. Despite a recent positive experience in a rural hospital, he stated he would delay seeking care if he were planning to travel through an urban area, "if I knew I was going to be in Denver in three or four days and it wasn't a critical situation, I would wait until I got to Denver (…) because I would have more opportunity to find qualified people." He reported that caregivers in the rural hospital gave him more personal attention than he would have received at an urban hospital, but he felt that rural providers were less qualified in general. He also reported that the emergency room in the rural town seemed overwhelmed. He explained that patients were being treated in the hallway when he brought his wife there and that she waited an hour and a half to see a provider for "heart attack symptoms."

Barrier: Waiting for Appointments

Participants often had difficulty accessing care because caregivers did not offer appointments that accommodated their planned route of travel. This was particularly challenging when seeking specialty care because many facilities or payers required a referral from a primary

care provider to schedule an appointment. This meant waiting to get an appointment to ask for the referral, before waiting for the appointment to see the specialist. If the specialist ordered tests, the additive waiting periods could accumulate into months to address a single concern. Participants explained that changing their travel plans to wait for appointments felt like putting their life on hold. They might miss out on places they wanted to go, people they planned to see, contracts they planned to work, or events they planned to attend. RVFANs also faced barriers to waiting that were outside of their control such as stay limits at public campgrounds, lack of availability at RV parks, or the impending arrival of inclement weather. Participants reported that many facilities offered little flexibility to accommodate their travel, which resulted in delayed care. P18 described repeated challenges arranging appointments for her breast cancer follow up during the time she would be in town despite calling ahead:

> I finally started saying you can work with these dates, or just telling them no. (…) I can't just sit there, twiddle my thumbs for months on end making an appointment. So, and she just kind of wasn't understanding. (…) I was like put me on a waitlist, we can make it for these three weeks, or I will be back in April. "[office staff] Well you can't do that." "Yes, I can."

Nomads visited their medical bases to obtain healthcare, but they were not at home and did not want to be stuck in those locations. P18 had events plans with friends in other states that she did not want to miss, she also felt healthier when she avoided winter weather. P15 explained that appointment waits longer than two weeks made it impossible for nomads to follow up when they were camped on public lands. She offered a suggestion for providers who recommend follow up care for nomads:

> My best advice for any medical professional is, don't say "follow up with the specialist." Schedule the appointment and make it within a two-week span because nomads have to move every two weeks. If you're on public land, you have to move and so if you don't schedule that follow up within two weeks, it's not gonna happen.

P22, a middle-aged woman with asthma and diabetes, reported that she avoided healthcare because they would not accommodate her travel:

> Don't tell me to come in now, and then next month, and then in two months. I can't. I'm not going to be here, so figure it out. You know, like make your services match the customer's needs. Because that's what every business does. But healthcare feels like it doesn't have to because like, they know that you're fucked if you don't, you just won't get it. And honestly, I think a lot of people do exactly that. They don't get care. I don't. I don't get healthcare because it doesn't work for me.

These quotations illustrated the impact of appointment wait times on RVFAN's healthcare experiences. Waiting in one spot for healthcare felt like putting their life on hold because the place that they accessed healthcare was not their home. Nomads make their home while traveling, and these participants had plans and other places they wanted to be.

Barrier: Distant Social Support

Participants who traveled alone sometimes skipped or delayed care or drove great distances to be near family to prevent dealing with the unanticipated outcomes of healthcare alone. Being alone also presented a barrier to reaching care when participants did not feel safe to drive, or did not want to leave pets unattended. P2, an older adult traveling alone, preferred to stay at RV parks for security and in case she needed help from someone who was stronger than

her. She reported that the staff at RV parks were always willing to help. She explained that she had delayed receiving vaccines due to concern about having a reaction when she was alone:

> I thought I had a reaction to one of the Modernas, a real reaction. And so for some reason, now, I'm just a little concerned about any of these shots when I'm by myself. You know, there's no one around in case something happens.

In addition to the COVID booster, she had delayed receiving her shingles vaccine. P3 described pulling over for safety when he was traveling alone and felt too sick to drive:

> Not always do you have stuff. I mean, I had one where I had, I don't know if it was food poisoning or what, but I just started vomiting. And so I had to park at the nearest place I could pull off safely, which happened to be a truck stop, for which I was blessed. I mean, it could have been the middle of nowhere, but I just sat on the side of the road for three, four hours until, you know, it calmed down enough that I could go drive somewhere.

Luckily, his symptoms resolved. P14 experienced serious allergic reactions. She described her reluctance to leave her dog when she experienced an allergic reaction while she was alone:

> Because I had actually gotten out of my van. I was on the road and I'm like, oh shit. I mean, I pulled over and I saw a cop. And I'm like hobbling over with an EpiPen in one hand, and an EpiPen in the other hand, just like 'help'. I'm worried about the dog, because that's me. And he took the dog and I went straight to the ER.

People who traveled as couples benefited from spousal support, but sometimes only one partner could drive the RV. Their mobility would be limited if the designated driver was sick. A few participants purchased transportation insurance that promised to provide emergency transportation by land or air to a 'home' location for the patient as well as for their RV and their family or pets. None of the participants reported having used the coverage.

Barrier: Disconnected from the Grid

A few participants described difficulties that arose from disconnection with a street address. P4f described her difficulty arranging an ambulance when her spouse sustained an injury while they parked on open public lands:

> That was the single worst moment of my life seeing the blood gushing while we're at a campsite out of his wrist and I literally thought it was horrible (...) because you're not in your place. And it's like, that moment of panic. I just could not for the life of me, and then just trying to communicate, but we're also in the horse camp. And I just remember that feeling of just like*, I don't know how to tell them where we are* [emphasis added].

She was distressed because she did not have a street address to give the 911 operator and had no idea how far away the ambulance was, or if the ambulance would be able to find them. Her stress was reduced by the 911 operator who remained on the phone with her until the ambulance reached their travel trailer. P5 described losing her Medicare supplemental insurance because she did not receive her mail, "they said that, 'we sent you a letter, you didn't get it, so we're canceling you'." After this event, she arranged to use the address of a relative for mail delivery.

Some participants reported their smartphones helped to connect them to the grid in emergency situations. P8 described the emergency features on his iPhone, "Just by pressing two things it'll do a 911 call anywhere in the country. It does not use cell, it uses GPS, therefore they know where I am." P14 also used her smartphone to pinpoint her location for emergency services, "Basically, what happens is they'll give me a number to text. I pull it up, and then you pull up that added part on your phone and you pin drop where you're at and they can find you." Although some participants had developed strategies to overcome the challenges of disconnection with a street address, others were not aware of the resources that were available.

Facilitator: Route to Resources

Mobility was a facilitator for nomads when they adapted their routes to visit locations where more resources were available. A common strategy was to plan travel routes around routine visits to the location of their providers and schedule all their visits within the same time frame. P1m and P1f described returning to their medical home every six months, "we'll usually call in advance and get all of our doctors in that one week." To maximize the efficiency of their visits, they had routine laboratory specimens drawn wherever they were two weeks prior to the visit, so that they were prepared with the results to review during their appointments.

Some participants changed their routes to reach social support, or to visit locations where care was more available or was of better quality. P16, a retired healthcare professional, was concerned that her decision to drive 900 miles before seeking care could result in a serious health outcome, but she did not want to be admitted to a rural hospital where she would be distant from social support:

> I did not want to go someplace where I didn't know people, you know (…) I figured if anything was going to get complicated, where I might get admitted somewhere, I didn't want to be admitted in the middle of nowhere, unless it was an emergency. And, of course, I don't know what constitutes an emergency. I drove all the way home with the idea that you could have a blood clot in your leg and you don't know about it.

She was uncertain about the best course of action but felt more comfortable dealing with a new diagnosis in a location with more healthcare resources that was near her family. P21 had waited about 6 weeks to receive permission from the Veterans Affairs to have a tooth fixed locally when she reached out to her social network to find a location that had appointments available, "My friend said, 'come on,' (…) 'come on down to [city about 450 miles away], they'll get you right

in'. And they did." She drove 450 miles and had to establish care with a new dentist but had an appointment within a couple of days.

Sometimes participants anticipated their care needs, arranging care ahead of time in places where they expected to be weeks or months in the future. P9f described anticipating where they would be when they needed a prescription refill:

> If it takes a couple of days to get there and we're moving on we just, when we are in or are approaching the next town that has a CVS, we just call them and have it transferred from wherever it was originally prescribed to, to wherever we're going to be, and then we pick it up.

Planning a route in anticipation of healthcare needs and capitalizing on the resources that were available in different locations was complex, time-consuming, and sometimes expensive; but participants perceived that their efforts improved the care that they received. Unfortunately, their efforts became doubled when unanticipated route changes meant cancelling and rescheduling appointments that had been made previously.

Affordability & Ability to Pay

Participants reported barriers to the affordability of care including high direct and indirect costs of care. They described several strategies for arranging discounted care. Participants' ability to pay was influenced by their income and their insurance coverage.

Barrier: Costs High, Incomes Variable

Several participants reported deferring healthcare visits and prescription medications due to the cost. P22, a middle-aged writer, explained, "when people are living in tiny homes, because

that's all they can afford. They can't afford this Cadillac pricing on healthcare." She had deferred dental care for years despite having teeth that ached on a daily basis:

> An extraction here in America is 250 bucks. And that's with, if nothing goes wrong, you know. And like, if I need to get a root canal, that's going to be $750. My god, you know, I don't have that.

She had recently received a referral for a Mexican dentist from a fellow RVer and was considering receiving her dental care over the border to save money. P17, a woman with Medicare but without prescription drug coverage reported, "the medication they had wanted me to try for fibromyalgia I decided to opt out of because it was just too expensive (…) it was gonna be like 500 a month." She felt like she was doing ok without it, since she had reduced her symptoms with lifestyle changes.

In addition to the direct costs of care, participants reported that indirect costs such as gasoline and RV parking were a burden. P14 reported that financial concerns caused her to decline visits to specialists, "Every time I turn around, it's like we want you to see this specialist and this specialist and this specialist. I'm like, do you know how much gas that is through my car? Could we stop please?" A self-employed middle-aged couple reported reluctance to seek care because they were concerned that they would have to relocate to an RV park if the time to resolve the health issue exceeded the stay limits on public land. P4f explained:

> If you get stuck somewhere, there's a huge expense that gets associated with it. Like, if you have to stay at a campsite for a long time. If you think about campground fees. This one's cheap, but often they're 40 to 60$, and take 60$ times 30 days (…) like if it's something that's going to require follow ups.

Her spouse added, “it definitely complicates it because you’re just like, we don’t know how long. We don’t know how much this is going to cost for us.” Waiting 30 days in an RV park for an appointment could cost them $1800 for accommodation, which would be free if they continued traveling from site to site on public lands.

Barrier: State-Bound Insurance

Participants spanned a range of income levels that impacted their ability to pay for services. Some reported that saving money on housing was a motivator for RV living, while others maintained homes that they did not live in. Unfortunately, those with the lowest incomes were also less able to afford nationwide insurance. Several participants named state-bound insurance networks as the most pressing issue affecting nomads. Some nomads went without insurance because the options available to them did not suit their needs. P3 reported that his travels were partially motivated by altruism, a friend told him “you have the gift of the helps, wherever you go is where people need help.” With his traveling lifestyle, he did not feel that the state-bound insurance policies that were available to him would be useful:

> When I found out I couldn’t get the insurance I wanted, I just stopped looking. I’m like, why bother, you know. If I can’t get something that’s going to work for me (…) I mean, because that’s what you’re doing is you’re insuring the person. If I insure my car, I insure my car in the state I’m in but when I drive out of state lines, my car insurance still counts.

His body, inside of the car, would not be insured across state lines with the policies that were available to him. Since he was across state lines most of the time, paying premiums would provide him with little benefit. P14 described delivering fellow nomads to their coverage states to receive care, “I’ve had nomads damn near dead out here trying to get across state lines to their home state to have the insurance. (…) I’ve driven one 700 miles to get them across the state line

to the first hospital." P4m chose his domicile state because the insurance offered on the state exchange was less expensive. He reported that their policy covered emergency care out-of-network, but the hospital billed him anyway, "the insurance company is like you billed 2500 bucks, but we think it should be $1500, so just make it that. And then the hospital is like well, we don't have to. Like you're Nevada, we're Ohio." Participants under the age of 65 who did not have employee-sponsored insurance, like P4m, had difficulty finding or affording policies with nationwide networks. Some had coverage for emergencies when they were outside of their domicile state, while others reported having no coverage out of state.

Facilitator: Nationwide Insurance or Multiple Insurance

Participants with nationwide insurance coverage reported fewer concerns about medical bills. Some participants reported purchasing multiple policies, as many as four different health insurance policies, to cover different situations that could arise. A few participants emphasized that insurance brokers or agents were essential to helping them find options that were appropriate for their nomadic lifestyle. Some participants were insured so well that they received no bills at all. P1f, a vivacious older woman who lived with her spouse in a travel trailer, had Original Medicare with supplemental insurance and transportation insurance:

> We went to somebody that helps seniors transition into Medicare (…) she says this is the best one for traveling, because it doesn't have restrictions. It doesn't have strict state restrictions or any of that. So that's why we got that. We're glad we did. It's a little more pricey per month, but there's no deductible. And for the last almost 12 years now, we haven't paid one penny to anything other than prescriptions (…) all of these surgeries we never paid a penny.

Between the two of them, they had had four surgeries and one hospitalization for illness, without receiving any bills. P8, had four insurance policies: Medicare, a nationwide insurance policy, a policy for prescriptions, and a policy to cover emergency transportation. He noted, “It has been excellent. We have not had a single bill, from my bariatric surgery, to my recent hospitalization, doctors, whatever.” Insurance coverage was an asset for those with the ability to pay.

Facilitator: Discounted Care

Participants reported several strategies for obtaining discounted care including negotiating with providers, applying for financial aid programs, finding coupons for medications, or engaging in medical tourism. P19, a middle-aged business owner, illustrated the emotional burden of medical bills when she told her story about finding a financial aid program:

> Those thousands of dollars, almost 10 grand or something in my diagnostic journey with all the MRIs and the treatment and the blah, blah, blah, and spinal tap. I applied for that program through Kaiser that they did because of COVID, and I got approved. And I called the lady up at Kaiser (…) and she’s like, “oh honey, let me look you up.” And she looks me up and she’s like, “oh yeah, you’re zeroed out.” I started crying. So they paid, they paid everything. And I started crying, and I’m gonna cry again. And I was like, “this is incredible, thank you so much.” And it was just luck that I was talking to a women from Kaiser who was knowledgeable enough and kind enough to tell me that this existed.

She also reported that buying Kaiser insurance through the Affordable Care Act website instead of directly through the Kaiser website saved her $300 a month despite upgrading from a bronze level plan to a platinum level plan. She had been paying for the more expensive, lower tier insurance for years before investigating the state marketplace website. P22 described her relief

when a pharmacy worker told her about a prescription discount service that helped her obtain her medication:

> And then when I took that script to CVS, holy shit. I had to get five tubes of this ointment, and it was $133. And I stood there and I couldn't help it, tears came to my eyes, because I had not anywhere close to that much money to spend, and I was in such pain, and I was like, feeling so hopeless. And God love that girl behind the counter. She goes, "I see this is a problem for you." I couldn't even talk, I just nodded. She went in the back, and she got this little tab (…) and she just hit that. It went down to 28 bucks. So first of all, I had this massive feeling of gratitude, and then I just felt angry. Because I'm like, that's wrong, to have that kind of margin, where you can like take it down by 80 percent, you know, and oh my god.

After the visit, she subscribed to the discount service and continued to use it and tell other nomads about it. She also saved money on medication by buying generic over-the-counter medications online and by purchasing her prescription asthma medication in Mexico. P5, an older retiree, traveled to Mexico for cheaper dental care:

> I went to two dentists in Coolidge, and they both told me different things, but you know it was $4000 and $6000 and I'm like I'm not putting that kind of money into my teeth. I'm [age] years old. Why would I do that? So I asked for recommendations around the park. Everybody I talked to said go to Mexico (…) so I ended up going to Mexico and I mean, the whole thing probably cost me $1000, but I had a deep cleaning and a tooth pulled out and three veneers.

She was happy with the quality and the cost of the care that she received by walking three blocks across the border. These stories illustrated the emotional impact of the cost of care and some of

the strategies that nomads used to obtain cheaper care. The costs varied so widely that they did not seem to bear any connection to the value of the product and the participants described the people who helped them to find discounts as heroes.

Appropriateness & Ability to Engage

Participants reported barriers to the appropriateness of their healthcare including state-bound licensure that limited the provision of telehealth across state lines and difficulty accessing prescription refills or medical records on the road. They reported that telehealth access, national chains of providers, and caregivers that listened to them when they described their lifestyle and collaborated with them to make care plans, facilitated the appropriateness of their healthcare. To engage with providers healthcare participants recommended becoming an expert in their health, practicing self-advocacy, and carrying medical records.

Barrier: Difficulty Accessing Medical Records

A frequent concern cited by participants was that the care they received might be less effective because of difficulty accessing medical records from visits at other facilities. P16, a retired healthcare professional, was frustrated by her unsuccessful efforts to make records of a previous visit available to her cardiologist for a follow up appointment:

> And then you have to think about, I need my records and information to go to the other doctor, are you doing that? Because you always have to follow up on this stuff (…) and I said, make sure you get this to the doctor before I come in. And they didn't have it in my file when I got to that office. And I'm just like, *I made all these phone calls* [emphasis added].

Some participants requested records at the time of each visit due to the difficulty of obtaining records of visits retroactively. Participants who obtained care from health systems with online

medical records that were coordinated and convenient to access expressed delight. P16 gushed about the electronic records in another health system "their electronic record is wonderful, absolutely wonderful." P19 chose her insurance provider because of their coordinated online medical record system:

> Everything's in the system, and I don't have to worry about, you know, tracking my records and moving them around (…) because the ease of it (…) at least I would actually go to the doctor because it was simple, versus not getting any healthcare.

Participants frequently expressed support for a standardized system of medical records. On the other hand, several participants who had medical records split between multiple patient portals expressed frustration. P9f, a retired healthcare professional, described this frustration:

> Everybody [should] have the same documentation system. Because how many, how many damn passwords do I have to remember? Cause every doctor has got a different one it seems like and if you want to go into your records you know you've gotta, and I don't remember 'em. And I get frustrated with that.

P2, a retired teacher, expressed a similar sentiment:

> That's something that's getting very confusing for people that travel around. You make an appointment with the doctor. They want you to go on their website or, you know, join their program. How many of these programs can an older person handle?

While some participants relied on looking things up in patient portals during visits with unfamiliar providers, others carried medical records with them. Some carried complete records, while others carried abbreviated medical histories. Some preferred paper format, some preferred digital format, and some carried both. Participants noted that caregivers were sometimes

reluctant to view records provided in the digital format. P8 surmised that providers were worried about computer viruses:

> If you give somebody a USB, you may have a virus on it and you transfer it to them, they don't want that and you don't want it from them. So they tend to be a little, "uhh I don't really want to do that."

One participant noted when moving her oncology care to another town, that the provider only accepted faxed medical records. This was a hardship because she did not have a fax machine in her van. She explained her frustration when this inconvenience delayed her appointment:

> Because emails are not secure via HIPAA [Health Insurance Portability and Accountability Act of 1996] compliance at a lot of offices, which is bullshit because some places are figuring that out. And some places you can go in your MyChart [website] and upload documents there. And that is ideal, but this place hadn't figured it out yet I guess (…) it took almost a couple of months before I could get all the paperwork sorted out so that I could have an appointment.

The participants' stories illustrated that they recognized the importance of medical record access to promote continuity of care, but the use of technology varied from facility to facility. Participants perceived some systems as facilitating care, while others were perceived as barriers.

Barrier: State-Bound Licensure

Several participants regretted that they were not able to maintain continuity of care with their established providers when they left the state where their clinic was located. Although some of their providers offered telehealth services, they were restricted to caring for patients who were

situated in the state of the provider's license. P21 reported that her provider encouraged her to say that she was in the same state to enable her to continue to provide care:

> So last year, I was doing a telehealth, and I was in Nevada. And I happened to mention, "oh yeah, I'm in [town]. I'm having a great time." "[mimics voice of therapist] You have to be in California. So next week, when I call, you have to be in California." It's like, why, it's telehealth? Isn't that crazy?

This story illustrated how the patient's desire to seek care and the provider's desire to give care were thwarted by a licensure barrier. P18 stated that her mental health improved when she traveled, but traveling also meant pausing her treatment for post-traumatic stress disorder due to her provider's state licensure barrier:

> I can tell my counselors are like, "yeah, you're not really ready to go but." They understood why I wanted to come down here as well. And coming down here was just as important for my mental health as well. (…) My counselors that I was seeing at the time, and even the group therapy, I'm not able to continue care with them because they're not licensed in the state and no one is multistate from what I understand.

Licensing barriers also prevented the use of telehealth services for pain management. P14 reported that her symptoms improved when she traveled to avoid temperature extremes, but traveling required her to forgo treatment for her chronic pain:

> Pain management which is something that I live without because it's such a pain in the butt. It's still every two weeks and they expect you to show up in person because they need to look and see if you're actually in pain.

Since she could not attend the clinic appointments while traveling, she went without pain medication for her fibromyalgia. P16 noted that providers interpreted license regulations differently and that regulations changed over the course of the pandemic:

> They were covering telehealth during COVID without any question, but now apparently, there's a question on there that asks where the client is located. So the pulmonologist told me that the way that he deals with that (…) he figures that he has a relationship with that client, and so if they call from another state, it's like, they're here. I'm talking to them, you know, and so he makes his, he practices and charges on that basis as though they were present. So it could be subject to interpretation.

In contrast to the reports of state-line barriers to telehealth, several participants reported that they did maintain relationships with their providers using telehealth from other states and did not mention licensure barriers.

Barrier: Prescription Refill Logistics

Many participants reported difficulty obtaining refills for prescriptions for medications and medical supplies while traveling. Some participants reported having to establish primary care providers in alternate locations in order obtain prescription refills. P8 explained the reason why he established care with a second primary care provider in another state, "We needed a physician to redo our prescriptions. We could have called Wisconsin, but our physician there tends to want to see us every time. She doesn't necessarily do it over the phone, even though we were traveling." P12, a retired healthcare professional, reported that it was even difficult to get refills from different locations within her health system:

> Sometimes I find it harder within the system than without (…) I had to do the biggest song and dance to get, I had to become a guest member to Washington's Kaiser, and then

> they transferred all my prescriptions from [city] up to there. And I had to have the [same city] pharmacy bring the prescriptions back when I was no longer in Washington. It was just really hard.

She was surprised that it was sometimes easier to receive care from a facility outside of her health system, than it was to receive care from another branch of the health system

Participants encountered varied and changing rules from site to site and received inconsistent information from pharmacies and medical equipment suppliers. P9m, an older man with diabetes, reported difficulty getting a refill for his glucose sensors, "when I contacted Edgepark again and they said that even though I'd had the thing for a couple of months and when I had to get the second batch of sensors, then they said it wasn't covered." He had to request intervention from his insurance company to resolve the issue, which was time consuming and frustrating. P1m reported that he usually received a 3-month supply of glucose test strips but due to a sudden change in rules he was informed that he could only get one month at a time and he had to wait until his prescription ran out before he could pick up the refill. This made it difficult to arrange to pick up his test strips on their travel days:

> Well something happened the first of this year, and now I can only get one vial of strips at a time, I used to get three (…) but if you're traveling that can be a real problem. (…) You have to get a new prescription every time (. …) That's the other thing too is Medicare has shortened their timeframe, when you can apply for another round of your meds (…) There's no wiggle room now. You have to be out and then you get it.

This delayed him from checking his blood sugar on the days that he ran out of test strips, preventing him from following his provider's recommendations for blood sugar monitoring.

When they faced challenges to obtaining refills through their established providers, some participants reported obtaining refills for their medications through unfamiliar telehealth providers, or buying their medications in Mexico. To avoid logistical hurdles, P18 was considering obtaining her cancer medication in Mexico, "my cost isn't really an issue (…) it's just ease of being able to say 'yeah, I'd like 90 days of this'." She described an experience about obtaining her medication in the U.S. to illustrate the difference in convenience:

> Because I switch pharmacies a lot, I had a prescription sent to one place, and I couldn't pick it up there anymore because it wasn't even close. But they wouldn't send it to the other place because I guess they had already filled it, even though I told him not to fill it. And then I tried to call my doctor's office and they're like, "no, you contact the pharmacy to contact us." And then the pharmacy said, "no, you contact the doctor's office," and it took a few days. And it's like how can I even think about having a job when honestly some of these, like by the time you make appointments, and call, and make all these phone calls. It finally got sorted out, but it took a few days.

In anticipation of logistical hurdles, several participants reported that they felt safer when they kept large stocks of medications on hand. P13m described his efforts to "stockpile" insulin:

> I asked her [provider] for 18 months and she gave it to me. So, and then I maximize my estimated insulin usage so that I could get one per month, and I tried to keep like three to five months on hand.

Participants did not want to risk their health by running out of medication.

Facilitator: Telehealth

Although participants noted that there were some situations when in-person visits were most appropriate, many participants expressed gratitude when they were able to use telehealth

maintain relationships with their trusted providers. P15 explained that telehealth allowed her to maintain a relationship with a consistent psychiatrist:

> COVID already made some of these improvements for us. With Teladoc and virtual doctors. That was the best thing came out of COVID. (…) I can now see my shrink, on my phone. Yeah, I don't have to go find a new counselor when I'm feeling like my mental health is in jeopardy. I can get with my therapist, my counselor, my psychiatrist, anywhere in the country, anytime I need to.

She was proud of the strategies that she had developed over many years to manage her mental health and maintaining a consistent provider meant that she did not have to start over with a new provider if she experienced a symptom exacerbation. P12 used telehealth for monitoring after thyroid cancer, "Even though I've had my thyroid out I have never seen my endocrinologist, because this all happened right around COVID, and so we just talk on the phone." She was heading to Mexico and planned to continue her telehealth visits from there. P19 explained how she maintained continuity of care with her neurologist on the road, "if it's anything that I think might be neurological I immediately email my neurologist." P2 felt more secure traveling because she knew that she could reach out to her primary care provider from anywhere, "I think it's very effective, and I think in rural America telemedicine is very effective (…) I can email my provider any time, and she answers immediately." P6 noted "Telehealth is huge, huge. If they could just do telehealth forever." Some participants were concerned that they might lose the ability to connect remotely with their providers if telehealth regulations returned to what they were before the COVID pandemic.

Facilitator: Collaborative Providers

Participants were more engaged with healthcare when their providers collaborated with them to ensure that the plan of care was a good fit with their resources and lifestyle. The amenities of participants' RVs ranged from simple to complex. Participants' income, available time, and social support also varied. P1m described how his provider adapted his plan of care for sleep apnea to accommodate his limited access to 120 volt electricity, "he pulled out that one [12 volt converter]." The converter allowed him to use his CPAP when he camped without an electrical hookup. P4f described the spatial limitations in her 21 foot travel trailer when she collaborated with her physical therapist to make a treatment plan for back pain:

> It's really hard for me to do like floor stretches (…) I have limited availability to get on the ground (. …) There's the space between our bedroom and that which is our kitchen, or you look at the ground, there's bugs all over and you're like, I don't want to get down there (…) I couldn't do certain exercises for my back.

Her therapist recommended alternative exercises that she could do in her space. Participants described trusted providers as those who took time to listen when they described elements of their lifestyle that might require altering the treatment plan. P1m offered a suggestion for providers who aim to collaborate with RVFANs:

> I think it would be nice if they would say, here is my plan for your treatment. Do you have any reason why this is not going to work? And then they could say, well, we're full time RVers and da di da. And the doctor would say, okay, you can get a converter, or maybe we should look at another option for you.

This suggestion would facilitate tailoring the plan of care to resources of the individual RVFAN and avoid the risk of making erroneous assumptions.

In addition to offering telehealth services to facilitate continuity of care on the road, it was helpful to nomads when they were provided with at least 90 days of medication and subsequent refills that could be transferred between pharmacies wherever they went. When participants needed recurrent labs, some caregivers provided participants with prescriptions that they could bring in to other locations. They could discuss the results via telehealth. P7 reported that a provider gave her a portable referral after a telehealth visit:

> Right now I've got an open referral for a gastrointestinal doctor because I get heartburn and stuff like that. They're like, "well, whenever you get somewhere, just go and see a gastrointestinal doctor and you can take this referral with you."

This would allow her to call ahead to arrange her specialist visit in the next place that she planned to be. P14 reported encounters with providers that were not familiar with her rare medical conditions. When she experienced an exacerbation of her condition, she collaborated with her remote specialist to educate local healthcare providers:

> It's become a habit now that I actually end up having to text her that I'm on my way to an ER [emergency room] so that she can tell them to stop being stupid. Because irresponsible treatment has put me in danger more than once.

Information from her specialist prevented unfamiliar providers from questioning her diagnosis and requests for specific treatments.

It was essential to participants that their providers worked with them to arrange appointments that accommodated their dates of travel. P4f collaborated with her physical therapists to arrange visits during her planned stay:

So how often should I come, because I'll be here ten days and then gone, and then again. And so they had me come like two or three times in those first ten days. They're like, let's do something a little bit more frequent. And then we'll give you some things to do.

Her therapists saw her more frequently while she was there and prepared her to continue her treatment independently after she left. When P13m advised his provider that he would not be in the area to do the recommended 30 day follow up for treatment of a skin lesion, the provider prepared him to care for himself on the road. "Then they said what to watch out for, this is how you take care of it, it's not cancerous but if it comes back, maybe you have it seen again." P22 recommended that providers should ask nomads, "How long they're going to be here, if they're going to come back through? If so, when is that going to be, and how long do they expect?" This question would give providers information that they need to accommodate dates of travel that might not be proffered by nomads who are not accustomed to collaboration.

Participants noted that education was another important element of collaboration with providers. If their condition worsened in the next location, or did not resolve, the nomad would need to explain the situation and the previous care given to a new provider in the next location. P1f described planning for this situation, "Just the logistics of it. If you take care of me here, and we move, what do we need to do to continue with your care? I guess we would just have to have that conversation with them." To resolve an episode of cellulitis, P9f had visits to two urgent cares, an emergency room, and an infectious care provider in three states over the course of several weeks. She recalled that the first provider in Indiana stated, "there's a nasty gnat that bites that causes, we see a lot of infections with that." She regretted that the provider had not given her more information that she could have shared with subsequent providers:

> Maybe take a few minutes to look it up and tell me what the name of the gnat is. So I have more information, you know, that I could say to the next person, "you know I was seen at the Minute Clinic, and this is what she thought, this gnat." And you know, because I had no idea and he didn't know what I was talking about.

Perhaps information about the insect, might have helped providers at the next location to select the most effective treatment. Several participants stated that education about regional health conditions would be helpful because it would help them to avoid risks and prepare them to educate caregivers in subsequent locations if they developed symptoms of a regional illness in an area where the illness was less known. P9f described how the anticipation of caregivers' lack of knowledge about a regional illness had limited the travel of a friend:

> She had Valley Fever. She had to stay several months because she was getting the antifungal, and you know to get the blood work done. So she had to stay because [doctor] didn't feel like, because she wanted to go up north, that a lot of places are not familiar with Valley Fever. It's just like if people came to doctors, or nurses went and worked up in Ohio, histoplasmosis is huge there.

Nomads reported that education was important not only to increase their own knowledge, but also to enable them to collaborate with caregivers that they encountered down the road.

Although collaboration was an important facilitator in nomad's engagement in healthcare, participants sometimes reported that their caregivers only offered one path for care and did not make any effort to adapt to the circumstances of their lifestyle. Sometimes their request for accommodation did not make it past the staff who answered the telephone, who enforced strict procedural rules and would not relay their concern to the provider. P9f, a retired

nurse practitioner, requested a prescription refill from an unfamiliar telehealth provider after experiencing push back from the staff at her primary care provider's office:

> Because there was one that he didn't want to renew. And we were only about three weeks away, getting home. So I just said 'get this'. They gave me a hard time on the phone. I knew that they weren't going to give him the message because they kept giving me a hard time on the phone, at the office. So I said, "I'm just gonna call the insurance company and get it that way" (…) the front office just *did not* understand that we were RVers, and that we were not in the state. And we were not gonna be anytime- we're not going to drive all the way from Ohio to Texas, just to see [doctor].

P9m added, "We were 1000 miles away." After experiencing these difficulties with their prescription refills, the couple opted to transfer their care to another physician who they hoped would be more collaborative:

> We had a lot of problems with, the first year, the first time we went out, getting prescriptions renewed. And we explained [to the new provider] is this going to be a problem? He goes, "no." So he says he'll be glad to do 90 days, with a couple of renewals when we leave.

Finding collaborative providers was essential to maintaining continuity of care on the road, but individual providers varied substantially in their willingness to accommodate traveling clients. A couple of participants advised that it would be helpful if there were an application that contained lists of providers who were willing to accommodate the lifestyle. At the time of the study, participants were limited to trialing providers to determine their willingness to collaborate or obtaining referrals from other RVers.

Summary

Participants gave descriptions of their healthcare experiences which provided answers to the research questions. Three overarching themes were identified which illustrated the sentiments and overall approach of participants towards seeking healthcare while living and traveling in RVs in the United States. Combinations of personal attributes and external factors that helped or hindered RVFANs to access healthcare influenced the participants' overall experiences. Participants' descriptions of specific barriers and facilitators to healthcare access provided the answer to research questions two and three. Barriers and facilitators to healthcare access correlated with nine of the theoretical concepts of LCMAH. The next chapter will focus on the importance of the findings, situate the findings within the existing body of knowledge, and discuss their implications.

Chapter V: Discussion

RV-dwelling nomads have lived in the United States since the 1920s (Counts & Counts, 2001), but there is little acknowledgement of their existence in healthcare research. Healthcare policies based on assumptions of stationary residency may have unintended consequences for people who are geographically mobile. This study aimed to explore the experiences of recreational vehicle-dwelling full-time American nomads (RVFANs) when seeking healthcare in the United States, and to identify factors that help or hinder RVFANs from seeking care. Discussion of the findings that addressed each research question are presented below.

The key findings of the study included three themes that describe the healthcare experiences of RVFANs: *overwhelming logistics, don't need healthcare, and orchestrating a web of care*. They highlight the complexity of maintaining quality healthcare while traveling. In addition, specific barriers and facilitators to healthcare access were identified within nine constructs of Levesque's Conceptual Model of Access to Healthcare. The results of this study illustrate the importance of collaboration between caregivers and RVFANs to ensure that the healthcare options available to them are appropriate within the context of their lifestyle and resources.

Sample

The sample was socioeconomically diverse; however, some groups were underrepresented. These included people of color, families with children, and young adults. These groups were present at campgrounds, although in smaller numbers. The sample split between male and female participants aligned with research reported from the RV Industry Association (RVIA, 2022). This study sample was comprised of participants who were older (52% were over 55 versus 35%) and included more retirees than was reported by the RVIA (52%

versus 43%). This may have been related to the recruiting strategies that included responding to flyers posted in campgrounds or socializing with the researcher. The investigator observed young people in campgrounds socializing with fellow campers less frequently, and people who were working may have been more reluctant to dedicate their off-hours to research participation. One mother did volunteer for the study, but then withdrew before the interview. She explained that she was concerned about being referred to child protective services due to her unconventional lifestyle. This concern may have dissuaded other families. Future investigators studying families who are nomadic should consider data collection methods that are anonymous as well as confidential.

Counts & Counts reported that "most RVers say they feel young and healthy" (2001, p. 207). While the sample for this study included several participants who reported good health, it appeared to be a sicker sample; with 72% who reported long-term health conditions compared to 43% in the larger Counts' sample (n = 286). Several factors may explain this variation. The two studies had different purposes and designs. Counts & Counts (2001) study was conducted by anthropologists using an ethnographic approach to explore RV dwelling as an alternative lifestyle to traditional retirement. It contained a small amount of information about health, but health was not its main focus. Research flyers for the current study specifically sought volunteers for interviews about healthcare, so may have attracted volunteers who had greater healthcare needs. Three participants reported that they were partially motivated to move into an RV due to difficulty affording housing after incurring large medical debts. It is possible that more people may be choosing the RV lifestyle in this era as an adaptation to the rising costs of healthcare and housing. While this is a possibility, it is one that should be considered with caution as the small sample size of this study (n = 25) and the qualitative design do not support generalizations.

Research Question 1: What are the experiences of RVFANs when seeking healthcare in the United States?

Three main themes were identified which described RVFAN's experiences when seeking healthcare in the U.S.: *overwhelming logistics, don't need healthcare,* and *orchestrating a web of care. Overwhelming logistics* described the dread that many participants experienced when they considered accessing the healthcare system due to the complexity of finding a match between services and needs. *Don't need healthcare* described nomad's self-reliant avoidance of healthcare based on doubts about the effectiveness of services, barriers to access, or past negative experiences. *Orchestrating a web of care* described the extraordinary efforts that some participants expended to coordinate care linking distant and local providers while on the road.

Underpinning these three themes is the experiential knowledge that maintaining quality healthcare while traveling requires an outsized investment of effort. The healthcare system in the United States is renowned for its administrative complexity, high costs, and inequity when compared to other wealthy nations (Butkus et al., 2020; Crowley et al., 2020; Tikkanen & Abrams, 2020). These challenges are exacerbated when geographic mobility is superimposed. Americans who are nomadic must coordinate healthcare from their established providers at a distance, or navigate varied cultural norms, rules, and regulations at multiple sites to access healthcare at temporary locations. Barriers to healthcare portability disproportionately affect Americans who are nomadic.

Some similarities were noted in themes developed from a study of the healthcare experiences of Grey Nomads in Australia (Calma et al., 2018). The theme *experts on the road,* identified by Calma et al. (2018), is similar to *orchestrating a web of care* in that both emphasize the importance of taking responsibility for identifying healthcare needs and managing one's own

healthcare while traveling. Another similarity was noted in the theme *travel for health,* described by Calma et al. (2018). Grey Nomads reported improvement in their physical and mental health when they were traveling. In contrast to RVFANs, Grey Nomads did not describe disengagement from the health system as was reflected in the theme, *don't need healthcare*. This may reflect better healthcare access for nomads in Australia. Although Grey Nomads did report barriers to healthcare access and continuity of care while on the road, their healthcare system ranked higher than America's in access to care, administrative efficiency, equity, and healthcare outcomes (Schneider et al., 2021). It is noteworthy that the sample size in the study examining the experiences of Grey Nomads was smaller and less diverse with regard to age than the sample in this study. In Calma et al.'s (2018) study, thematic saturation was reported after eight interviews with participants who were all in their sixth decade of life.

Australians from the general population who sought care for chronic pain management did report disengagement from the healthcare system. Themes identified in another study on healthcare access that used LCMAH emphasized the complexity of accessing services for chronic pain management and their variable quality and effectiveness (Hopkins et al., 2022). Similarity in the themes identified with the population in the current study may reflect the influence of complexity, and experiences with services of variable efficacy, on perceptions of the value of healthcare. To be motivated to seek something, one must believe that it has value. The second Australian study included 26 participants of all ages, so the difference in themes could reflect the difference in sample sizes and characteristics. Hopkins et al. (2022) reported that some participants reengaged with the health system after a period of disengagement, with increased emphasis on becoming experts in their treatment and advocating for themselves. This conversion was not apparent in the narratives of some disengaged RVFANs, who remained disengaged after

years of nomadism. This may, again, reflect better healthcare access in Australia. It is possible that what RVFANs needed to reengage with the healthcare system was a change in the resources available to them, rather than a change in their intrinsic motivation.

Research Questions 2 & 3: What are the barriers to healthcare access for RVFANs? What are the facilitators to healthcare access for RVFANs?

This discussion of the results that responded to research questions two and three is organized by the correlating concept within LCMAH. After telling stories about their healthcare experiences, RVFANs were asked several questions that correlated with specific concepts in the model. This improved the thoroughness of the investigation, although it may have altered the emphasis of the resulting themes. For example, some participants did not mention whether they trusted the healthcare system when they relayed their initial stories about accessing healthcare. A subsequent interview question associated with the theoretical concept *ability to perceive*, asked whether they trusted the healthcare system. Some responded instantly, having clearly considered the topic prior to the interview. Others waffled, saying they did, then they did not, or vice versa. This illustrated the mixed benefit of using a theoretical model in exploratory research, since participants who did not feel strongly about the trusting the healthcare system would have been unlikely to initiate conversation about it, resulting in its appropriate absence from the resulting themes. Participants' emphasis or uncertainty was considered in the analysis of the data.

Overall, the researcher felt that the model was useful because the deductively based interview questions triggered participants to share more information. Several participants shared multiple stories about accessing healthcare which resulted in longer interviews and yielded more information. In addition, the researcher anticipates that organizing the discussion of barriers and

facilitators by theoretical concept may prove useful in application for future researchers who want to quickly find results related to a specific concept.

Approachability & Ability to Perceive

The barriers reported by participants in the area of approachability and ability to perceive included difficulty finding and vetting healthcare resources in unfamiliar locations, and difficulty trusting new providers. The facilitators reported included sources of trusted information such as online health information, online reviews, referrals from locals or RV neighbors with more local experience, flyers at campgrounds, and one campground health fair. The challenges of locating local health services in unfamiliar areas was shared by nomads in Europe and Australia (Calma et al., 2018; McFadden et al., 2018). Nomads in Africa and Europe who experienced ethnic discrimination also reported uncertainty about trusting healthcare services (Gammino et al., 2020; McFadden et al., 2018). Similar concerns about trusting the healthcare system were also reported as a barrier to the ability to perceive in the general population of Americans who live in rural areas (Coombs et al., 2022).

Poor health literacy was described as a barrier to ability to perceive amongst nomads in Africa, Asia, and Europe (Ali et al., 2019; Gammino et al., 2020; McFadden et al., 2018). In contrast, the sample in this study was notably educated and technologically literate. Four of the participants were retired healthcare professionals. While participants did describe challenges in navigating the healthcare system, this was more likely an attribute of the complexity of the U.S. healthcare than poor health literacy in participants. Considering the added complexity of navigating the healthcare system while in motion, RVFANs may benefit from some of the same interventions that have been used in nomadic populations abroad, such as community health workers (Ali et al., 2019; McFadden et al., 2018).

Campground outreach from local healthcare facilities was appreciated by RVFANs but was rarely reported. Truck stops cater to the needs of frequent travelers. Lalla-Edward et al. (2017) reported that wellness centers located in travel corridors were a successful form of outreach for mobile populations in South Africa. Ali et al. (2019) reported that mobile clinics were useful to address basic health needs for nomads in Africa. Vulnerable populations in the United States have used mobile clinics have been used for illness prevention and treatment (Coaston et al., 2022). Coaston et al. (2022) reported that mobile clinics improved chronic disease management for vulnerable populations and reduced costs by reducing ER visits. There was no reference to nomadic mobility. Hence, it is unclear whether any mobile clinics have targeted RVFANs. Mobile clinics were suggested by participants in this study as a form of healthcare outreach that *would* be useful, but no participant reported experience with existing mobile clinics.

Acceptability & Ability to Seek

Lack of empathy for the nomadic lifestyle was a barrier to the acceptability of healthcare services in the United States. Participants noted that some caregivers could not comprehend that they traveled full time, and instead assumed that they were either homeless or on vacation. Although these assumptions could present barriers to the acceptability of services, they were sporadically experienced and were not comparable in magnitude to the racial or ethnic discrimination reported by nomads in Asia, Europe, and Africa (Ali et al., 2019; Aziz et al., 2015; Gammino et al., 2020). McFadden et al. (2018) noted that Roma in some European countries were asked to use segregated medical facilities. In Pakistan, nomadic peasants were excluded from public spaces based on their caste (Aziz et al., 2015). These groups were less able to seek care due to their social exclusion. In contrast, RVFANs in America and Grey Nomads in

Australia are members of the majority culture who have opted for an alternative lifestyle. Although lack of understanding of their lifestyle influenced the acceptability of care, they were not excluded from seeking care. Although several participants expressed concerns about the attitudes of some of the caregivers they had encountered, most also described finding other providers who treated them well. RVFANs sometimes attributed negative attitudes to the office staff who controlled access to their providers.

Participants described caregiver knowledge of the nomadic lifestyle as a facilitator to acceptability. RVFANs reported that providers that were familiar with the nomadic lifestyle were more likely to treat them like any other patient and to be willing to collaborate with them to design plans of care that aligned with their lifestyle. Increasing the body of knowledge about nomads' experiences in the healthcare literature may help to familiarize a larger number of providers with the nomadic lifestyle and improve the healthcare experiences of nomads. It could also improve the caregiving experiences of providers by increasing their confidence working with this population. Additionally, it may be useful to disseminate education on the nomadic lifestyle through formats that are readily accessible to clinical staff who control access to providers.

Availability and Accommodation & Ability to Reach

Barriers to availability and accommodation and ability to reach included limited rural healthcare resources, the mismatch between appointments offered and dates of travel, distant social support, and disconnection from the grid. Facilitators included the use of smartphones to connect with the grid, transportation insurance, and the mobility that enabled some participants to plan their routes to areas where resources were available.

Challenges with resources in rural healthcare facilities were documented in the literature in every region, including the U.S. (Ali et al., 2019; Aziz et al., 2015; Calma et al., 2018; Coombs et al., 2022; Erdenee et al., 2017; Gammino et al., 2020 Rural Health Information Hub, 2022). The failure to account for seasonal nomadic movement creates a burden for rural facilities during population surges (De Bellis et al., 2021; Gammino et al., 2020; McFadden et al., 2018; Rural Health Information Hub, 2022). A white paper that examined the impact of seasonal population variation on rural healthcare in the U.S. confirmed that counts were unreliable and that estimates of the winter population in Quartzsite, Arizona (year-round population of 3,400) ranged from 250,000 to 2 million (Office of Rural Health Policy, 2006). The Office of Rural Health Policy (2006) noted that many of the visitors accessed healthcare elsewhere, nevertheless, there was a strain on emergency services during peak season. It is necessary to have adequate counts that reflect seasonal variation in population to accommodate dissemination and planning of healthcare resources. Mobile phone data has been used to track population movement related to the spread of infectious disease (Lai et al., 2019; Turner Lee et al., 2020). Perhaps this technology could also be used to facilitate distribution of resources to rural facilities that accounts for the movements of nomadic populations. In addition, De Bellis et al. (2021) suggested that the use of telehealth could reduce the burden on rural facilities by enabling Grey Nomads to manage their care through their home clinics while traveling.

While some of the participants in this study had learned techniques to manage their care on the road such as using smartphones to pinpoint their location for emergency services, others were not familiar with the resources and techniques that were available, or they faced barriers to using them. Disseminating information to nomads about strategies and resources for coordinating care on the road could improve the ability of this population to plan for care of anticipated needs

in areas with greater resources. This could improve healthcare experiences not only for RVFANs, but also for rural residents in areas that experience large seasonal variations in population.

Affordability & Ability to Pay

Reported barriers to affordability and ability to pay for healthcare included high costs of care, the costs of travel, the costs of campgrounds for RVFANs who had to wait for appointments, and insurance policies that limited payment for care provided outside of the coverage state. Facilitators to affordability and ability to pay included obtaining nationwide insurance coverage, purchasing multiple insurance policies, and finding discounts on care.

In Counts & Counts' ethnographic study of RVers, they reported, "most Americans do not seem to worry much about the cost of healthcare" (2001, p. 207). America has the most expensive healthcare in the world (Tikkanen & Abrams, 2020), so it was not surprising that most of the participants in the current study were worried about medical costs. Per capita healthcare spending has increased substantially since the 1990s, when Counts' study was conducted (Telesford et al., 2023). This reinforces the necessity of maintaining a current body of knowledge about the concerns of this population. While participants in this study were not asked to specify their income level, substantial variations in affluence were apparent among the participants. Some participants described cost concerns as an annoyance while for others they were a major source of stress and a reason to defer care.

An interesting finding in this study was that people under the age of 65 were more often concerned about the cost of care than people over the age of 65. Although they had more maladies, participants over the age of 65 were more likely to have nationwide insurance coverage or multiple insurance policies. The Affordable Care Act was successful in reducing the

number of people without insurance, however, many state marketplaces do not carry nationwide policies (Norris, 2022). Some participants reported that nationwide insurance policies were available, but they were prohibitively expensive. The predominance of state-bound insurance policies in the marketplace disproportionately limits healthcare access for nomads. Participants whose out-of-state insurance coverage was limited to emergencies described postponing their care until they felt that it was appropriate to go to the emergency room. This study has illuminated an area of inequity that necessitates further inquiry and advocacy. Although nomads in other countries also reported difficulty with cost of care and with purchasing insurance, they did not describe insurance coverage that was limited by region (Ali et al., 2019; Aziz et al., 2015; Gammino et al., 2020).

Participants described finding discounted healthcare as a form of luck that depended on the happenstance meeting of caring people with insider knowledge. A few participants reported that insurance brokers were essential to helping them obtain appropriate insurance coverage, but their use was not widespread. RVFANs lack of knowledge about existing resources illustrates the need for improved dissemination of information regarding financial aid and other programs that ease the burden of payment for care. A few participants suggested that community health workers would be helpful to assist RVFANs to navigate the healthcare system. Yu et al. (2017) supported the recommendation for employing community health workers to improve access to healthcare for vulnerable populations. Since RVFANs face disproportionate barriers to healthcare access that are not widely understood, the use of RV-dwelling community health workers is a solution that deserves further exploration.

Appropriateness & Ability to Engage

Barriers to appropriateness described by participants included difficulty accessing medical records and administrative issues with refilling prescriptions. Appropriateness of healthcare was facilitated when participants were able to maintain relationships with providers who agreed to collaborate with them to build plans of care that aligned with their travel. Telehealth was a facilitator that helped participants maintain those relationships, unfortunately, it was not available to all participants. Some participants reported that their providers were restricted from caring for them across state lines. Similar barriers to healthcare portability that detracted from the appropriateness of healthcare were reported by nomads in Africa, Europe, and Australia (Calma et al., 2018; Gammino et al., 2020; McFadden et al., 2018).

Participants who were engaged advocates for their healthcare described a number of tools that were helpful to coordinate care on the road. Other participants were unaware of their strategies. Collaboration with a provider who was willing to accommodate the nomadic lifestyle was key for the function of their webs of care. Strategies for orchestrating the web of care should be shared with the healthcare community and with other RVFANs.

Barriers to healthcare portability such as lack of access to medical records, prescription transfers, and telehealth disproportionately impact continuity of care for people who are geographically mobile. The participants in this study who had access to telehealth were grateful for the ability to stay connected with their trusted providers across geographical distances. De Bellis et al. (2021) reported that Grey Nomads' use of telemedicine also increased during the pandemic. Several participants in this study were concerned about the potential of losing their access to telehealth after the pandemic. For nomads, the absence of telehealth meant postponing care or seeking care from unfamiliar providers in multiple locations. The importance of

telehealth for maintaining primary care in underserved and vulnerable populations, including rural populations in the U.S. has been reported, and researchers have advocated for addressing the licensure, coverage, and reimbursement barriers that restrict its use (Coombs et al., 2022; Turner Lee et al., 2020). Bailey et al. (2021) noted that the most effective telehealth programs were designed to be culturally appropriate in coordination with the populations they intended to serve. There is a need for further research to design and test programs of telehealth that are suited to the needs of RVFANs.

Lack of political advocacy was a barrier reported for nomads internationally (Ali et al, 2019; Marchi, 2010). The World Health Organization's definition of universal health coverage indicated that healthcare services should be available where and when they needed (World Health Organization, n.d.). Barriers to healthcare portability often restrict healthcare services to locations where nomads are not located. Healthy People 2030 aims to improve the number of Americans who receive high quality primary care (ODPHP, n.d.-c.), however barriers to healthcare portability prevent continuous primary care relationships for people who are mobile. One participant in this study mentioned concern about the lack of political advocacy for nomads in the U.S., but it was not a common theme. Perhaps it should have been. The absence of discussion about nomads in the health literature in the United States is conspicuous and indicates that this population could benefit from more advocacy with decision-making bodies. Decisions about the rules and regulations that prevent the portability of healthcare in the U.S. should be made with consideration of the barriers that they present to this population of Americans.

Limitations

This study was exploratory in nature and qualitative in design. The methods were designed to facilitate the depth of responses. The study design and sample were not appropriate

for generalization of findings or for drawing conclusions about causation, or the incidence of specific phenomena within the population of RVFANs. RVFANs are a diverse group. Although the goal of interpretive description is to identify shared experiences, the uniqueness of individual RVFANs should also be considered (Thorne, 2016).

Participants were recruited at multiple campgrounds ranging from free public lands to expensive resorts in six states, and at one large social gathering. Recruiting from multiple locations was a strength of the study because it increased the socioeconomic and cultural diversity of the sample. However, personal attributes that made people more or less likely to volunteer may have affected the findings. Some exceptions from the sample were identified that limit the transferability of results. Only one participant was traveling with a child. Adults under the age of 40 were underrepresented. Although race was not asked, none of the participants appeared to be a person of color. None of the participants used a healthcare sharing plan for their medical expenses. In addition, the investigator noted some difference in discourse between nomads she met in Texas compared to those in the more western states. The focus of the study on western states may limit the transferability of findings to RVFANs who dwell in other regions.

The principal investigator's personal biases could have affected the results. The principal investigator had worked as a registered nurse for over twenty-five years. Although she had thirteen years of experience with nomadic travel as a contract nurse, she was relatively new to RV culture. Bias may have been introduced by her etic perspective. To reduce the impact of bias, the researcher lived and traveled in an RV for six months (Emerson, 2011; Tracy, 2020). Interviews were recorded and transcribed verbatim and the investigator wrote regularly in a reflexive journal (Polit & Beck, 2017). Three personal biases the investigator identified included

the belief that traveling is a desirable activity, that access to healthcare is beneficial and desired, and that culturally appropriate healthcare is a human right. When these topics were discussed or reviewed in the data, the investigator paused to reflect on her biases to avoid misconstruing participants' meaning. In addition, member checking was completed near the end of each interview in which the investigator reviewed initial impressions and asked the participant whether they were correct (Polit & Beck, 2017). On several occasions, participants responded by providing more clarity. Lastly, the investigator met on two occasions with a researcher who was an expert in qualitative research for peer debriefing. Feedback was obtained on the codebook, on emerging themes, and on the analysis process.

There was a risk of social desirability bias. To present this, the researcher encouraged participants to choose interview sites where they felt the most comfortable speaking openly without others overhearing (Bergen & Labonté, 2019). In addition, she used self-disclosure to build rapport, used probes to clarify information, and attempted to create a nonjudgmental atmosphere by providing assurances that there were no wrong answers to the interview questions (Bergen & Labonté, 2019; Polit & Beck, 2017).

Implications

The study findings have implications for practice, education, and policy. The dissemination of new knowledge about the healthcare experiences of American nomads will enable nurse practitioners and direct care nurses to familiarize themselves with the stress and complexity that RVFANs face when seeking healthcare and may increase empathy in caregivers. Nurses and other healthcare professionals could test strategies to improve their outreach to nomads by disseminating information about healthcare services in locations that cater to nomads such as campgrounds and truck stops. They could consider the barriers and facilitators that were

identified to construct plans of care, in collaboration with nomadic patients, that are safe and effective within the context of the nomad's travel plan and their available resources. Direct care nurses have a unique perspective, at the intersection between patients and healthcare professionals from many disciplines, which facilitates observation of the impact of implementation of healthcare practices on patients' lives (Risjord, 2010). They could use the information about RVFANs to identify facility rules and norms that may fragment care for nomads by forcing them to seek care from other providers, such as lack of appointment availability or limits on telehealth. Improving caregivers' empathy, outreach, and collaboration with nomads may reduce nomads' risk of disengaging from healthcare, which could improve nomads' health and supplement progress towards achieving public health goals. Two participants offered simple suggestions for clinicians to consider to facilitate collaboration with nomads: ask nomads how long they plan to be in the area, and whether there is any reason that the plan of care that is being recommended might not work for them. It will be important for educators to disseminate information to support clinicians to improve nomad's healthcare experiences.

The study results have implications for clinical and academic educators. Participants in the study reported that caregivers' understanding of the RV lifestyle impacted their willingness to collaborate on plans of care. Caregivers at all levels of responsibility, from the front office staff to licensed professionals, impacted their experiences. Educators in academic and clinical settings could include information about the healthcare experiences of American nomads when discussing cultural considerations for care. The findings support the importance of educating current and future clinicians on strategies for coordinating care for geographically mobile people such as the use of telehealth, the remote management of prescription medications, and the options of providing prescriptions for diagnostic tests and specialty referrals that can be accessed

at distant sites. Addressing policies that present barriers to the portability of healthcare will facilitate the application of the education.

Participants identified multiple healthcare policies that presented barriers to healthcare access for people who are seeking care away from their domicile, such as state-based insurance policies, barriers to medical record access, barriers to telehealth care, and barriers to transferring prescriptions. It is important for decision-making bodies to consider the impact of their decisions on people who are geographically mobile. Regulations that have a positive intent, such as preventing prescription drug abuse, may have negative unintended consequences, i.e. preventing people from maintaining continuity of care for mental health conditions when they are traveling. These findings suggest that political advocacy is needed to reduce barriers to care for nomads. Nurses and other clinicians who are informed about nomads' challenges can advocate for legislation that promotes healthcare portability in ways that are safe, effective, and cost-efficient. More knowledge is needed to support practice, education, and advocacy with this population.

Recommendations for Future Research

This study has demonstrated that accessing healthcare is complicated and can be stressful for American nomads. RVFANs experience barriers and facilitators to healthcare access, some of which are unique to this population and some which are likely to affect them disproportionately. Future study could include recruitment strategies to add knowledge about specific segments of the RVFAN population that were not represented here such as families with children, people of color, young adults, and nomads in other regions of the country. The scope of the problem could be better understood by enumerating the population and describing their demographics to include their health status and the incidence of illness and injury that this population experiences compared to the general population. In addition, some participants suggested that nomadism was

an adaptive strategy for coping with illness. This needs further investigation. Quantitative study could support prioritization of interventions by determining which of the identified barriers or facilitators are the most common, the most impactful, or the most feasible to address. Mapping of major travel corridors could generate knowledge that would be used for multiple purposes such as determining the best places and seasons to situate healthcare services or information for nomads, or examining the impacts of nomadic movements on healthcare facilities.

Wang et al. (2016) advocated for the study of healthcare outcomes based on a typology of mobility. This study provided information about the healthcare experiences of people who have adopted one type of mobility. Future studies could investigate other types of geographical mobility and their impacts on healthcare outcomes. National health surveys such as those used by the Agency for Healthcare Research and Quality could be replicated with geographically mobile populations to measure disparities in health or healthcare outcomes by mobility type. Development of a typology of mobility combined with the inclusion of a mobility variable in public health surveys would yield a rich source of ongoing information about this population and contribute to their inclusion in healthcare conversations.

Conclusion

For decades, America has housed a sizable population of people who live nomadic lifestyles. Their numbers are growing. This is the first study dedicated to exploring the healthcare experiences of recreational vehicle-dwelling American nomads (RVFANs). The study illustrated that accessing healthcare is a complex and sometimes frustrating process for RVFANs. Some RVFANs disengage from the healthcare system and others exert extraordinary effort to coordinate care. Barriers to healthcare portability give people who are geographically mobile a disadvantage when seeking healthcare. Creative RVFANs have collaborated with caregivers to

orchestrate plans of care that accommodate their movement, however, these practices are not widespread. Many nomads are offered a standard fare of care without accommodation.

The barriers and facilitators to care experienced by American nomads bear striking similarities to the experiences of nomads in other countries, in particular the Grey Nomads in Australia. A notable difference between the groups is the conspicuous absence of nomads in the healthcare literature in America. Existing bodies of research about the healthcare of nomads in Australia, Europe, Africa, and Asia are an asset for those who hope to improve healthcare experiences for nomads in America. Nomads across countries experience similar barriers to healthcare portability, although they live in different cultural contexts. Interventions that have successfully improved healthcare access for other nomadic populations may also be helpful for RVFANs in America, with adaptation to the cultural context. The application of telehealth to improve the health of nomads is understudied considering widespread smartphone use and technological literacy amongst nomads. Since nomads spend most of the year traveling they are disproportionately affected by limits to healthcare portability, but rural populations and short-term travelers may also experience healthcare needs when they are distant from their trusted providers.

Addressing barriers to healthcare access for RVFANs has the potential to improve care for other Americans such as rural populations, and short-term travelers. Rural healthcare resources are strained by the failure to account for seasonal population variation. Mapping seasonal population changes may facilitate the distribution of healthcare resources that provide an appropriate match to seasonal needs. Removing barriers to healthcare portability could reduce the strain on rural health resources and promote the effectiveness of care for nomads and short-term travelers. Rural people with stationary residences that are remote from their trusted

providers may also benefit from improved access to telehealth. Improving healthcare access for RVFANs has the potential to help the U.S. meet its public health goals by not only by improving healthcare access for nomads, but by also addressing challenges that are shared by rural populations and other people who travel. It is time that the experiences of geographically mobile people are considered in public health conversations in America and that administrative barriers to healthcare portability are addressed.

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Appendix A

Semi-structured Interview Guide for RVFANs

1. To begin, I will ask a few questions to determine whether you are eligible to participate in this study.
    a. What is your age? (< 18 not eligible)
    b. Do you live in your RV for more than 6 months of the year? (< 6 months not eligible)
    c. Are you a local RV resident, someone who lives in an RV for most of the year in the local area; a seasonal migrant, someone who returns to the same locations seasonally; or a nomad, someone who makes ongoing temporary moves to different regions? (Only nomads eligible)
    d. How long have you been a nomad? (< 1 year not eligible)
    e. What is your nationality? (Only Americans included)
    f. If person is not eligible, they will be thanked for volunteering and the interview will not proceed.
2. If the volunteer meets the eligibility criteria, the consent will be discussed here.
3. Rapport building: I became interested in studying the health experiences of nomads because of my own travels. I grew up traveling with a military family. Then I spent thirteen years as a traveling nurse before landing in Boise, Idaho. Since then I have enjoyed traveling in my RV. Observing my fellow RV travelers led me to wonder how they obtain healthcare.

4. To begin I would like to learn a little about you and your lifestyle. How many months of the last year did you spend living and traveling in your RV? (#4 through 15 will only be asked if the answers have not been revealed in casual conversation).
5. Who do you travel with?
6. Can you describe your RV?
7. Can you describe your travel patterns?
8. How often do you move?
9. Where do you prefer to camp?
10. Do you have a home base or domicile?
11. Which state is it in?
12. How did you choose where to establish your home base or domicile?
13. What was the highest level of education that you completed?
14. Do you work for financial gain?
15. What kind of work do you do?
16. Take a few minutes to reflect on a time in the past couple of years when you needed healthcare. Can you walk me through your experience?
17. (Follow up questions to explore factors mentioned by interviewee that could represent barriers to access. Follow up questions on factors that could represent facilitators to access.)
18. Appropriateness: how would you describe the quality of the health services that were offered?
19. Engage: How did the healthcare providers involve you in making decisions about your treatment?

20. How do you think this experience was different than it may have been if you had not been traveling?
21. Perceive: Do you trust the healthcare system?
22. Acceptability: If healthcare were designed specifically for RV-dwelling nomads, how would it be different?
23. Acceptability: What assumptions do you think healthcare professionals make when they learn that you are nomadic and live in an RV?
24. Pay: What kind of insurance do you have?
25. Perceive: Do you have any long-term health conditions that you manage while traveling?
26. Approachability, to seek: Who do you reach out to first for questions about your health or healthcare?
27. Do you have a primary care provider?
28. Availability & accommodation: If so, does your primary care provider offer remote consultations by telephone or online?
29. Appropriateness: Does your primary care provider help you to coordinate care that you receive in other places?
30. Affordability: Are there times when you have skipped healthcare visits or prescriptions due to cost?
31. Affordability: Have there been times when your insurance did not pay for services that you expected they would pay for?
32. What information do you think healthcare professionals need to provide the best care to nomads?

33. What information would you like to share with new nomads to help them obtain the best healthcare?
34. Member checking: It sounds like … helps you to obtain healthcare. It sounds like … makes it more difficult to obtain healthcare. Is my understanding correct?
35. Is there anything you would like to share with me that we have not talked about yet?
36. Do you know of any other RV-dwelling full-time nomads who may be interested in participating in this study?
37. I would like to speak to nomads who have had diverse experiences with healthcare. Is there anyone you could recommend that might have had a different experience?
38. How would this person be most comfortable being contacted?
39. Do you think they would they prefer it if you reached out to them or should I?
40. Thank you for taking time out of your day to participate in this study. To compensate you for your time I would like to give you a 10$ gift card for Starbuck's. The information you have provided will remain confidential.