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## Examination of Access, Utilization, and Barriers to Care Among Special Populations in the United States

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**EXAMINATION OF ACCESS, UTILIZATION, AND BARRIERS TO CARE AMONG SPECIAL  
POPULATIONS IN THE UNITED STATES**

By

**Jed R. Hansen**

A DISSERTATION

Presented to the Faculty of  
the Graduate College in the University of Nebraska  
In Partial Fulfillment of the Requirements  
For the Degree of Doctor of Philosophy

Graduate Nursing Program

Under the Supervision of Professor Kathryn Fiandt  
University of Nebraska Medical Center  
Omaha, Nebraska

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**EXAMINATION OF ACCESS, UTILIZATION, AND BARRIERS TO CARE AMONG SPECIAL  
POPULATIONS IN THE UNITED STATES**

Jed R. Hansen, Ph.D.

University of Nebraska, 2021

Advisor: Kathryn Fiandt, Ph.D., APRN-NP, FAANP, FAAN

Utilizing healthcare services is a complex phenomenon in the United States. While system-level barriers and facilitators of care, along with individual consumer choices, are known to affect access and subsequent use of services, the interaction among the factors that lead to utilization remains unknown. Examining access and utilization of healthcare services using a consumer framework incorporating both access barriers and facilitators and consumer-level dimensions that affect choice in seeking care may inform access and utilization research. The purposes of this dissertation were 1) to explore the presence of facilitators and barriers to care in ambulatory healthcare locations for non-emergent care needs; 2) explore the role and prominence of consumer facilitators and barriers in appointment behavior in a chronic disease population; and 3) explore alterations to access employed by organizations serving a vulnerable population (rural) during the COVID-19 pandemic. The specific aims were 1) to evaluate how patient decisions to use healthcare for non-emergent needs are shaped by access to care barriers and facilitators in U.S. ambulatory healthcare locations; 2) to examine saliency of consumer-driven healthcare utilization concepts that influence appointment behavior among a chronic disease population; and 3) to assess adaptive access strategies and health outcomes in rural Nebraska, specifically as a result of the COVID-19 pandemic. An integrative review of the literature looking at health consumer choices in ambulatory care along with a secondary data analysis of appointment behavior among emerging adults with type 1 diabetes from an

endocrinology clinic informed the background and theory development of the consumer model of utilization (CMU) presented in this dissertation. A cross-sectional descriptive study of rural healthcare professionals, informed by the CMU framework, identifying adaptive access strategies and examining associations between strategies utilized during the 2020 COVID-19 pandemic, community characteristics, and health outcomes of rural populations in a midwestern state were reported. Primary results from the integrative review suggest that utilization of ambulatory services is influenced by multiple, interconnected consumer-centric variables. Incorporating the consumer-based variables of the CMU; cost, comfort, convenience, capacity, and criticality, may provide insight into the understanding of access and the subsequent utilization of ambulatory services. Descriptive statistics and bivariate analysis were used for the rural COVID-19 survey and outcomes study. Alterations in access to increase comfort through safety were implemented by most organizations (91.3%), followed by convenience (81.3%), capacity (62.5%), cost (20%). Criticality was not measured. When looking at Q4-2020 in Nebraska, the height of the pandemic, rurality was significantly associated with fewer cases of COVID-19 ( $p=0.00$ ) and greater numbers of death ( $p=0.02$ ). The relative risk of death for rural residents compared to urban was 1.205 (95% CI 1.05 – 1.383). Associations between adaptive access strategies and COVID-19 outcomes were examined, but relationships were not observed.

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## **CHAPTER I: INTRODUCTION**

### **BACKGROUND**

Access to healthcare services has long been viewed as a complex and pervasive problem in the United States (U.S.) (Millman, 1993). U.S. health consumers rely on a complicated system of private and public insurance to gain affordable entry into ambulatory healthcare centers like primary care provider (PCPs) offices, urgent care clinics (UCs), and emergency departments (EDs). Challenges in affordable access, through insurance, often disrupt the utilization of PCPs, the ideal source for high-quality, lower-cost care (Friedberg et al., 2010). A shift away from PCPs toward alternative locations such as EDs, and to a lesser extent UCs, is considered a major driver for cost and spending increases in the U.S healthcare system (UnitedHealth. 2019).

In addition to the financial challenges present, non-financial reasons among distinct regional, geographical, and demographical groups can alter access and utilization for different individuals, populations, and communities. Transportation, distances between home and healthcare locations, clinic hours, and cultural differences are particularly challenging barriers in rural communities and for vulnerable populations in all communities and have been previously observed to affect use of service. (Tekesta et al., 2019; Benitez & Seiber, 2018; Siberholz et al., 2017). While non-financial access issues may not always create the hard barriers to care associated with cost, they may be just as pervasive and impactful in delaying care (Kullgren et al., 2012).

Although multiple theories on access have been proposed and studied over the past 50 years (Rickets and Goldsmith, 2005), a dearth of knowledge exists regarding the interaction between access components and the interactive effect of access components on utilization. As a result of these knowledge gaps, evidence-based strategies designed to improve access and

result in positive outcomes by U.S. healthcare systems continue to be elusive. Over the past decade primary care appointments have decreased over 30% while EDs, UCs, and retail clinics all saw increases (Chou et al, 2019; Poon et al, 2018). The over-utilization of high-cost services (i.e., ED usage) was observed to increase at the highest rates by those individuals most able to choose where they receive care (Greenwood-Erikson & Kocher, 2019). Estimates from 2018 indicate as many as 18 million avoidable visits to the ED occurred in the U.S., costing insurers over \$32 billion annually (UnitedHealth, 2019). Therefore, the complex relationship between access and utilization in ambulatory care settings needs to be better understood. As such, the overall purpose of this dissertation is to examine access and utilization of ambulatory care from a comprehensive theoretical framework.

### **Access and Utilization of Healthcare**

Access, barriers to access, and utilization of services are well studied in classic and contemporary literature. Access research gained popularity in the 1970s and early 1980s with work on the subject understood as a *component of utilization* (Donebedian, 1972) and *consumer satisfaction* (Penchansky & Thomas, 1981). Academic work on utilization, most notably by Aday and Andersen (1974), theorized access and healthcare utilization were a result of a healthcare consumer's *environmental, population, and health behavior* factors.

The National Health and Medicine Division (HDM), formerly the Institute of Medicine, along with HealthyPeople 2020, a federally comprised inter-agency group, have more recently recognized access as having three distinct, yet interrelated components: gaining access into the system through insurance (cost), having services located in a geographically available location (convenience), and having a health care provider that is trusted (comfort) (HealthyPeople 2020, 2019; Millman, 1993).

Factors influencing utilization of healthcare services goes beyond the factors influencing access. Utilization of healthcare requires a perceived need to receive care, knowledge of the need and how to obtain care, and the ability to access services to address the need (National Academies of Science, 2018). Therefore, utilization of a service depends on the intersectionality of the three access tenets laid out by the NDM that influence health consumer use of services (cost, convenience, and comfort) and adds the ideas of perceived criticality of a health need and the capacity to act.

Understanding all components of healthcare access and utilization is essential to better understand what helps and hinders the use of ambulatory healthcare services and the choice in location to receive services made by individual consumers. Perceived criticality of an event, the relative feeling of acute need, has previously demonstrated to affect where consumers seek care, particularly in EDs (Pearson et al., 2018). Additionally, capacity of an individual, specifically an awareness of disease, services, and ability to act in relation to healthcare, has been observed as influencing when and where care takes place (Wayment et al., 2020). Increased understanding in how criticality and capacity, along with how a location's access characteristics (cost, relative convenience, and comfort), influence utilization may improve insight of consumer healthcare choices and support effective strategies for optimizing efficient and effective access and utilization of healthcare.

### **Facilitators and Barriers**

Several theoretical models exist designed to explain facilitators and barriers to access and utilization. (Ricketts and Goldsmith, 2005). Andersen's model of healthcare utilization (1995) is often cited, see Figure 1. Most published works on the Andersen theory focus on population characteristics, those predisposing factors, enabling resources, and needs that influence healthcare use as facilitators and barriers (Babitsch et al., 2012). Although important

in understanding access and utilization, the attention paid to Andersen's demographic component, specifically, population characteristics, instead of a focus on behavioral drivers, specifically, environmental, health behavior, and outcome variables have meant that science has mostly focused on population-level barriers, and not on facilitators or individual barriers and facilitators. In other words, the application of Andersen's model has focused on, as examples, race, household income, and formal education, i.e. non-modifiable variables, and much less on the personal consumer reasons each person makes, as examples, comfort with a healthcare team, relative cost between services, and ability to make an appointment during convenient hours. Thus, leaving an important knowledge gap on the consumer-behavioral reasons for utilization of healthcare services.

Penchansky and Thomas (P&T) proposed a model, the 5 A's to Access, that links health consumer satisfaction and access to care. Often used, but to a lesser extent than Andersen, the P&T model, noted in Table 1, describes the fit between a health care service's availability, accessibility, affordability, accommodation, and acceptability and a health consumer's needs. The P&T model has been useful in describing barriers at an individual level. However, the relative ambiguity between P&T terms has created confusion on how to apply the model as first hypothesized (Saurman, 2016). Misalignment in studies resulting from the ambiguity of the P&T concepts include cases where terms are mislabeled, excluded, or both. Mislabeling terms would lead to obvious issues with results of a study with outcomes being incorrectly attributed to the wrong variable. An example of mislabeling would be in a study when the operational use of two or more terms, such as availability and accessibility, are switched. Exclusion of any P&T concepts would hinder a study's analysis as well with potential confounding variables making it difficult to fully decipher results. Moreover, exclusion of one of more concepts in a study reduces the ability to study the interrelated nature each access concept has on the other. An example of

excluding terms in a study would be using just two of the concepts, such as availability and accessibility, and not using the other concepts, affordability, acceptability, and accommodation. Because of its ambiguity, with issues of mislabeling and exclusion, the value of P&T as the sole conceptual model for understanding utilization and access to health care is limited.

### ***Redefining Facilitators and Barriers***

A conceptual model adapting synthesized components from P&T and informed by Andersen (1995) and the concept of convenience from Berry et al. (2002) is presented in Chapter 3. The conceptual model, the Consumer Model of Utilization (CMU), as presented, includes five consumer utilization concepts and are discussed as antecedents, both facilitators and barriers, in appointment behavior. Below are the synthesized concepts explored in this dissertation:

**Cost.** The relative financial impact of consuming a healthcare service by a consumer.

**Convenience.** The level of effort required to obtain a healthcare service by an individual.

**Comfort.** The belief an individual has in a healthcare professional, team, or organization to meet their needs and providing safe, effective care.

**Capacity.** The ability an individual has in understanding their health needs and how to obtain help.

**Criticality.** The perceived acuity of a health event or health need experienced by a consumer.

The exploratory use of the CMU in this dissertation uses components of the major theories on access but also leans into the HDM/HealthyPeople 2020 idea of access briefly discussed previously. Blending theoretical and conceptual ideas from dominant academic works of Andersen and P&T with modern institutional observations on access highlighted by HDM will

provide a nuanced approach that explores access, facilitators and barriers to access, and utilization, as a whole, that warrants scientific exploration.

### **Access, Utilization, and Vulnerable Populations**

In this dissertation, access and utilization of healthcare by two specific and different vulnerable groups were studied - emerging adults (EA) with type 1 diabetes and rural Americans. While not affected with the same types of access issues, both populations are known to have health consequences impacted by reduced access and utilization of services (Liese et al., 2019; Fortin et al., 2016; Douthit et al., 2015).

#### ***Access and Utilization Among EAs with Type 1 Diabetes***

Type 1 diabetes is a chronic condition with an average age at diagnosis between 12 – 14 years (Katsarou et al., 2017). Requiring a lifelong commitment to disease management, for most youth, initial diabetes management occurs in pediatric clinics with responsibility for coordination handled by a parent. As persons reach adulthood, responsibility of the care moves to the individual (Hanna, 2012). Included in the responsibilities is attending regular appointments.

Regular participation in health care, particularly clinic appointments, for emerging adults (EAs), those individuals between 18 – 30 years (Arnett, 2016), has been shown to improve long-term health outcomes throughout the lifespan (Fortin et al., 2019). However, emerging adulthood has shown to be a difficult period for individuals to manage their care (Fisher et al., 2018), including appointment attendance. Evidence suggests both clinical access characteristics and individual consumer preferences may be responsible for poorer attendance rates (Monaghan et al., 2015, Monaghan et al., 2016, Hynes et al., 2016; Garvey et al., 2014). Factors associated with low attendance within the EA population include a preference towards convenience (McMarrow et al., 2018), establishing a trusting and collaborative relationship with



a new provider (Hynes et al., 2015), and changes in insurance coverage (Buschur et al, 2017). Additional insight, through a consumer-based approach, into the reasons for poorer attendance among EAs with type 1 diabetes may provide additional understanding into the barriers and facilitators to access and utilization of health care experienced by this population.

### ***Access and Utilization in Rural Populations***

In the U.S., rural residents compose about 16% of the total population (USAFacts.org). Rural individuals tend to be older, have fewer financial resources, and experience greater challenges to healthcare access than their urban counterparts (Chartis Group, 2020; Henning-Smith, 2020; Douthit et al., 2015). Each are factors believed to contribute to the poorer health outcomes experienced in rural America (Baradaran et al., 2020). Ambulatory care needs in rural communities are most often managed through a network of critical access hospitals and their associated clinics and EDs, federally designated rural health clinics, and federally qualified health centers. Known barriers to access in rural communities include insurance, workforce shortages, distance and transportation, and health privacy and stigma (Rural Health Information Hub, 2019).

The COVID-19 pandemic has exacerbated both health and access issues for rural residents. During the pandemic, rural residents experienced a disproportionately high number of COVID related deaths and faced shortages in professional staffing and medical equipment. During the early stages of the pandemic many rural clinics and hospitals reduced ambulatory appointments and outpatient procedures as a means of slowing disease spread and freeing up vital resources. To adjust, rural healthcare consumers were asked to rapidly adopt telehealth visits to maintain care. Understanding the totality of changes that occurred as result of COVID-19 and the potential impacts to the health of rural Americans is needed. Application of a consumer-based model to study access and utilization of healthcare during the COVID may

provide insight into the factors that most impacted rural health consumers and provide new knowledge on how to improve utilization once the pandemic subsides.

**Defining Rural.** Definitions of what is and is not rural vary. However, in general, rural communities are characterized as having less population density, low outward commercial or industrial influence, and exhibit some level of geographic remoteness. This dissertation uses the Rural Urban Commuting Area (RUCA) codes to define rural. RUCA codes provide a continuum of urban and rurality and score given areas from one to ten. Codes one to three are classified as urban, four through six as micropolitan, and codes four to 10 are non-urban, or rural. RUCA codes four to ten will be classified as rural, which aligns with other research and federal agency practices (Health Resources & Service Administration, 2021).

### **The COVID-19 Pandemic and Access**

The COVID-19 pandemic has had a profound impact on all facets of U.S. life. Included in the changes, healthcare professionals were asked to make unprecedented changes in access to and delivery of care during the ongoing crisis. Challenges in equitable access continue to mount with increases in uninsured rates due to unemployment (Collins, 2020; Garrett & Gangopadhyana, 2020; Health Management, 2020). Additionally, cancelled elective surgeries (American College of Surgeons, 2020; Centers for Medicare & Medicaid [CMS], 2020), changes in patient intake processes (CMS, 2020), reduced hours of operation, limits to routine care (Lewis et al., 2020), and rapid adoption of telehealth (Koonin et al., 2020) have modified how consumers can access the care they need.

Moreover, the COVID-19 pandemic has altered public perception to receiving care with many Americans delaying services out of concern of risk of exposure to the virus in healthcare settings (Hamel et al., 2020; Henry J Kaiser, 2020). In response, some hospitals and clinics have altered access strategies to increase safety but also to acknowledge changing consumer

sentiment. Some strategies include changing check-in procedures to improve social isolation procedures, increasing telehealth appointments, and stacking well-visits and sick visits during different times of the day (Centers for Disease Control [CDC] , 2020a; Lewis et al., 2020).

Although necessary in response to COVID-19, changes in access may have unknown immediate and future impacts on the health of rural communities due to delayed care.

Along with access and care delivery problems from in-person appointments, a rapid adoption of telehealth occurred (Galewitz, 2020). The swift implementation of remote appointments presented its own issues. Longstanding fundamental challenges exist regarding telehealth delivery including provider training, administrative support, technology, rural infrastructure, licensure and billing, and security that may inhibit delivery of quality care (LeRouge & Garfield, 2013). Whether or not telehealth receives large-scale acceptance following the pandemic is yet to be seen. Regardless, remote health services created new experiences in access.

## **SIGNIFICANCE**

Health disparities due to a lack of access and inappropriate utilization are estimated to cost the U.S. economy more than \$230 billion per year (National Institutes of Health, 2016) and are associated with higher mortality rates among the uninsured (HealthyPeople 2020, 2020; Woolhandler & Himmelstein, 2017). In 2010, the US government passed the Affordable Care Act (ACA) with the intent to improve access through insurability. Since passage of the ACA, the number of individuals obtaining insurance has risen (CDC, 2020b) with 16 million new individuals receiving coverage through 2017 (Agency of Healthcare Research and Quality [AHRQ], 2018a; Henry J Kaiser, 2020). Despite gains made with the ACA, the U.S. ranks last among high-income countries in overall performance on access, equity, and health care outcomes (Papanicolaus et al., 2018; Schneider et al., 2017)

Prior research has indicated insurance alone does not translate into access and utilization of healthcare. Non-financial barriers to care are common, even among the insured (Kamimura et al., 2018; Allen, 2017) and are reported to disproportionately affect individuals that also experience financial barriers (AHRQ, 2018a). Obtaining access and establishing regular care with a medical provider has been shown to reduce health-related costs and improve health outcomes (Phillips & Bazemore, 2010), making access to and subsequent use of non-acute ambulatory care a top health priority in the United States (AHRQ, 2018b; Department of Health and Human Services, 2018; and Robert Wood Johnson, 2018).

Numerous synthesized analyses of studies on access identify multiple system-level access facilitators and barriers that affect consumer choice such as transportation, cost, and convenience (e.g., time) (Vogel et al., 2019; Coster et al., 2017; Kraaijvanger et al., 2016). However, exploration of the relationship between system-level access facilitators, barriers, and individual consumer drivers remains unexplored. This important gap in the literature has meant that while access has been studied at great length, outcome data suggests little progress has been made to alter consumer behavior to reduce over-utilization of high-cost services like those provided in EDs (Greenwood-Erikson & Kocher, 2019). Moreover, the consequences of the pandemic, and the important work of re-engaging the public in preventive care, provides a real-time need to better understand the forces that shape utilization of healthcare services.

*This research is significant because it will provide unique insight into identifying and understanding facilitators and barriers that influence consumer access and utilization of ambulatory care locations and will provide data to guide improved access strategies, increase consumer use of high-quality, low-cost healthcare encounters, and improve patient health outcomes.* Improved access and more appropriate use of high-quality, low-cost health care are projected to improve patient health outcomes.

## **PURPOSE & AIMS**

The purpose of this dissertation was to explore access to care in the United States and to better understand how facilitators and barriers to care influence utilization choices in special populations. As such, this project sought to 1) to explore and describe the state of the science related to the presence of facilitators and barriers to care in ambulatory healthcare locations for non-emergent care needs, 2) explore the role and prominence of consumer facilitators and barriers in appointment behavior in a chronic disease population from the perspective of the consumer model of utilization, and 3) explore alterations to access employed by organizations serving a vulnerable population (rural) during the COVID-19 pandemic.

Therefore, the specific aims used to design this study are:

Aim 1: to evaluate how patient decisions to use healthcare for non-emergent needs are shaped by access to care barriers and facilitators in U.S. ambulatory healthcare locations

Aim 2: to examine saliency of consumer-driven healthcare utilization concepts that influence appointment behavior among a chronic disease population

Aim 3: to identify and explore adaptive access strategies and health outcomes in rural Nebraska, specifically as a result of the COVID-19 pandemic

## **Overview**

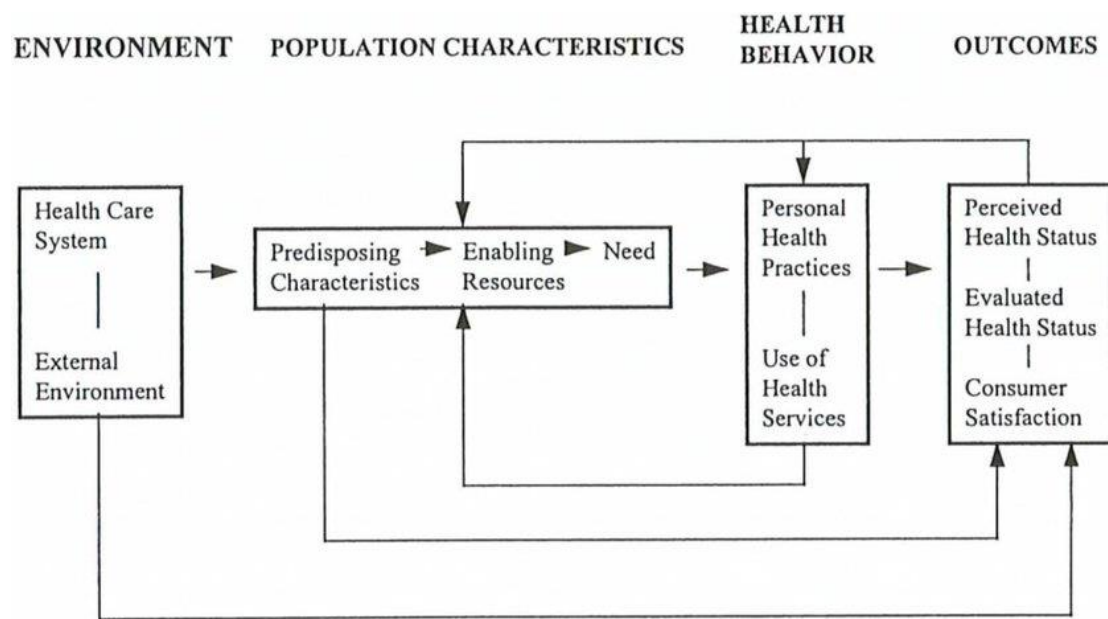
This dissertation has been prepared using the three-manuscript format. To address Aim 1, chapter 2 provides an extensive review of the literature on access to care and the barriers and facilitators that influence choice in ambulatory location for non-emergent care needs using the Penchansky and Thomas access concepts. Findings from this manuscript lay the foundation for concepts explored within the theoretical framework applied later in this dissertation study.

In Chapter 3 a proof-of-concept application of a consumer-based model influenced by, and synthesized from, the P&T access constructs, along with influences from Andersen (1995),

and Berry et al. (2002) is described. The manuscript is titled “Framing Facilitators and Inhibitors in Appointment Behavior Among Emerging Adults with Type 1 Diabetes: A Secondary Data Analysis.” Findings from this manuscript support Aim 2 and suggest that consumer utilization concepts may influence appointment behavior as associated access concepts for routine care in a chronic disease population.

Addressing Aim 3, Chapter 4 describes alterations to access initiated by rural-serving healthcare organizations and explored health outcomes during the peak of the COVID-19 pandemic in the Fall of 2020. The manuscript is titled “Rural Access Strategies and Health Outcomes during the COVID-19 Pandemic: State of Nebraska Case Study.” Finally, Chapter 5 provides an in-depth discussion on the conclusion of the study, including implications for research and practice.

**Figure 1.** The Andersen Model of Healthcare Utilization



(Andersen, 1995)

**Table 1.** Penchansky and Thomas 5 A's to Access

Access Dimension	Definition
Availability	The relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs.
Accessibility	The relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost.
Affordability	The relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance.
Accommodation	The relationship between the manner in which the supply resources are organized to accept clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' ability to accommodate to these factors and the clients' perception of their appropriateness.
Acceptability	The relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of the client.

(Penchansky and Thomas, 1981)



## **CHAPTER II: Manuscript 1**

### Factors Guiding Health Consumer Choice of Service Location for Non-emergent Care: An Integrative Review

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## Introduction

Non-emergent acute care visits in the United States (U.S.) account for over 500 million encounters annually (Chou et al., 2019). Over the last two decades, comparative trends of aggregated visits showing when and where non-emergent visits take place is increasingly diverse. Primary care encounters have dropped by nearly 32%, while emergency department (ED) visits increased by 12% between 2002 and 2015 (Chou et al., 2019). More recent trends have shown an even greater migration of U.S. health care consumers away from traditional clinical encounters and toward alternative care delivery models. Since 2008, urgent care and retail clinics have experienced increases of 119% and 214% visits, respectively. (Poon et al., 2018).

Choice to seek care at locations other than primary care clinics may be driven by both consumer wants and perceived medical needs (Coster et al., 2017; Mehrotra, 2013; and Bachrach et al., 2015). However, the choice regarding where to receive care may not be benign. Concerns have been voiced regarding the overall cost and quality of care resulting from the shift to primary care delivery in ED, retail, and urgent care locations (Villaseñor and Krouse, 2016; Weinick et al., 2010; and Incze et al., 2018). A 2019 industry report by United Healthcare estimated that the cost of performing primary care visits is 16% higher when managed in an urgent care setting and over 1200% higher in an emergency department (UnitedHealth, 2019). Moreover, individuals that receive regular care through primary care have been shown to have lower mortality rates, fewer preventable ED visits and hospitalizations, and improved health outcomes (Phillips & Bazemore, 2010).

Recent literature reviews on non-emergent use of EDs have recognized the role of consumer-based reasons for driving the observed increases in utilization of ED, urgent care, and retail clinics. Findings suggest that a combination of frustrations in primary care access,

perceived quality of care received outside of primary care clinics, along with increased convenience in location, hours of operation, and cost of alternatives to primary care clinics largely contribute to where consumers seek healthcare (Vogel et al., 2019; Coster et al., 2017; Kraaijvanger et al., 2016; Uscher-Pines et al., 2013).

However, positive outcomes based on ED utilization research appear to be absent, particularly among those ablest to choose where they receive care. Between 2005 and 2016, increases in visits to urban EDs were significantly associated with non-urgent visits, adults younger than 65 years, and individuals with insurance (i.e., private or public) (Greenwood-Erikson & Kocher, 2019), signaling a potentially important gap in the literature.

Absent from many literature reviews on ED utilization for non-emergent care is a theory-based approach. Framing current literature through a widely accepted theory may help provide insights not otherwise observed in reviews and, additionally, provide a pathway towards new explanatory models and potential interventions.

Understanding that multiple access models exist (Ricketts and Gold, 2005), this integrative review was carried out to explore the use of the Penchansky and Thomas (1981) concepts as an encompassing model for individual choice in response to access barriers. The Penchansky and Thomas model (1981) (P&T) concept of access provides a reasonable frame to conduct a literature review on both access and consumer utilization of services as it addresses both the push and pull of consumer markets to find healthcare service “fit”. Colloquially known as the *5 A's to Access*, the P&T model utilizes the following five dimensions to define access (Penchansky & Thomas, 1981, pp. 128-129):

- *Availability*: the relationship between the volume and type of existing services (and resources) and the clients' volume and type of needs.

- *Accessibility*: the relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance, and costs related to travel.
- *Accommodation*: the relationship between the manner in which the supply resources are organized to accept clients (appointment systems, hours of operation, walk-in facilities) and the clients' ability to accommodate to these factors.
- *Affordability*: the relationship between the price of services and providers' insurance or deposit requirements (copays) and the clients' income, ability to pay, and health insurance status. Clients' perception of value along with knowledge of prices, total cost, and available credit are also considerations.
- *Acceptability*: the relationship between clients' attitudes about personal and practice characteristics of the existing providers including age, gender, location, type of facility, and religious affiliations, along with provider attitudes about personal characteristics of the clients.

Understanding the important relationship between service location type and the consumer perspectives that influence choices is essential to reduce costs and produce better patient outcomes. The purpose of this study was to better identify patients' perceptions and experiences of barriers and, when described facilitators, that affect patient choices when making decisions to utilize health care services for acute, non-emergent needs, and how their choices are shaped by access barriers using the P&T framework.

## **Methods**

### **Design**

To address the purpose of this study, an integrative review was conducted using the Whittemore and Knafl (2005) framework for organization and analysis of literature as a guide for

the review process. Relevant articles were identified using PRISMA guidelines (Moher et al., 2009).

### **Search methods**

A systematic search of electronic databases and reference lists identified relevant literature. The databases used in this review were CINAHL, Medline, PsycINFO, and Scopus. The search was conducted in September 2020 with the assistance of a medical librarian. Key terms used to identify the research articles included in this integrative review included: “health service accessibility,” “patient acceptance of health care,” “patient preference,” “choice behavior,” “barriers,” “primary care,” “ambulatory care,” and “outpatient care.” A full sample of the search strategy developed for the Medline database is provided in Appendix A, Medline via EBSCO search strategy.

### **Inclusion and exclusion criteria**

Articles were eligible for review with the following criteria: a) peer-reviewed, full-text articles published between January 2008 to September 2020; b) study population included adults 18 years and older, c) articles examined initial access into the health care system, and d) specifically addressed patient perceptions and experiences. The 12-year range was selected for this review to identify current health consumer trends. Market forces such as the emergence and growth of retail and urgent care clinics (Burkle, 2011), the presence of the Affordable Care Act (ACA), revisions to mandates of the ACA, and a continued rise in consumer demand for greater convenience affect how individuals view and use all forms of healthcare services.

Articles were excluded that studied: a) non-U.S. healthcare systems; b) parent access decisions for minor children; c) chronic disease; or d) did not focus on patient perspective. Ambulatory health care delivery in the U.S. has several characteristics that make access to care unique from other countries. Specifically, the reliance on private insurers for payment, the use of

for-profit healthcare centers, and large geographic catchment areas in rural areas. Because any or all of these differences can affect access and choice of services, and because these differences may partially or fully be present in all comparable high-income countries, articles not focused on U.S. healthcare systems were excluded. Minors are unable to legally make choices in where and when they receive care. The focus of this review was on consumer choice in ambulatory healthcare settings, as such, studies focused on minor (pediatric) populations were excluded. Studies focused specifically on populations with chronic diseases were excluded due to the potential homogeneity of access experiences this population may have with navigating and using health care services with medical homes, specialty services, case management services, and disease process management.

### **Search outcome**

The initial search retrieved 1,902 citations, of which 439 citations were removed due to duplication. The remaining 1,463 citations were screened at the title and abstract level, resulting in 170 articles that were assessed with a full-text review. Of the full text articles reviewed, 154 were excluded using the previously described criteria. After reviewing reference lists and additional databases, one additional article was included. In total, 17 articles were included for final analysis and synthesis. Figure 1 shows the flowchart of the search strategy and subsequent screening results. The included articles for this integrative review used quantitative ( $n = 13$ ) and qualitative ( $n = 4$ ) analysis methodologies.

### **Quality appraisal**

All articles in this integrative review were published in peer-reviewed journals. Articles were assessed for quality using the Sirriyeh et al. (2012) evaluation of studies with diverse designs, including qualitative and quantitative approaches. Articles were scored based on 16 criteria with zero to three points awarded for each quality domain. Quality scoring for the

articles ranged from 43% to 76%. Average study score was 51% and 59% respectively, for qualitative and quantitative studies. Missed quality points among articles occurred most often with 1) a lack of use or explanation of a theoretical framework (average score 0.88/3.00), 2) evidence of sample size considerations (average score 0.59/3.00), and 3) statistical assessment of reliability and validity among quantitative studies (average score 0.36/3.00). Basic elements of the articles, including study design, key findings, and quality score, are reported in Table 1.

### **Data abstraction and synthesis**

Barriers and facilitators identified in the 17 studies were grouped using the P & T model's five dimensions of access: 1) availability; 2) accessibility; 3) affordability; 4) accommodation; and 5) acceptability. Those barriers and facilitators identified that did not explicitly fit within the conceptual framework were not included in the aforementioned categories and were instead reported as *additional barriers and facilitators*. Each dimension of the P & T model, along with a description of the central element of access and an example of each dimension, are provided in Table 2.

## **Results**

The following section provides an overview of the population and study characteristics along with findings of included studies synthesized into the 5 A's to Access and other categories that do not easily align with the P & T model.

### **Sample Population Characteristics**

Studies assessed for this review included U.S. adults. Participant sizes varied considerably. Three articles reported on national survey data with population sizes ranging from 23,413 to 230,258 (Capp et al., 2014; Cheung et al., 2012; Rust et al., 2008). The National Health Interview Survey (NHIS) was used for each of these studies. The NHIS uses probability sampling with oversampling of certain racial and ethnic minorities. The largest study sample population

combined data from multiple NHIS surveys (1999-2009) but included only patients that identified as having Medicaid coverage (Cheung et al., 2012). Data was collected from the 2005 NHIS data set (Rust et al., 2008) and from the 2011 survey (Capp et al., 2014) in the other two large survey studies. Other quantitative studies ranged in size from 126 to 5,451. Most (Andrews & Kass, 2018; Capp et al., 2015; Enard & Ganelin, 2017; Lobachova et al., 2014; Rocovich & Patel, 2012; Schumacher et al., 2013) were single-site studies. Cunningham et al. (2016) included synthesized data from two earlier studies at a single location each. Mukamel et al. (2020) elicited responses to utilization scenarios from a large urban academic center. Qualitative studies were predictably lower. Study sample sizes ranged from 30 to 349 participants. Similar to the quantitative studies, all but one qualitative study (Wang et al., 2010) used a single recruitment site.

Study location was more homogeneous. Nationally representative populations were studied in three papers, urban population areas were studied in ten, with the remaining four studies taking place in suburban cities. No articles exclusively targeted rural individuals, communities, or health systems, highlighting a notable gap in the literature.

### **Findings within the Penchansky and Thomas Access Dimensions**

**Accessibility.** Location of services or the ability to travel to a service location were discussed in 11 of the 17 studies as a reason for health service location choice. Findings suggest that transportation was a barrier to primary care use for participants (Capp et al., 2016; Enard & Ganelin, 2017; Hefner et al., 2014; Kangovi et al., 2013; Schumacher et al., 2013; and Shaw et al., 2013) and increased the odds of an individual reporting to the ED by 77% (adjusted OR = 1.77; CI 1.61 – 1.94) (Chueng et al., 2012) and 88% in the Rust et al. (2008) article. Additionally, proximity to an ED (Capp et al., 2014) or retail clinic (Wang et al., 2010) was indicated as a reason for choice over a primary care provider (PCP) office. A single study reported that 33.1%



of respondents indicated that they chose an ED because they lacked access to a PCP or urgent care location (Andrews & Kass, 2018).

**Acceptability.** Acceptability of service was also addressed in the majority of studies ( $n = 11$ ). This access domain addresses patient attitudes and experiences regarding the care they receive at a health service location. Enard and Ganelin (2017) reported 53.2% of respondents felt ED clinicians provide better overall care than other places. Schumacher et al. (2013), reported that individuals with low health literacy were more likely to view the care they received in the ED as better ( $p=0.04$ ) and that they preferred the ED environment for their care ( $p<0.001$ ).

Acceptability of a service not only represents positive sentiments that consumers have with their care but can also be expressed inversely with negative encounters. Previous negative experiences with a PCP (Capp et al., 2016; Wang et al., 2010), or a feeling of not getting what is needed from a PCP ( $p < 0.001$ ) (Cunningham et al., 2016), were reported as influential reasons to seek care in the ED for non-urgent health needs. Access to advanced technology in the ED was identified in four studies (Capp et al., 2015; Hefner, Wexler, & McAlearney, 2015; Kangovi et al., 2013) along with a feeling that only the hospital could help when sick (Capp et al., 2013) as a reason in choosing the ED for primary care needs. Conversely, Mukamel et al. (2020) found previous experience with a location to be predictive of location choice.

Consumer confidence in receiving safe, effective, and culturally sensitive care acceptable to the individual was noted in several studies. Trust in hospital-based care was found to be statistically significant ( $p = 0.011$ ) when comparing ED usage between individuals that use the ED for their usual source of care (USOC) compared to those that do not (Enard & Ganelin, 2017). Shaw et al. (2013) reported on one participant's response of preferring the ED over a

Federally Qualified Health Center (FQHC) because of their own (the participant's) racial bias toward other patients that receive care at the FQHC.

**Accommodation.** Accommodation explores access issues that are controlled at an operational level. Appointment systems, hours of operation for clinics, walk-ins, and ability to contact a health care provider are examples of access concerns that address the ability of service location to meet or adjust to the needs of its patients.

Most studies ( $n = 12$ ) reported on the perceived system level factors affecting primary care utilization. Common findings indicate that many individuals considered receiving care from their PCP for non-emergent issues but that they were unable to do so because of clinic hours or that their usual USOC was closed (Capp et al., 2014; Cunningham et al., 2017; Hefner et al., 2014; Lobachova et al., 2014; Rocovich and Patel, 2012; and Shaw et al., 2013). Studies also reported that patients tried but were unable to get an appointment soon enough based on their needs resulting in delayed care or use of emergency services (Cheung et al., 2012; D'Avolio, Strumpf, Feldman, Mitchell, & Rebholz, 2013; Rust et al., 2008; Shaw et al., 2013). Retail clinic consumers cited having little wait time as a primary reason for their choice (Wang et al., 2010).

Complications and frustrations with phone systems were also a common finding (Cheung et al., 2012; D'Avolio et al., 2013; Rust et al., 2008) that influenced higher rates of ED usage among study participants. Retail clinics were used by 62% of patients because they found the service to be faster than the options available through a primary care office (Wang et al., 2010). Conflicting results on accommodation were reported in the Enard and Ganelin (2017) article. Study participants were more likely to visit an ED because of convenient hours ( $p=0.021$ ), but the study also reported that patients found it easy to contact their PCP after regular hours ( $p=0.001$ ) and that their PCP was easy to see for preventative care ( $P=0.001$ ).

**Affordability.** Affordability was a salient issue addressed in all but three of the studies included in this review. The ability to defer payment was a significant reason ( $p = 0.003$ ) in health service location choice for patients who preferred the ED as their USOC (Enard & Ganelin, 2017). Cost (Cunningham et al., 2017; Hefner et al., 2014; Schumacher et al., 2013; and Shaw et al., 2013) and income level (Andrews & Kass, 2018; Rust et al., 2008) were reported as reasons for choosing to go to alternative locations instead of a PCP. The lack of associated value in seeking care with a PCP was identified in a single study as a reason for not seeking care in a primary care setting (Capp et al., 2016), as was price transparency (Wang et al., 2010).

Insurance was listed as a barrier (Andrews & Kass, 2018; Hefner et al., 2014; Lobachova et al., 2013; and Schumacher et al., 2013). Variations in insurance were used as variables to describe ED utilization in multiple studies. Capp et al. (2014) found that individuals with Medicaid (OR = 1.50; CI 1.06 – 2.13) or dual enrollment in Medicaid and Medicare were more likely (OR = 1.94; CI 1.18 – 3.19) than individuals with private insurance to seek the ED for their care. Similar results were reported in Chueng et al. (2012) with Medicaid beneficiaries at greater odds of reporting at least one access barrier (OR = 1.41; CI 1.30 – 1.52). Medicaid enrollees were also more likely to utilize the ED when at least one barrier was reported (i.e., transportation) (OR = 1.66; CI 1.44 – 1.92) and when two or more barriers were present (i.e., transportation and copay amount) (OR = 2.01; CI 1.72 – 2.35). However, when comparing ED usage during regular office hours, insurance status was not found to be a predictive factor (Rocovich & Patel, 2012).

**Availability.** Supply versus demand issues that affect patient access to primary care was reported in a single study. Hefner, Wexler, and McAlearney (2014) reported that 6.9% of their respondents answered that it was difficult to find a PCP due to a lack of openings based on insurance type. Issues with availability were not reported in the three studies that focused on the Medicaid population (Capp et al., 2015; Capp et al., 2016; and Cheung et al., 2012) or in the

other studies that examined variations in insurance (Capp et al., 2014; Hefner et al., 2014) No other PCP, ED, specialty provider, or health service availability issues were reported.

### **Additional Barriers and Facilitators not addressed by Penchansky and Thomas**

**Perceived acuity.** Acuity is a group of access issues that acknowledge the relative need of a consumer to seek and receive immediate care to alleviate a medical issue. Patients' perceptions regarding acuity of their health care needs were reported as a reason for presenting in over half of the studies (n = 10). Severe pain, as an acuity issue, was reported in four studies as a reason for presenting to the ED (Andrews & Kass, 2018; Capp et al., 2015; D'Avolio et al., 2013; Schumacher et al., 2013). Andrews and Kass (2018) explored differences in acuity perceptions between patients and ED medical providers. The highest discrepancy in acuity score was observed with patients that presented with acute-on-chronic musculoskeletal pain ( $p = 0.0445$ ). The lowest acuity score difference between sub-acute patients and ED providers was observed by patients that attempted to contact their PCP prior to presentation at the ED ( $p = 0.042$ ). Insurance type did not change the odds of an individual reporting an acuity issue as a reason for using the ED over a PCP office. Medicaid (OR = 1.05; CI .79 – 1.40) and Medicare (OR = 0.98; CI .66 – 1.47) enrollees had similar rates of perceived acuity issues as private insurance holders (Capp et al., 2014). Variability in health insurance type was found to be more significant in explaining ED usage than perceived acuity in the Capp et al. (2014) study.

Seven studies also reported patients being deferred to the ED after contacting their PCP – indicating that a trained clinician felt that a medical issue needed emergent care. Table 3 lists the percentages of patients that self-referred to the ED based on a perceived need for immediate care along with percentages of patients that were directed to go to the ED by a health care professional (provider deferment) because of perceived acuity.

The ability to get controlled substances more easily in the ED versus a PCP office was also reported as a reason for choosing an ED (Kangovi et al., 2013). The reason behind needing a controlled substance (pain versus opioid addiction) was not explored.

**Knowledge of health services.** Schumacher et al. (2013) reported individuals with lower health literacy were just as likely to have a PCP as individuals with higher health literacy. However, those with lower health literacy scores were more likely (OR = 1.7, 95% CI, 1.09 – 2.66) to report not being able to get an appointment when needed. Enard and Ganelin (2017) found that patients who report using the ED for their USOC were more likely to report coming to an ED because they did not know where else to go for their care ( $p = 0.008$ ). Similarly, Shaw et al. (2013) reported that patients use the emergency department by default when other health service locations are not known by the individual. Schumacher et al. (2013) reported a high correlation between low health literacy and those that reported always using the ED for their care ( $p < 0.001$ ). Patients with adequate health literacy were less likely to utilize the ED and more likely to report having PCP visits than those with limited health literacy.

**Convenience or no barriers identified.** The term “convenience” was identified in six studies (Andrews & Kass, 2018; Capp et al., 2015; Enard & Ganelin, 2017; Kangovi et al., 2013; Lobachova et al., 2014; and Rocovich & Patel, 2012) as a reason for preference. Studies that reported convenience as a reason did not provide additional information regarding the term.

Capp et al. (2015) found that 5.8% of their respondents had no reason on why they preferred using the ED. In the same study less than half of the Medicaid recipients, compared to frequent ED utilizers, those with < 10 annual visits to the ED, reported “other” as the most appropriate reason for presenting to the ED ( $p = 0.035$ ). These “other” options were PCP availability, perception of care provided in the ED, the perceived acuity, and money as a barrier.

Hefner et al. (2015) reported 25% of their study's respondents noted no barrier to timely care but still presented to the ED for non-urgent needs.

### **Discussion**

Findings from this review identified each of the five themes (See Table 1) of the P&T model for access. Along with the access dimensions constructed by P&T, two distinct additional themes, perceived acuity and knowledge of health services, along with a broad theme of convenience, were also present. Table 4 provides a visual of the various dimensions identified in each study and notes statistically significant findings for the quantitative literature.

Findings from this review align with other work on access regarding the complex relationship between barriers, utilization of services, and the choices in location health consumers make (Vogel et al., 2019; Coster et al., 2017; Kraaijvanger et al., 2016; Uscher-Pines et al., 2013). However, understanding the intricate nature of access and subsequent use of services remains an important yet elusive task. Current policy efforts in the U.S. have mostly focused on access through insurance with the Affordable Care Act in 2010. Nevertheless, studies have shown a persistence of access issues remains despite improvements in financial coverage (CDC, 2018 and Kullgren et al., 2012) and that non-financial considerations may help with the uptake of primary-care services (Hong et al., 2019). Studies included in this review show a similar pattern to that of U.S. policy of siloed analysis of access dimensions. Addressing utilization and choice of service location as a complex phenomenon where the interactive effect of two or more access dimensions is explored may help researchers better understand where and why certain services are chosen. Future studies with robust designs and analysis are needed to better understand these possible interactions.

One issue with the P & T model's conceptual dimensions is the relative ambiguity of the terms. This vagueness was identified by the original authors in their subsequent work (Thomas

& Penchansky, 1984) as well as other access theorists (Ricketts & Goldsmith, 2005). The use of convenience, a term identified in six studies, is a good example of such a term. Convenience is not well defined in the studies identified in this review. A more precise use of the concept could allow future studies to collapse terms such as accessibility and availability into a more health consumer relatable term that better captures utilization choices. Some work on a reconceptualization of the P & T dimensions of access has already been introduced with the addition of awareness by Saurman (2016). The exercise of expanding terms and then collapsing them into more consumer-based terms may be both a conceptual and semantical solution that helps researchers and clinicians find pragmatic interventions to affect patient utilization behavior. Findings from this integrative review suggest the need for a broader, yet more discrete, group of access terms. Additional work on convenience and awareness, along with other access terms in this review, should be considered.

Primary care was a central search term used in this integrative review yet sampling from the included studies did not occur in a primary care setting. The conventional approach to access research relies on the tenet that EDs function as safety net locations for individuals (Samuels-Kalow et al., 2021; Anderson et al., 2016; Morganti et al., 2013). As a result, access barriers in the U.S. health system are more likely to manifest in the ED care setting than in other locations. Studies that focus on facilitating factors in primary care clinics could provide rich information on factors that encourage the use of primary care services for non-emergent needs. Future research is needed to explore this potential gap in the literature.

Additionally, no studies identified for this review specifically addressed rural populations. Although this may have been a function of the search terms or inclusion and exclusion criteria, federal organizations like the Health Resources and Services Administration have recognized that key gaps exist in understanding rural access (Health Resources and

Services Administration, 2019). Revisiting rural bypass, a process where rural health care consumers skip the nearest clinic or hospital and seek care elsewhere, with a consumer-friendly access theory may help explain this phenomenon. Future work is needed to address rural health care access and particularly rural bypass with theories that explore consumer choice in services for non-emergent needs among this diverse population.

### **Implications**

To the best knowledge of the authors, there have been no integrative reviews on patient choice of service location for non-emergent care needs using the P & T model. Clinicians may find results from this study can help shape conversations with their patients to better address health needs and the consumer-based barriers and facilitators that lead to ED overutilization and missed PCP appointments. Continued work is occurring among health system leaders and policymakers to help individuals better navigate their care needs. Findings from this study may aid efforts to uncover solutions to increase high-value, low-cost care for non-urgent medical needs by highlighting the multiple factors that shape utilization at the individual level. Academically, this study may help scientists by adding to the current body of knowledge by synthesizing access dimensions with a well-established theory. The inclusion of the 5 A's to Access helps frame the use of health care utilization through the lens of complex grouping of access inhibitors and facilitators. Findings from this study, aided by a theory, may help in the creation of new conceptual models and innovative study designs that allow clinicians, administrators, and policymakers to better shape where and when utilization of certain services occurs.

### **Limitations**

As with all integrative reviews, effort was taken to assure a full inclusion of the relevant literature. However, screening for this review was performed by a single researcher and may



lack the inclusion and exclusion rigor performed with multiple reviewers. Interpretive discrepancies between the fit of some results and access dimensions may be present. Previous research on P&T has noted the ambiguity of the conceptual terms causing potential issues with omission and mislabeling of concepts (Saurman, 2016). Although mislabeling was possible during the synthesis of the data for this review, care was taken to apply the P&T terms as originally conceptualized. The finding of additional barriers and facilitators beyond P&T point to the objectiveness applied in synthesizing data for this review and in holding to the original use of terms by Penchansky and Thomas. Beyond the application of the P&T model, reasonings for its use in lieu of an alternative theory, such as Andersen (1995), could be argued. However, the intent of this review was to identify perceptions and experiences of healthcare consumers and the barriers and facilitators they experience that alter choice. Whereas, Andersen's model provides good utility in understanding demographic characteristics that influence utilization of services, P&T provides insight into consumer fit between needs and healthcare systems, making it a more appropriate access model for the research question asked for this review. Andersen's Model of Health Care Utilization (1995) uses population characteristics.

### **Conclusion**

This integrative review demonstrates that choice in ambulatory care location for non-emergent care needs is a complex phenomenon. The use of the P & T model to describe care utilization choices offers an alternative method to data synthesis in access research. Consideration should be taken to incorporate dimensions like convenience, perceived acuity, and health service knowledge, into both existing and new access models. Incorporation of these additional barriers could increase the scientific understanding of the existing barriers and enhance the overall explanatory ability of models like the Penchansky and Thomas access concepts.

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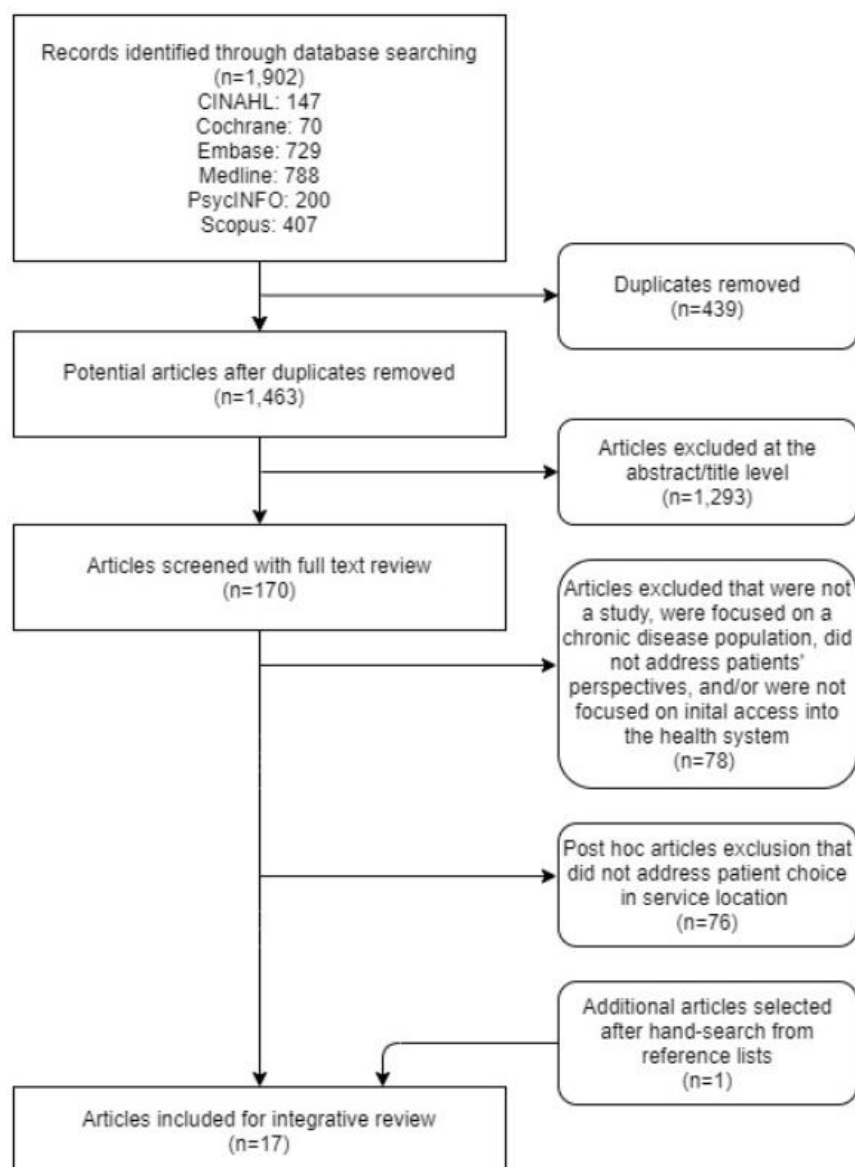
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**Figure 1.** Flowchart of search and screening process



**Table 1.** Summary of key elements present in articles

Study	Purpose of research	Study Design	Sample Size	Setting	Gender/ Race (%)	Key Findings	Quality score
Andrews 2018	Identify which patient populations are most likely to have high estimations of acuity compared to ED MDs	Cross-sectional	126	Suburban Emergency Depart.	Male (49) Female (51)  Race not reported	<ul style="list-style-type: none"> <li>Patients with acute-on-chronic musculoskeletal pain had the highest acuity discrepancy versus ED providers (<math>p=0.0445</math>)</li> <li>Patients with physician deferment to the ED had the lower discrepancy of acuity versus ED providers than self-arrival (<math>p=0.042</math>)</li> </ul>	52%
Capp 2014	Evaluate the association between insurance type, acuity, and access in the ED population	Cross-sectional	32,737	National Survey	Male (49) Female (51)  White (68) Black (12) Hispanic (14) Other (6)	<ul style="list-style-type: none"> <li>65% of adults reported at least 1 acuity issue (CI 63.0 – 66.9)</li> <li>79% of adults reported at least 1 access issue (CI 77.3 – 80.5)</li> <li>Medicaid enrollees had similar rates of acuity as those with private insurance OR = 1.02 (0.68 – 1.51)</li> </ul>	62%
Capp 2015	Explore location preferences of patients that present with low acuity complaints to the ED	Cross-sectional	95	Suburban Emergency Depart.	Male (28) Female (72)  White (26) Black (22) Hispanic (34) Other (8)	<ul style="list-style-type: none"> <li>Patients with <math>\geq 1</math> chronic condition reported preferring the ED for low acuity reasons (<math>p = 0.03</math>).</li> <li>Less than half of Medicaid enrollees would prefer to use a PCP if an appointment were available.</li> </ul>	52%
Capp 2016	Understand why patients that want to receive primary care coordination continue to use the ED	Descriptive interview	100	Suburban Emergency Depart.	Male (27) Female (73)  White (16) Black (50) Hispanic (28) Other (6)	<ul style="list-style-type: none"> <li>Previous experience with PCPs and lack of trust shaped ED usage for Medicaid recipients enrolled in a primary care navigator program.</li> <li>Lack of value associated with PCP visits and minimized day-to-day health priorities were reported as reasons for continued ED usage.</li> </ul>	55%
Cheung 2012	Understand the relationship between insurance type and barriers to timely primary care	Cross-sectional	230,258	National Survey	Male (47) Female (53)  White (76) Black (9) Hispanic (11) Other (5)	<ul style="list-style-type: none"> <li>Medicaid beneficiaries with at least two access barriers were most likely to have higher ED utilization compared to private insurance with barriers OR = 2.01 (1.72 – 2.35)</li> </ul>	59%

Study	Purpose of research	Study Design	Sample Size	Setting	Gender/ Race (%)	Key Findings	Quality score
Cunningham 2016	Describe utilization practices and perceptions of frequent ED visitors that use the ED for primary care needs.	Cross-sectional	1,113	Two Urban Emergency Depart.	Male (45) Female (55)  White (44) Black (43) Hispanic (nr) Other (13)	<ul style="list-style-type: none"> <li>Those with less than 10 ED visits in calendar year were statistically likely to state "other" as a reason for why the ED was the best option (<math>p = 0.035</math>) over PCP availability, acuity of disease, or perceptions of care, or money.</li> <li>Frequent ED users (<math>\geq 10</math> visits/yr.) were more likely to use the ED because they felt that they couldn't get what they need from their PCP</li> </ul>	62%
D'Avolio 2013	Describe healthcare access experiences of older adult patients	Descriptive interview	62	Urban Emergency Depart.	Male (40) Female (60)  White (15) Black (56) Hispanic (3) Other (26)	<ul style="list-style-type: none"> <li>Barriers to care for older adults include frustration with phone systems and lack of open appointments.</li> <li>Front office and reception staff are a perceived issue with older adult patients</li> </ul>	64%
Enard 2017	Describe challenges and opportunities related to the perceived value of primary care	Cross-sectional	329	Urban Emergency Depart.	Male (33) Female (68)  White (9) Black (38) Hispanic (52) Other (2)	<ul style="list-style-type: none"> <li>Individuals that use the ED for their USOC cited an ability to pay later (<math>p = 0.003</math>), more convenient hours in the ED (<math>p = 0.021</math>), availability of services in the ED (<math>p = 0.040</math>), and acuity (<math>p = 0.009</math>) as motivating factors for ED usage</li> </ul>	55%
Hefner 2014	Understand barriers to primary care for non-urgent ED patients	Descriptive case study	349	Urban Emergency Depart.	Gender not reported  White (48) Black (45) Hispanic (3) Other (5)	<ul style="list-style-type: none"> <li>Infrastructure issues including a lack of PCP appointment openings, wait time in the office, and a lack of medical equipment were reported.</li> <li>Cost and transportation were identified as major individual barriers for urban patients</li> </ul>	57%

Study	Purpose of research	Study Design	Sample Size	Setting	Gender/ Race (%)	Key Findings	Quality score
Kangovi 2013	Understand why low SES patients seek low value care from acute care facilities	Descriptive interview	40	Urban Emergency Depart.	Male (30) Female (70)  Black (90) Other (10)	<ul style="list-style-type: none"> <li>Both low and high ED utilizers identified as low SES patients reported convenience and perceived trust in ED providers over PCP as a preference reason.</li> <li>Ability to get controlled substances in the ED was identified as reason for utilization.</li> <li>Viewing the hospital as a source of a calming environment was noted in the low SES population</li> </ul>	62%
Lobachova 2014	Measure the frequency of reasons why patients choose the ED for their care	Cross-sectional	1,062	Urban Emergency Depart.	Male (52) Female (48)  Race not reported	<ul style="list-style-type: none"> <li>A majority of patients (61%) and ED physicians (80%) stated acuity as the reason for selecting the ED for their care.</li> <li>48% of patients stated coming to the ED based on the advice of a PCP</li> </ul>	67%
Mukamel 2020	Identify care setting preference for non-emergent illnesses	Cross-sectional	4844	Urban Academic Center	Male (33) Female (66) Other (1)  White (42) Black (2) Hispanic (20) Other 26)	<ul style="list-style-type: none"> <li>Familiarity with a provider was associated with higher likelihood of utilization across all care settings</li> <li>Education level was related to use of Emergency Department and Urgent Care for care</li> </ul>	57%
Rocovich 2012	Identify reasons for primary care visits to the ED during regular clinic hours	Cross-sectional	262	Suburban Emergency Depart.	Male (50) Female (50)  Race not reported	<ul style="list-style-type: none"> <li>When comparing emergent and non-emergent visits to the ED during normal business hours, being employed statistically significant factor (<math>p &lt; 0.05</math>)</li> </ul>	43%
Rust 2008	Examine the relationship between ED visits and perceived barriers to timely primary care	Cross-sectional	23,413	National Survey	Male (51) Female (49)  White (75) Black (10) Hispanic (10) Other (5)	<ul style="list-style-type: none"> <li>Patients were more likely to use an ED if they experienced issues with setting up PCP appointments over the phone OR = 1.27 (1.02 – 1.59), not being able to get an appointment soon enough OR = 1.45 (1.21 – 1.75), or having to wait too long in PCP office OR = OR = 1.20 (1.02 – 1.41)</li> <li>Patients were more likely to present to the ED because of transportation issues OR = 1.88 (1.50-2.35)</li> </ul>	51%

Study	Purpose of research	Study Design	Sample Size	Setting	Gender/ Race (%)	Key Findings	Quality score
Schumacher et al., 2013	Examine the relationship between health literacy, primary care access, and ED usage	Cross-sectional	492	Urban Emergency Department	Male (45) Female (55)  Black (28) Other (72)	<ul style="list-style-type: none"> <li>Patients with limited functional health literacy were more likely to have greater ED utilization OR = 1.6 (1.0 – 2.4), fewer PCP visits OR = 0.60 (0.4 – 1.0).</li> <li>Patients with limited health literacy chose the ED because of a perception of receiving better care (<math>p = 0.04</math>), always receiving the care they need (<math>p &lt; 0.001</math>) and preferring the ED environment (<math>p &lt; 0.001</math>).</li> </ul>	71%
Shaw et al., 2013	Explore reasons for ED versus primary care use for non-urgent needs	Grounded theory	30	Urban Emergency Department	Male (60) Female (40)  White (30) Black (50) Hispanic (17) Other (3)	<ul style="list-style-type: none"> <li>Lack of knowledge of health service options is a factor in ED usage</li> <li>Patients perceived need for care may override other access factors</li> <li>Perceived discomfort due to racial bias towards and from patients shapes care location choices</li> </ul>	76%
Wang et al., 2010	Understand why patients choose retail clinics for their care	Descriptive Interview	61	Urban Retail Clinics	Male (43) Female (57)  Race not reported	<ul style="list-style-type: none"> <li>Individuals enjoy using retail clinics for convenience in location and hours.</li> <li>Fixed, transparent pricing were reasons for preferring retail clinics</li> <li>Retail clinics may be viewed as an ED substitute and not a PCP alternative.</li> </ul>	67%

**Table 2.** Penchansky and Thomas Access Dimensions and Examples

Access Dimension	Element of Access	Example
Availability	Supply and demand of providers	The ability of an individual with Medicaid benefits to find a primary care provider accepting new patients.
Accessibility	Location and transportation	The ability of an individual to find and use a nearby clinic or use private or public transportation to travel to a clinic.
Affordability	Relative cost of services	The out-of-pocket deductible or co-pay that an individual with private insurance is required to pay for a primary care visit.
Accommodation	System level organization of care	The effort required to call a primary care office to make an appointment and the wait time between when the call is made and when the appointment can be scheduled.
Acceptability	Perceptions, attitudes, and cultural	The cultural ability of a primary care provider to meet the needs of a non-English speaking individual.

**Table 3.** Perceived acuity of patients and providers as a reason for presenting to an ED

Study	Patient self-perceived as too sick or injured to go to a PCP (%)	Provider deferment (patient sent to ED by provider) (%)
Andrews and Kass (2018)	27.8	28.2
Capp et al. (2014)	42.6	19.4
Capp et al. (2015)	7.7	3.8
Cunningham et al. (2016)*	52.8	-
Enard and Ganelin (2017)*	87.8	-
Lobachova et al. (2013)	61.0	35.0
Schumacher et al. (2013)*	51.8	-

\*Cunningham et al. (2016, Enard and Ganelin (2017), and Schumacher et al. (2013) did not report provider deferment

\*\*Capp et al. (2016) and Shaw et al. (2013) were qualitative studies and did not report frequency

**Table 4.** Access dimensions explored by article

Study	Availability	Accessibility	Affordability	Accommodation	Acceptability	Perceived acuity	Provider deferment	Health knowledge	Convenience	No Barrier or Other
Andrews & Kass, 2018		●	●			●	●	●	●	
Capp et al., 2014		●	●	●	●	●	●			
Capp et al., 2015*					●	●	●		●	●
Capp et al., 2016*		●	●		●	●				
Cheung et al., 2012		●	●	●						
Cunningham et al., 2016			●	●	●	●				●
D'Avolio et al., 2013*				●						
Enard & Ganelin, 2017		●	●	●	●	●		●	●	
Hefner et al., 2014*	●	●	●	●	●					●
Kangovi et al., 2013*		●			●	●	●		●	
Lobachova et al., 2014			●	●		●	●		●	
Mukamel et al., 2020			●		●	●		●		
Rocovich & Patel, 2012			●	●			●		●	
Rust et al., 2008		●	●	●						
Schumacher et al., 2013		●	●	●	●	●		●		
Shaw et al., 2013*		●	●	●	●	●	●	●		
Wang et al., 2010*		●	●	●	●					

● = statistically significant result reported; ● = access dimension addressed in study; \* = qualitative study

### **CHAPTER III: Manuscript 2**

#### **Framing Facilitators and Inhibitors in Appointment Behavior Among Emerging Adults with Type 1 Diabetes**

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## Introduction and Background

Type I diabetes (T1D) is a chronic condition that requires a lifelong commitment to regular care. With a peak diagnosis among individuals with T1D between 12 - 14 years (Katsarou et al., 2017), establishing care of diabetes is paramount to improving health outcomes across the lifespan (Fortin et al., 2016). Diabetes care among youth is typically managed through a pediatric clinic with primary responsibility of care coordinated by a parent. As individuals reach emerging adulthood, 18 – 30 years of age, responsibility for their care transitions to the individual (Hanna, 2012); which includes among other activities, regular attendance with diabetic appointments.

Understanding the transition from pediatric to adult diabetic care is recognized as an important factor in overall diabetic care (Helgeson et al., 2013). Regular adherence to appointments in patients younger than 30 years of age has been shown to predict better disease management with lower HbA<sub>1c</sub> levels for those with higher attendance rates (Fortin, et al., 2016).

Yet, concerns over decreased attendance and adherence to diabetic appointments have been voiced during this transitional period (Levy-Shraga, et al., 2016; Monaghan and Baumann, 2016). Emerging adulthood has been shown to be particularly challenging for individuals to manage care surrounding their diabetes needs (Fisher et al., 2018). Estimates have shown that only 14% of young adults are able to achieve optimal glycemic control (Miller et al., 2015) – defined as maintaining HbA<sub>1c</sub> around 7.0% or 53.0 mmol/mol. Establishment of care with regular attendance has been shown to increase adherence to self-management activities, is associated with a 0.51% decrease in HbA<sub>1c</sub> (Liese et al., 2019), and is important for positive long-

term outcomes (Fortin et al., 2016) - making appointment behavior during the transition period of particular interest within the Emerging Adults (EA) population.

Reasons, both facilitators and inhibitors, for non-attendance among Emerging Adults (EA) with T1D is not fully understood. Evidence suggests both consumer-level preferences and clinical access characteristics may facilitate and inhibit appointment behavior observed among this population (Monaghan, Helgeson, & Wiebe, 2015, 2016, Hynes et al., 2016; Garvey et al., 2014). Preferences towards service convenience (McMorrow et. al., 2018) and establishment of collaborative relationships with service providers (Hynes et al., 2015) have been reported as schedule constraints involving education, employment, and social relationships making this age group sensitive to competing time demands. Moreover, as a result of increased independence from parents, EAs have unique system-level access concerns related to changes in financial resources and insurance coverage that are associated with less-than optimal utilization of services (Buschur et al., 2017). As such, addressing appointment behavior among EAs with T1D may benefit from a systems approach, such as healthcare consumerism, that addresses both individual and system-level facilitators and inhibitors to utilization of adult endocrinology care.

The application of a consumer-based theory to appointment behavior could help expand the knowledge surrounding utilization of diabetes services and what factors help or hinder attendance. Healthcare consumers feel strongly about what matters to them when receiving care. For many individuals, that means placing higher importance on relationships, perceived value, and convenience over clinical outcomes (Cordina, Kumar, & Moss, 2015). Insights of consumer facilitators and barrier may lead to future research with targeted consumerism-based strategies. These strategies, in turn, could facilitate more consistent attendance to recommended scheduled appointments (American Diabetes Association, 2020) and improve health outcomes related to diabetes management. Therefore, understanding

consumer discernment over service characteristics like cost, convenience, and comforting clinical environments may provide insight into the decisions, as facilitators and inhibitors, that influence appointment attendance among EAs with T1D.

### **Purpose**

To address the gap in understanding of consumer-based antecedents that help or hinder appointment behavior in EAs with T1D, this study explored and described facilitators and inhibitors for their appointments. Consumer-based concepts, using a blended framework applying healthcare access and consumerism convenience was applied. The blended concepts in this study were adapted from the Penchansky and Thomas *5 A's to Access* (1981) and additionally influenced by the Berry et al., (2002) *Model of Service Convenience*. Concepts were applied for 'tentative conceptualization' and saliency of the adapted consumer concepts (Hinds et al., 1997).

### **Framework**

The Penchansky and Thomas model, *5 A's to Access*, and the Berry et al., *Model of Services Convenience* provide the theoretical background for this secondary analysis. *The 5 A's to Access* is an established framing model used to explain "fit" among interrelated concepts of resources, need, and demand between systems and individuals (Kirby & Yabroff, 2020; Ricketts & Goldsmith, 2005). *5 A's to Access* applies system characteristics to individual needs using the concepts of availability, accessibility, affordability, acceptability, and accommodation (Penchansky & Thomas, 1981). The use of these concepts has been applied to numerous studies looking at a range of topics from equitable access, distance to services, and utilization of care by individuals with chronic conditions including diabetes (Scott, O'Cathain, & Goyer, 2019).

Health service convenience is increasingly acknowledged as an important factor in utilization of services (Mehrotra, 2013; Tuzovic & Kuppelwieser, 2016). The *Model of Services*

*Convenience* offers insight as a behavioral framework that accounts for the ‘time and effort’ needed by an individual to utilize a service. The *Model of Services Convenience* applies a continuum of decision, access, transaction, benefit, and post-benefit convenience characteristics that influence consumer utilization.

The resulting blended model offers conceptualization to account for both system-level access components and endogenous consumer values that may affect utilization of services. The posited model is meant for framing purposes in understanding the multifaceted nature of access and utilization of ambulatory care services. Blended concepts applied as facilitators and inhibitors for analysis include cost, convenience, comfort, criticality, and capacity.

#### *Cost*

Cost and affordability are well-established components among access literature (Tolbert et al, 2019; National Academies Sciences, 2018). Insurability plays an important role in utilization of services, particularly among poorer Americans (Henry J. Kaiser Family Foundation, 2018). Adding to the cost complexity in the U.S. healthcare system, out-of-pocket costs and clinical payment systems can vary significantly even among the insured (Allen et al., 2017). Healthcare consumers’ choice to use or purchase a service may elicit varying responses of utilization (National Academies of Sciences, 2018). For EAs with T1D, cost components that may help or hinder appointment attendance during the transition to adult care include insurance eligibility, co-payments, and other out-of-pocket expenses like medical supplies (Buschur et al., 2017).

#### *Convenience*

System-level factors such as clinical hours of operation and ease of making appointments are known to alter utilization (Wang et al., 2010). Other factors including distance between a consumer and health care location and reliable transportation modify the timeliness

and utilization of services (Levesque et al., 2013). Research has shown that young adults with T1D may opt for shorter waits and flexible appointment times as a matter of convenience over seeing a particular medical provider or nurse (McMorrow et al., 2018).

### *Comfort*

Healthcare consumers' need for comfort with their providers and health service locations is an important component of utilization (HealthyPeople 2020, 2019). Comfort includes perceptions of competency and safety with providers and health service locations, communication, informed participation, symptom management, and holistic care (Wensley et al., 2017). Trust, communication, and personal relationship between consumers and their providers have shown to influence utilization of services (LaVeist et al., 2009). Coordinated access to psychological services, establishing trusting relationships, and having adequate time to visit with patients have been expressed as potential barriers during the transition period for EAs by care providers (Michaud et al., 2018).

### *Criticality*

An individual consumer's perceptions on the frequency and level of care needed influences the decision to utilize services (Fernandes et al., 2016). Perceived criticality can vary greatly among individuals and populations with similar health-related events. For EAs with T1D, the willingness to attend may depend on the relative level of distress experienced at the time of the appointment by the individual (Hynes et al., 2015).

### *Capacity*

The ability to obtain and understand valid and reliable information, to make autonomous decisions, and to have an awareness of available services have been proposed as overlooked components of access and utilization (Saurman, 2015). General diabetes knowledge along with understanding the importance of health care visits, diabetes management skills, and

communication with the diabetic healthcare team are posited as necessary components for a healthy transition (Bowen, Henske, & Potter, 2010). Misalignment of diabetes knowledge between EAs with T1D and their adult providers may hinder clinical attendance.

The consumer dimensions of cost, convenience, comfort, criticality, and capacity may exhibit both facilitating and inhibiting characteristics among individuals depending on unique intrinsic and extrinsic factors surrounding the person. An example of this dichotomy can be illustrated by the use of a standard appointment schedule. If an adult endocrinology clinic prefers to schedule EAs on Wednesday afternoons to help coordinate labs, mental health resources, and clinician times this may affect two EAs with T1D differently. The first EA may view this as a helping characteristic, scheduling structure, for both their diabetes appointment and other care and personal needs like school, work, or child-care coverage. For the second EA, the rigidity of only being able to schedule appointments on Wednesday afternoons may hinder attendance. Set times would make it difficult to attend appointments if other activities and responsibilities like school, work, or child-care have concurrent scheduling needs. Thus, a facilitator for one individual can be an inhibitor for another, and vice versa.

## **Methods**

### **Design**

This study, using a qualitative approach, utilizes a secondary data analysis from a subset of a qualitative study of 25 EAs with T1D. The primary study to this manuscript used a multi-method approach with qualitative and quantitative portions. The qualitative arm of the parent study explored diabetes care behaviors, including appointment behavior among EAs with T1D (Hanna and Hansen, 2019) The initial study revealed salient habits and routines for self-management (diet, exercise, insulin administration, and glucose monitoring), however, analysis of appointment behavior was limited in terms of habits and routines. Thus, this study was a

secondary data analysis of appointment behavior guided by consumer-based concepts described previously to investigate the data with a “new” research question (Heaton, 2008).

### **Sampling**

A total of 100 participants (77% participation rate) were recruited from a diabetic clinic that is part of a large tertiary medical center in the midwest United States. All individuals were approached by their diabetic care provider about participation in the study. Those interested in sharing their perspectives were screened for inclusion and the study was explained. Interested individuals signed informed consent before participating in the study. Each participant was asked to answer the quantitative portion first. After completing the first portion, a purposeful sample of 25 EAs was further recruited to participate in interviews. Those EAs recruited for the qualitative arm were selected based on differing transitions among the studies population inherent to this age group as reported to the research team by the participant’s provider. Examples of transitions include participants moving away from home, starting college, graduating from college, starting a job, and starting a family.

Qualitative interviews were performed with participants describing events surrounding specific times when diabetic care (i.e., blood-glucose monitoring, insulin administration, meals, and exercise) did and did not occur during a transitional event of the interviewees. It is recognized that estimating sample sizes in qualitative work *a priori* is difficult (Sim, et al., 2018). The target of 25 participants was selected based on the projected number of diabetic situations that would be described throughout the interviews. With participants asked to describe times when regularly scheduled diabetic appointments were attended and missed during their transition, between 25 to 50 situations were estimated to be elicited for analysis involving appointment behavior. A total of 74 unique scenarios were obtained.

Eligibility criteria for the sample included: 19 - 30 years of age, diagnosed with T1D for at least one year prior to the interview, able to speak and read English, and did not have a secondary chronic disease or mental health issue that interfered with independence. Arnett (2016) considers emerging adulthood to be between 18 – 25 years, recognizing those up to 30 years in age. The minimum age of 19 for this study aligns with the age of majority in the state where recruitment occurred. A diabetic provider established independence in those with a secondary chronic diagnosis. Patients were not excluded based on diagnosis alone. As an example, a patient with an autism spectrum disorder whose symptoms did not interfere with an ability to live independently would not be excluded. However, a potential participant with an autism spectrum disorder that was unable to live independently from their parents or other caretaker would be excluded.

### **Data Collection**

The study was approved by the institutional review board of the associated investigator. After consent, and completion of the quantitative questionnaire, interviews were conducted by research assistants (RAs) over the phone at a mutually agreed time between the RAs and study participants. Scripted guides applying critical incident technique (CIT) – a known method that helps elicit understanding or what helps or hinders an activity (Viergever, 2019) – were utilized for each interview. Interviews averaged about 25 – 30 minutes in length. Interviews were audio recorded and transcribed verbatim by a third-party professional transcriptionist. Transcripts were reviewed by the RAs conducting the interview for accuracy and tone. As an incentive to participate, individuals who completed the interview received a gift card for \$50.

Guided interview questions focused on events that facilitated or impeded appointment attendance during transitional events for emerging adults. Interviewers asked study participants to describe times when diabetes care, specifically appointment behavior, was and was not



performed. Specific to appointments, participants were asked about routine diabetes endocrinology visits and to “Think about a time after one of these changes when [they] did go to an appointment as scheduled,” and “...did not go to [their] appointment as scheduled”. Follow-up questions were also posed to elicit contextual information including time of the appointment, what assistance or reminders were given, and who or what got in the way of attending the appointment. Responses to appointment attendance questions and follow-ups were the focus of this secondary analysis.

### **Data Analysis**

Responses from the interviews were analyzed via directed content analysis (Hsieh & Shanon, 2005) for thematic exploration (Gremier, 2004). The subset of appointment attendance responses explored in this study were examined in a similar but more focused approach than the primary study, a valid methodology for secondary analysis (Hinds et al. 1997), with a specific interest in appointment behavior. This author and the primary investigator of the study read each transcript line-by-line and coded responses to the questions specific to appointment behavior as facilitating or inhibiting attendance. Responses were coded as inhibitors when an appointment was missed or rescheduled by the participant. Facilitating factors were recognized with responses when appointment attendance was achieved when regularly scheduled. Inhibitors and facilitators were further collapsed based on *a priori* definitions for each domain of the consumer-based construct – capacity, criticality, cost, convenience, and comfort – as previously described in framework (see Table 1 for definitions). The proposed conceptual themes were applied to the dataset, *a priori*, to explore consumer-like behavior (Jayanti & Burns, 1998), where acceptance and utilization of health services differs among individuals based on fit between the perceived value of service provided and balanced against financial,

personal, social, and time constraints they find important (Penchansky and Thomas, 1981; Berry et al., 2002).

### **Rigor**

Established literature outlying rigor of secondary analysis of qualitative is sparse (Ruggiano & Perry, 2019). Based on literature available, consideration guiding the study was made in regards to the consistency, sensitivity, and approach of the secondary analysis in relation to the primary purpose of data collection (Hinds et al., 1997; Szabo and Strang, 1997). The analysis for this secondary study was conducted promptly, and in parallel to the primary study by the primary research team. The concurrent analysis of this secondary analysis to the primary study by the same research team also helped the “aggregate(d) impression,” sensitizing the researchers to data (Hinds et al., 1997). Furthermore, the researcher team involved with participant interviews and analysis for the primary study were also those involved with the analysis for this study, which allows for “appropriate sensitization” of data material (Hinds et al., 1997).

## **Results**

### **Sample Characteristics**

A total of 25 EAs with T1D were interviewed. The average age of participants was 21.8 years (range = 19 to 26 years) with an average age since first diagnosis of 11.4 years (range = 1.9 to 21.9 years). There was nearly equal representation with gender (female = 12, male = 13). Glycemic control measured as percent of HbA<sub>1c</sub> was on average 9.1% (range = 6.2% to 13.9%), or 79 mmol/mol (range = 44.7 to 128.6 mmol/mol). The sample was mostly Caucasian (n = 22), with the remaining participants identifying as African American (n = 3). Educational enrollment at the time of the study included individuals in school (n = 14) and not in school (n = 11). Employment status consisted of full-time (n = 9), part-time (n = 13), and those not working (n =

3). Most individuals' financial perception was that they "had just enough" (n = 16), while others perceived they "had more than enough" (n = 5), or that they "don't have enough" (n = 4).

### **Consumer-level factors**

Consumer-level factors as both facilitators, those characteristics that influenced participants to attend scheduled appointments, and inhibitors, characteristics that discouraged attending scheduled appointments were identified during analysis. Table 1 provides exemplars of facilitators and inhibitors for each consumer dimension.

<Table 1 about here>

#### *Facilitators*

Consumer-level factors that influenced attendance included criticality, capacity, convenience, and comfort. Cost was not identified as a facilitator among those interviewed. Consumer characteristics that were facilitators described situations that were associated with attending an appointment or remembering that an appointment was scheduled. Criticality, the importance placed on a health event, was reflected as both an explicit characteristic of the appointment process and as an implied component of the decision-making process. Explicit criticality was noted when participants stated making an appointment or attending an appointment as a behavior with central importance. An example of explicit criticality was: "I would schedule around like [sic] all my stuff." Implied criticality was more prominent. Implied criticality as a facilitator was expressed when participants noted that they made or kept an appointment in proximity to another event. These statements were considered implied because patients made a planned, cognitive effort to make an appointment or attend their regularly schedule diabetic appointment without directly stating the act as important. Examples were: "I've always planned my appointment with those, like returns to the city;" and "I had an

appointment and ... even though we had all that stuff going on we were able to still remember the appointment.”

Convenience, a component of a service that allows for reduced time or effort, was noted as a facilitator when participants discussed appointment reminders. Examples of the types of reminders that helped included: “I get text message alerts from [clinic name] saying you have an appointment at this time, this day;” and “I’m kind of just dependent on the phone call that they make the day or two before [the appointment].” Additionally, reliable transportation was noted by participants. An example was: “Because right now I can’t drive so she [the mom] kind of is helping me out get [sic] to my appointments and stuff.

Participants reflected on comfort, a service characteristic that makes an individual feel safe or valued, with statements that made them feel valued as a patient at the clinic. Examples include: “... I do like that they send the text just so I know that they are still expecting me;” and “I really enjoy that [clinic reminders], because it’s just nice to have that reminder and the text updates I get.” Comfort was also noted as a facilitator when an individual expressed an ongoing relationship with a provider – see table 1 for quote.

Capacity, the ability of an individual to gather, understand, and use health-related information, was reflected in quotes that discussed the use of patient portals to remind them of appointments. A distinction between text messages and phone calls, as reminders via the clinic (e.g., convenience), and clinical reminders from a patient portal (e.g., capacity) is in the activity of the participant. Texts and calls are pushed to the recipient in a passive manner whereas looking up a scheduled appointment in a patient portal requires knowledge about resources and active retrieval by the individual. Examples of capacity were made when participants described how they remembered to go to appointments, including: “I think they called me or text [sic] me

and then I also have [patient portal] set up;" and "If I don't get a phone call, I just check the [patient portal] patient website."

### *Inhibitors*

Inhibitors that affected appointment behavior included criticality, capacity, convenience, comfort, and cost. Inhibiting characteristics were described during situations where appointments for regular diabetic care were missed or forgotten. Similar to its facilitating role, criticality as an inhibitor, was expressed as an explicit factor as well as implied. Explicit criticality occurred when individuals forgot about an appointment or decided not to attend their appointment without any other competing event such as school, work, or child-care needs. An example is: "... I totally spaced off the date and my mom told me like a few weeks before and I just spaced it off and forgot totally about it." Implied lack of criticality involving appointment attendance was a prevalent theme. Participants often described competing demands that were viewed as a priority over attending a scheduled appointment. Some examples include "I think I had a group project and that was the only time we could meet;" and "I was not able to get to the appointment because of the restrictions that were at my job. If you missed, you could possibly be terminated".

Lack of convenience as an inhibitor was reflected in statements where scheduling an appointment in advance was viewed as too rigid for the participants. An example of an inhibiting situation is, "you have to make them [appointments] so far in advance...then come to find out I have a big exam on this day...I need to go to class so it's more challenging to work around that." Interestingly, implied criticality may interact and override inconvenience. One participant recounted, "You have to make it work. You have to say hey, sorry I can only go to the doctor from this time to this...but no matter what, I'm always going to miss something or have to reschedule something."

Lack of comfort was discussed by a single participant when comparing the ability to make an appointment at the adult endocrinology clinic compared to the pediatric clinic where they had been receiving care. The patient stated, “I guess it’s made it harder though, because I’m at the same clinic like [sic] the adult one when I was just at like [sic] [pediatric clinic name].”

Lower capacity was noted as an inhibitory characteristic to appointment behavior when participants described situations where an appointment was missed due to a change in resources. An example was:

*For some reason they weren’t doing the calls, so I had to reschedule two of the appointments because I just straight up didn’t know it had happened and me being young, I don’t have a calendar or anything like that. I don’t plan far enough ahead to remember those kinds of schedules, especially months in advance.*

The highlighted situation can be contrasted from explicit criticality as an inhibitor because the participant expressed a lack of knowledge or ability to perform a self-management task when an external resource was removed. Further delineation from criticality is made when the participant reflected a sense of not being able to perform an autonomous task due to age. A similar sentiment was expressed with a participant recalling missed appointments because, “My mom stopped going with me to appointments once I turned 16 [when discussing a series of missed appointments]”. Similar to the first example, an expression of a reduced ability to act because of age was noted.

Cost was noted as an inhibiting factor in absolute terms as affordability, the ability to pay for a service, and in relative terms as opportunity cost, the loss of revenue or time when making one choice over another. Cost as an absolute inhibitor was described when patients discussed their financial and insurance vulnerability. An example was: “I was a bit low on income, I didn’t have insurance, so I couldn’t really see a doctor.” Financial opportunity cost to

attend appointments can cause a loss in wages, paid time off, or sick leave for an individual. One EA described the difficult trade-off for appointments when stating, “I work hourly; I’m not salary, so trying [sic], scheduling appointments is difficult. It takes up my leave time as well as stuff like sick leave ...I’m also losing money going to appointments if I choose to do so.”

### **Discussion**

Findings from the study suggest that consumer-based factors are present in appointment behavior among emerging adults with T1D. Framing attendance patterns in diabetes appointments as a function of consumer behavior may provide additional insight into utilization of adult diabetic services during transitional periods of young adults.

Both facilitators and inhibitors were identified for each dimension with the exception of cost, with no facilitating behavior identified associated among those interviewed. Reasons for a lack of cost as a facilitating factor within the study could be based upon participants continued insurance coverage under their parents, the small sample size, or as a limitation of the secondary data analysis design.

However, cost may be more unidirectional in terms of appointment behavior as an inhibitor only – an individual can either afford the clinic visit or cannot. In viewing access illustratively as a door to a clinic, cost is inhibitive (i.e., the door is closed- cannot afford) or noninhibitive (i.e. the door is open – can afford). This is juxtaposed against the other consumer components of access behavior that, can be inhibitive (i.e., the door is open, but I do not want to walk through the door), but may also serve as facilitating appointment behavior as motivators for emerging adults (i.e. the door is open and I want to walk through the door). Further research is needed to verify both the directionality and relationship among concepts of the framework and regular attendance.

Multiple consumer access characteristics were perceived by each participant suggesting that a dynamic relationship among all consumer-based constructs interact as facilitators or inhibitors to appointment behavior among EAs with T1D. The multifaceted association between consumer dimensions observed in this analysis aligns with previous literature on access (Ricketts and Goldsmith, 2015; Saurman, 2015) indicating that all consumer-based behavioral constructs may influence each other. This may be explained by unique, competing life demands and constraints among each participant where one or two consumer dimension(s) takes a lead over the other dimensions. To further explain, a college student whose medical care is supported financially by their parents may not perceive cost as an inhibitor or facilitator but places a lot of importance on having a good relationship with the clinical care team. Conversely, another EA may have recently graduated or moved from their parents' home and is financially independent. For this individual, having a cost affordable option that conveniently aligns with work or school is vital for them to attend appointments regularly. Lastly, individuals that have few complications with their diabetic care, despite having malglycelia may not feel that it is critical to attend an appointment despite efforts to reduce cost and improve convenience by the care team. Additional research into the association among consumer characteristics is needed to better understand the dynamic relationship among consumer characteristics and study the implications among more heterogeneous populations.

### **Clinical and Research Implications**

Findings from this study provide an expanded lens understanding of appointment behavior. Assessing which consumer-based factors are likely to facilitate or inhibit regular attendance in a clinical setting may improve the transition process for EAs between pediatric and adult care. In research, the saliency of concepts explored in this secondary analysis has shown promise for the use of a consumer-based theory in explaining the variability of



appointment behavior observed in the EA with T1D population. Application of the consumer constructs explored in this manuscript could expand the approach of how appointment behavior and utilization of services is examined, adding to the knowledge base in emerging adult studies and health services research. Beyond this secondary analysis exploring use of consumer-based theory, future primary research is needed to investigate the concepts in greater depth and verify the relationships among the theoretical concepts of the framework with regular attendance. Additionally, a broader application of the consumer-based construct using cost, convenience, comfort, capacity, and criticality to the general population should be explored as consumer sentiment regarding regular ambulatory care is potentially analogous among different clinical populations.

### **Limitations**

Limitations to this study are known with specific concerns regarding a secondary data analysis of qualitative studies acknowledged. The authors are aware that much debate on secondary analysis of qualitative data is present, including in health services research (Ziebland and Hunt, 2014). However, the application of a secondary analysis to the data on appointment behavior should not be wholly dismissed. The guided questions and follow-ups asked to elicit responses from participants were designed to address the primary study question - to assess diabetes habits and routines during transitions. Responses gathered, and analyzed, on appointment behavior were not internally influenced by the research design or question posed of this study – what helps or hinders appointment attendance. Thus, responses, in relation to this study's aim, were unencumbered by wording and questioning bias.

The use of *a priori* analysis using the blended consumer-based concepts to the data creates additional limitations that should be acknowledged including overall validity. Clearly, and with concern, confirmatory projections should be considered. Writings on CIT warn it is

important that analytical interpretations of the data are not assumed through prior knowledge (Schuler et al., 2007). Yet, it is important to consider the limitations, and confirmation bias, within the context and purpose of the study itself. Generalizability of the study was never within the purview of the aims, nor was the intent of the study to solidify theory. Findings from the study are in line with the aim of the study to explore tentative conceptualization of a consumer-based construct.

### **Conclusion**

This study was able to successfully demonstrate the proof of concept regarding the saliency of consumer dimensions among EAs with T1D. Cost, convenience, comfort, criticality, and capacity may be consumer-driven concepts that facilitate or inhibit appointment behavior among EAs with T1D. Secondary analysis, and CIT methods, allowed for a pragmatic and novel assessment of consumerism and appointment behavior among EAs with T1D. A more classically structured study should be performed to assess depth and relationship among cost, convenience, comfort, capacity, and criticality and appointment behavior.

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Figure 1. Blended model of healthcare consumer facilitators and inhibitors

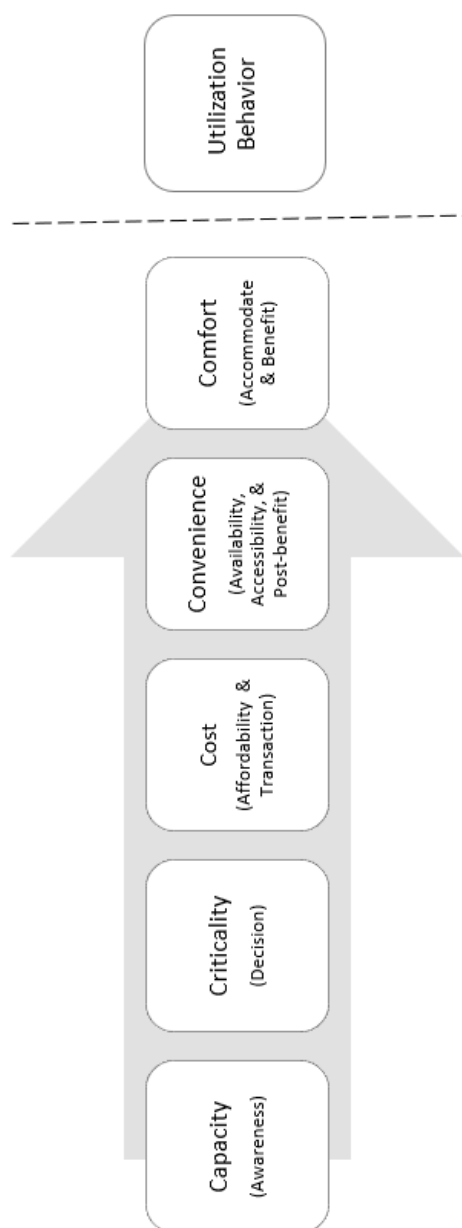


Table 1. Examples of consumer access dimensions as facilitators and inhibitors

Consumer Dimension	Definition	Facilitator	Inhibitor
Capacity	The capability of an individual to obtain and understand information to autonomously make health-related decision.	“If I don’t get a phone call, I check the One Chart® patient website”	“For some reason they weren’t doing the calls, . . . because I just straight up didn’t know it had happened and me being young. . . I don’t plan far enough ahead to remember those kinds of schedules”
Criticality	The importance placed on a health-related event.	<p>“I make sure to schedule it on a day that I had off from school”</p> <p>“I usually schedule all my appointments around breaks because I know them beforehand. . . I’ve never missed an appointment”</p> <p>None identified.</p>	<p>“I started school and I totally spaced off the date”</p> <p>“I actually usually have to reschedule, so I think every time I make an appointment [. . .] just because life gets that [sic] in the way”</p> <p>“I was a bit low on income, I didn’t have insurance, so I couldn’t really see a doctor”</p>
Cost	The ability to pay for a service along with perceived value of a service in relationship to the price.	None identified.	“I was a bit low on income, I didn’t have insurance, so I couldn’t really see a doctor”
Comfort	The perceptions of competency, technology use, and communication styles that allow an individual to feel safe and understood.	“I’ve had to reschedule, but I think I’ve done a pretty good job since I’ve been working with the same provider for so long”	“I guess it’s made it harder though, because (now) I’m at the same clinic, like the adult one, when I was just at like [sic] Children’s”
Convenience	A characteristic of a service that allows for a reduction in the threshold to act (consume).	<p>“I get it scheduled up to 3 months in advance, so that I can plan accordingly”</p> <p>“To get the call from the doctor’s office is, the call or text is the best thing in the world”</p>	<p>“You have to make them [appointments] so far in advance. . . then come to find out I have a big exam on this day”</p> <p>“You have to say hey, sorry I can only go to the doctor from this time to this. . . but no matter what, I’m always going to miss something</p>

## CHAPTER IV: Manuscript 3

### Rural Access Strategies and Health Outcomes during the COVID-19 Pandemic: State of Nebraska Case Study

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## Introduction

The COVID-19 pandemic was uniquely deadly to rural America. During the second half of 2020, rural counties experienced greater numbers of COVID-19 deaths per 100,000 adults than their urban counterparts (Dobis and McGranahan, 2021). In sheer numbers, the last quarter, was even deadlier. During the final months of 2020, rural individuals, comprising roughly 20% of the United States (U.S.) population (Health Resources & Services Administration [HRSA], 2021), experienced over 27% of total deaths (Cromartie et al., 2020).

Composed of diverse geographical, economic, and culturally distinct communities, rural Americans tend to be older, have a greater number of chronic health problems, and less access to healthcare than their urban counterparts (Chartis Group, 2020; Henning-Smith, 2020, Douthitt et al., 2015). Each of these health factors (age, chronic disease, and limited access to care) make rural individuals more susceptible to negative effects of the SARS-Cov-2 virus responsible for the COVID-19 pandemic (Baradaran et al., 2020).

Rural health is primarily managed through a network of Critical Access Hospitals (CAH), private and federally funded rural health clinics, and rural-serving regional hospitals (American Hospital Association [AHA], 2019). Challenges in providing adequate access from these organizations to their rural constituents are complicated. Most of these rural designated entities work within a complex environment of socioeconomically disadvantaged patients, high regulatory burden, and challenging staffing situations (Henning-Smith, 2020; AHA, 2019, Hostetter & Klein, 2017). Moreover, in general, and in light of the COVID-19 pandemic, rural healthcare organizations were short on vital medical resources needed to care for those who were infected and became critically ill. In many cases, rural-serving regional and critical access hospitals had fewer intensive care beds, specialty-trained physicians and nurses, and medical supplies such as ventilators to care for the sickest COVID patients (Orgera et al., 2020).

In March 2020, the U.S. Department of Health and Human Services (DHHS) performed a survey to assess the current state of hospitals across the country. Among the findings, specific challenges related to patient access to care due to social distancing and operational resource mitigation efforts were identified (Office of Inspector General [OIG], 2020). Based on information from this report, along with other federal agency recommendations, a number of federal guidelines and recommendations were offered to healthcare organizations across America during the early stages of the COVID-19 pandemic in 2020. Some recommendations included reducing or eliminating outpatient services, elective surgeries and procedures, and alterations to in-person appointments (Centers for Medicare & Medicaid Services, 2020; American College of Surgeons, 2020, Centers for Disease Control, 2020, Lewis et al., 2020). While necessary to slow the spread of the virus responsible for COVID-19, and to better respond to community outbreaks, the changes in care delivery may have altered perceptions and created additional barriers to timely care already present in rural health care. To date, little is known about both the general and specific access strategies utilized in rural communities and the potential impact of those strategies on COVID-19 outcomes.

As such, the purpose of the following study was to describe access strategies implemented by rural healthcare organizations during the Fall 2020 pandemic surge in the Midwest. Additionally, associations between rural versus urban designations, community characteristics (e.g., number of hospitals, hospital bed density, and meat packing plant density), and COVID-19 outcomes were explored. The specific aims of the study were 1) identify and describe access strategies utilized by rural healthcare organizations in a rural Midwestern state; 2) explore associations between COVID-19 confirmed cases and deaths and community characteristics in rural designated communities; and 3) explore associations between access strategies used, COVID-19 reported cases and deaths, and community characteristics.

## Methods

A cross-sectional survey was administered to rural hospital and clinical healthcare professionals in the State of Nebraska between October 19 and December 4, 2020. Participants, including rural administrators, medical providers, and nurses, were recruited with assistance from the Nebraska Hospital Association (NHA), University of Nebraska Medical Center Office of Rural Health Initiatives, and Nebraska Nurse Practitioners.

Individuals were eligible for the study if a) their primary place of employment was located in a Rural-Urban Commuting Area (RUCA) of more than or equal to four, b) were an administrator (e.g., CEO, COO, CFO, CNO, or office manager) or registered clinician (e.g., MD/DO, APP, or RN), and c) were a working professional prior to 2020. Participants were excluded if a) their primary place of employment was in a community with a RUCA code of 1 – 3, b) if the clinic or hospital was considered a specialty location (e.g., orthopedics), c) if they were employed as an intern, medical resident, or post-graduate, or d) if they were a student.

Definitions of rural can vary. For this study, rurality was defined using RUCA. RUCA codes use a primary classification system ranging from one to ten as a measure of population density, urbanization, and daily commuting habits of an area. Codes one to three on the continuum are considered metropolitan, four through six micropolitan, seven through nine small towns, and ten as rural areas. Micropolitan areas, RUCA codes four through six, with populations between 10,000 and 49,999 residents, with varying levels of commuting flow, are considered the upper bound of rurality for this study. Using RUCA code four as an upper bound of rurality generally aligns with other research and federal agency practices of defining RUCA communities four through ten as rural (HRSA, 2021).

A total of 64 critical access hospitals and 209 rural-serving family practice, internal medicine, and pediatric clinics were eligible and recruited, with 165 responses received. After

removing incomplete surveys (n = 26; 25 partial online and 1 partial paper), along with surveys that were completed but listed a RUCA zip code of  $\geq 3$  for their primary place of work (n = 11), a total of 128 surveys were eligible for analysis. An additional 36 respondents elected not to complete the access questionnaire, leaving 92 completed surveys eligible for the study. Final response rate included 35 unique CAHs (55%) and 45 unique clinics (22%). There are a total of 120 rural communities in the State of Nebraska with a minimum of one clinic or hospital with 61 unique communities (51%) and 49 of 93 counties (53%) were represented in the data.

### **Data Collection Procedures with Health Care Professionals**

The survey included three sections, each with a distinct focus, specifically, operation support, clinical support, and adaptive access strategies implemented in response to the COVID-19 pandemic. Sections one and two of the survey were focused on understanding operational and clinical support respectively. As such, eligible administrators were asked to complete section one of the survey and not section two and vice versa for eligible medical and nursing professionals, completing section two, not section one. Section three of the survey asked both administrators medical and nursing professionals to answer questions about changes in access strategies used by their organizations because of the pandemic. Responses from section three of the questionnaire, which focused on access, are reported in this manuscript.

Surveys were available in both paper and electronic versions. Paper forms were mailed directly to targeted rural clinical locations and provided with a stamped-return envelope. Locations were identified using zip code and clinical specialty designations as provided by the Health Professions Tracking Services database maintained by the University of Nebraska System. Electronic surveys were sent to rural administrators and clinicians in partnership with state-level professional associations who directly emailed their rural members with a link. Returned paper forms were entered and spot checked to ensure accuracy. Electronic data was collected and

maintained using the REDCap electronic data capture tool hosted at the University of Nebraska Medical Center.

Participation was voluntary and all surveys contained a consent message along with contact information of the principal investigator and research compliance office of the host institution. This research was approved by the Institutional Review Board of a large academic medical center.

### **Access Measures with Health Care Professionals**

Adaptive access variables were measured by asking rural health care professionals to select all access strategies that applied to their individual organizations for each variable, i.e., comfort, convenience, capacity, and cost. Criticality is theorized to be a personal belief about a health event (i.e., chest pain) and was not measured as part of this survey because health consumers, and their perspectives were not the focus of this research. Five scenarios each were asked for convenience, capacity and cost; six scenarios were asked for comfort. Additionally, each scenario provided “other” as an option with the ability to write-in strategies not specifically mentioned.

Convenience was measured by asking participants if their organization made any changes to hours of operations for clinics, alterations to appointment times, changes in patient flow (e.g., separating sick and well visit times during the day), curbside appointments, or changes to telehealth visits. Capacity was measured by asking participants about patient information strategies to increase awareness of COVID-19 related changes; including, for example, symptom and treatment information, changes in services, safety, and community spread. Specific capacity questions asked about active and passive communication strategies including the telephone hotlines, website updates, social media campaigns, mailed letters, and other local media outlets like newspapers and television news stories. Cost was measured by



asking participants if any organizational changes were made that changed cost obligations for their patients. Cost questions asked about accepting new self-pay patients, accepting new Medicaid patients, offering flexible payment plans, and postponing collection efforts. Comfort was measured as safety and support of patients. Questions included masking requirements, social distancing directions, increased signage, symptom and temperature screening, hand washing stations, and visitor and guest policy changes.

### ***Framework***

The access adaptation survey was developed using, in-part, questions asked in the March 2020 DHHS report (OIG, 2020), along with the Consumer Model of Utilization (CMU) - see Figure 1. The CMU is an exploratory framework, guided by the Penchansky and Thomas 5 A's to Access domains (Penchansky & Thomas, 1981), Andersen Health Utilization Model (Andersen, 1995), and influenced by the Model of Service Convenience (Berry et al., 2002). Within the CMU framework, five distinct consumer concepts - comfort, convenience, capacity, cost, and criticality - are posited to influence access and utilization of healthcare services. An initial draft of the survey was reviewed by a multidisciplinary team consisting of academic researchers, healthcare providers (e.g., MDs, APPs, and RNs), rural healthcare managers, and professional association leaders with rural-serving members. The survey was revised for clarity and ease of use based on the input from these reviewers.

### **Data Collection Procedures of COVID-19 and Community Data**

Outcomes and community characteristic data, including hospitals, hospital beds, and meat processing facilities (i.e., meat packing plants), were obtained from national datasets. COVID-19 data from rural and urban communities was aggregated from a USA FACTS (2021) dataset and analyzed against rural-urban commuting area (RUCA) codes (United States Department of Agriculture [USDA], 2020). COVID-19 data used for final analysis included

confirmed cases and deaths reported between January 1, 2020 and December 31, 2020 and was grouped by county. RUCA codes, linked to zip codes, were compiled and averaged for each county in the state.

Hospital and certified hospital bed data were obtained from the U.S. Department of Homeland Security (DHS) Homeland Infrastructure Foundation-Level Data set, last updated in December 2020 (DHS, 2020). Hospitals included public, not-for-profit organizations with general medical care. Specialty, behavioral health, military and other federal hospitals, along with free standing emergency departments were excluded. Pediatric hospitals, if present in a community, were included. Certified hospital beds are registered and approved beds by a state board of health as being available for permanent use and have adequate staffing to support patient care. Beds in hospitals used for overflow or relocated between departments are not considered certified and were not included for analysis.

Meat packing plants information was gathered from the U.S. Department of Agriculture (USDA) Meat, Poultry, and Egg Production Inspection Directory updated in January 2021 (USDA, 2021). Zip codes listed for each meat packing plant was cross-referenced and matched by county-level data using Microsoft Excel. No exclusion criteria were placed on USDA regulated agricultural facilities, which included meat, poultry, and egg facilities.

### ***Data Analysis***

Compiled data was analyzed using IBP SPSS 27. To address Aim 1, descriptive and frequency data analysis was performed on access data. To address Aim 2 and 3, correlational and relative risk analysis was performed with COVID-19 cases and deaths for per 10k residents for 2020, COVID-19 cases and deaths per 10k residents for Q4 2020, RUCA codes, number of hospitals, number of hospital beds. Significance was set at  $p < 0.05$ . No power analysis was

performed for this study as a complete state-level dataset was available for all variables under study.

## Results

### Health Care Provider Characteristics

In total, 92 individuals provided access information about their organization. The sample was broadly representative of rural healthcare with participation nearly equally distributed between rural hospitals ( $n = 45$ ) and clinics ( $n = 47$ ). Respondents were mostly female ( $n = 63$ ), held administrative positions ( $n = 54$ ), and did not have a meat packing facility in their community ( $n = 66$ ). A plurality of participants had more than 20 years of professional experience ( $n = 27$ ) and were from very rural communities (RUCA 10 = 40). As mentioned previously, participants represented 54% of the CAHs, 22% of the rural-serving clinics in the state and represented 51% of the state's rural communities with at least one hospital or clinic. State-level reporting efforts for the COVID-19 pandemic in Nebraska utilized the state's six Healthcare Coalitions (HCCs), comprised of public health agencies, hospitals, EMS providers, and emergency management organizations. Responses were received from all six HCCs in the state. General characteristics of the study participants are displayed in Table 1 with responses by unique counties in Nebraska illustrated in Figure 2. State aggregated data included COVID-19 data from all communities (i.e., RUCA 1 – 10).

### Aim 1: CMU Access Strategies

Access questions were aggregated from 80 rural hospitals ( $n = 38$ ) and clinics ( $n = 42$ ) in Nebraska. Table 2 provides frequencies of responses.

#### *Comfort as Safety and Support*

Most organizations (91.3%) implemented safety measures for patients and visitors ( $M = 4.78$ ,  $SD = 2.26$ , range 0 - 7) with symptom and temperature screenings (89.1%) and mask

requirements for patients (90.2) noted most often. Visitor policy changes were also common among organizations surveyed ( $M = 2.45$ ,  $SD = 1.17$ , range 0 – 6). Minor-aged patients were most frequently noted to have visitor or helper restrictions (61.3%) with non-English (40.0%) and labor patients (38.8%) having the fewest. Most organizations ( $n = 52$ ) plan to remove visitor restrictions after the pandemic has subsided with only 12.5% of organizations planning to keep at least one restriction in place.

#### *Convenience as Scheduling Changes and Telehealth*

Changes to appointment scheduling were also a common strategy among organizations surveyed with many (81.3%) altering ambulatory care appointments ( $M = 2.16$ ,  $SD = 1.75$ , range 0 – 6). Changes in patient flow, separating sick and well patients with designated locations, was a common strategy (65%). Specific flow changes with designated appointment blocks for well-visits and acute illness (28.8%) and offering curbside appointments (28.8%) were implemented by over a quarter of organizations. Telehealth was adopted as a common access strategy with the number of organizations offering remote appointments increasing from 21.3% to 70.0%. However, less than half (38.8%) plan to keep the service with another 17.5% of organizations surveyed undecided on keeping telehealth.

#### *Capacity as Increased Awareness*

Over half (62.5%) of the organizations surveyed provided outreach to their patients regarding safety measures and service changes resulting from COVID-19 ( $M = 1.18$ ,  $SD = .94$ , range 0 – 3). The most common (47.8%) active communication strategy was the use of local and social media (i.e., newspapers, Facebook). Passive information strategies included the use of organizational webpages and telephone lines (47.8%) for patients. Several organizations provided information in more than one language on phones ( $n = 15$ ) and webpages ( $n = 33$ ).

#### *Cost as Changes in Payment Plans and Collections*

Changes in patient payment models was not a common strategy with just 20% of organizations adopting a change ( $M = .26$ ,  $SD = 0.50$ , range 0 – 2). Providing new flexible payment plans and expanded charity care were reported a combined 12.5%. Other cost strategies not noted on the survey was the most common response (10%). Delayed collection efforts (7 of 8) and postponement of a down payment plan for large procedures (1 of 8) were the noted *other* responses.

## **Aim 2: Rurality and COVID-19 Cases and Outcomes**

The State of Nebraska in 2020 reported 120,274 confirmed COVID-19 cases along with 1,649 deaths for a case fatality rate of 1.37%. Table 3 provides aggregated confirmed COVID-19 case and death data experienced in Nebraska for both Q4 2020 and totals for the year 2020. Confirmed cases and deaths were standardized and reported at a population rate of per 10k residents. Table 4 provides correlational data between rurality, meat packing facilities, and hospital density against State of Nebraska COVID-19 related cases and fatalities.

### *Cases*

Total confirmed COVID-19 cases aligned with population spread across the state with a higher number of cases occurring outside of rural communities ( $p = .00$ ). The number of meat packing plants in a county was also associated with overall confirmed cases for the year ( $p < .001$ ) and during the peak in Q4 2020 ( $p = .02$ ). Rurality was again negatively associated with Q4 2020 confirmed cases ( $p = .02$ ).

### *Deaths*

Total deaths in 2020 as a result of COVID-19 in Nebraska was not associated with rurality ( $p = .21$ ), nor the number of hospitals ( $p = 0.29$ ) and hospital beds ( $p = .34$ ) per 10k residents in a county ( $p = .34$ ) or number of agricultural facilities in a county ( $p = .14$ ). When looking at Q4 2020 deaths, rurality was a factor. Q4 2020 deaths were statistically associated

with higher levels of rurality ( $p = 0.02$ ). Rural communities (38.36% of total population) recorded 40.48% of cases and 52.35% of total reported COVID deaths. Case fatalities rates for rural versus urban in Q4 were 1.26% and 0.78%, respectively, with a relative risk of death with infection from COVID-19 for rural residents of 1.205 (95% CI 1.05 – 1.383).

### **Aim 3: Access Strategies and COVID-19 Outcomes**

Rural access strategies (i.e., cost, convenience, comfort, and capacity) showed homogeneity at the county-level, for those specific counties represented by participants, when correlated with COVID-19 outcome data (e.g., confirmed cases and deaths). Statistical significance was tested, but not observed, between total COVID-19 outcomes and individual access strategies (i.e., adding up changes made within each variable such as cost, convenience, etc. per organization) or between total COVID-19 outcomes and total access strategies (i.e., adding up total changes for all variables - comfort, convenience, cost, and capacity, per organizations).

### **Discussion**

In this study the researcher sought to identify and describe access strategies of rural healthcare organizations during the pandemic and explore the association of rurality and COVID-19 outcomes information. State-level data comparing the effects of the COVID-19 pandemic among rural and urban communities in Nebraska was previously unreported. Results from the study indicate rurality was positively associated with death and inversely associated with confirmed cases. The finding suggests that rural Nebraskans were more likely to die if contracting COVID-19 than their urban counterparts during the Fall 2020 surge. The results align with other studies exploring the death burden associated with rural living (Shiels et al., 2019) and are a stark reminder that rurality remains an indicator of health disparity in the U.S.

The findings also suggest that certain community characteristics, specifically meat packing facilities, contributed to the spread of COVID-19 in Nebraska. Early in the pandemic, rural communities with meat packing plants experienced some of the largest outbreaks nationwide (Duffy, 2020; Lussenhop, 2020). These outbreaks were largely attributed to the close working conditions present in large-scale agricultural processing facilities along with longstanding health inequities, cultural differences, and poorer access to care of the workers and their families (Stone et al., 2019; Douthit et al., 2015). Data from this study aligns with earlier reports and suggests that meat packing facilities continued to play a role in spread of COVID-19 throughout the year (Middleton et al., 2020). Yet, meat packing plants were not associated with COVID-19 related deaths in this study. Although appearing as a juxtaposed relationship, the relative younger median age of minority groups in the U.S. (Schaeffer, 2019), those most likely to work in agriculture plants, would align the observed spread of disease without greater rates of death (Gold et al., 2020).

Access strategies were aggregated to assess if dominant approaches were being used statewide. Unsurprisingly, most health organizations focused on internal safety measures that could easily be controlled and provided a safe environment for both patients and staff. The rapid uptick in telehealth reported in other literature (Koonin et al., 2020) was also noted in this study with an over three-fold increase in adoption. However, not all locations felt that adoption was a good fit for the organization with just over a third definitely planning to continue with remote appointments. This finding suggests that continued barriers to telehealth adoption may persist in rural practices and communities. Further studies on telehealth utilization by rural organizations are needed.

Standardized hospital and hospital bed data per 10k individuals served as a crude measure of access in this study. Hospital density appeared relatively uniform at a county level

across the state with slightly more beds per resident in rural counties. Neither hospital nor hospital density residents appeared to be a factor in COVID-19 outcomes. Because hospital beds density does not measure medical resource availability, such as pulmonologists, intensive care nurses, and respiratory equipment, it alone may not have served as an effective substitute to measure the impact of medical access during the COVID-19 pandemic.

### **Limitations**

This study is limited by several factors. Although attempts were made to use previously published survey questions, and validate with multiple expert advisors, the novelty of the COVID-19 pandemic in the U.S. limited the ability to utilize vetted survey tools. As such, the survey questions, and associated framework, without the benefit of rigorous validity and reliability, may not have performed as well as intended. Moreover, the survey was administered in a single midwestern state during the peak of the Fall 2020 pandemic. Individual states may have taken different approaches due to geographical and legal differences that limit the generalizability of the study. Additionally, the COVID-19 pandemic, and the response to the pandemic, became politically charged. Selection bias may have occurred with only those individuals responding that either felt the pandemic was serious or not serious. The novelty of the pandemic may have also limited the correlational findings. Variables like age, income, local public health mandates, were not assessed in this study, and may have influenced the relationship of rurality and COVID-19 outcomes. Finally, data on access strategies may have been affected by the timing of the survey. The time between the beginning of the pandemic and the Fall 2020 peak, when the survey was administered, meant rural organizations had time to react, collaborate, and adjust strategies. As a result, best practices may have emerged and affected the variability of strategies observed in this study.



## **Conclusion**

Rural communities continue to experience inequities in health, including outcomes as a result of the pandemic with deaths from COVID-19 associated with rurality. This study provides supporting data that rural health inequities persist in the presence of novel population health events. Future research is needed to explore the effect of rurality on COVID-19 outcomes, particularly exploring co-variables such as income, age, co-morbidities, and access to specialists and tertiary care centers. Identifying underlying susceptibilities may help healthcare professionals better identify specific at-risk rural communities and residents for local, regional, and global public health disasters. Additionally, this preliminary study on access strategies hints that telehealth adoption may continue to face barriers in rural-serving organizations. Hospital and hospital bed density may not serve as appropriate proxies for access with specific diseases, such as COVID-19. Additional studies assessing telehealth adoption including billing, regulatory, technology, attitudes, and infrastructure barriers are needed. Studies exploring perceptions of access to care and its effects on utilization during the pandemic by rural residents are also needed.

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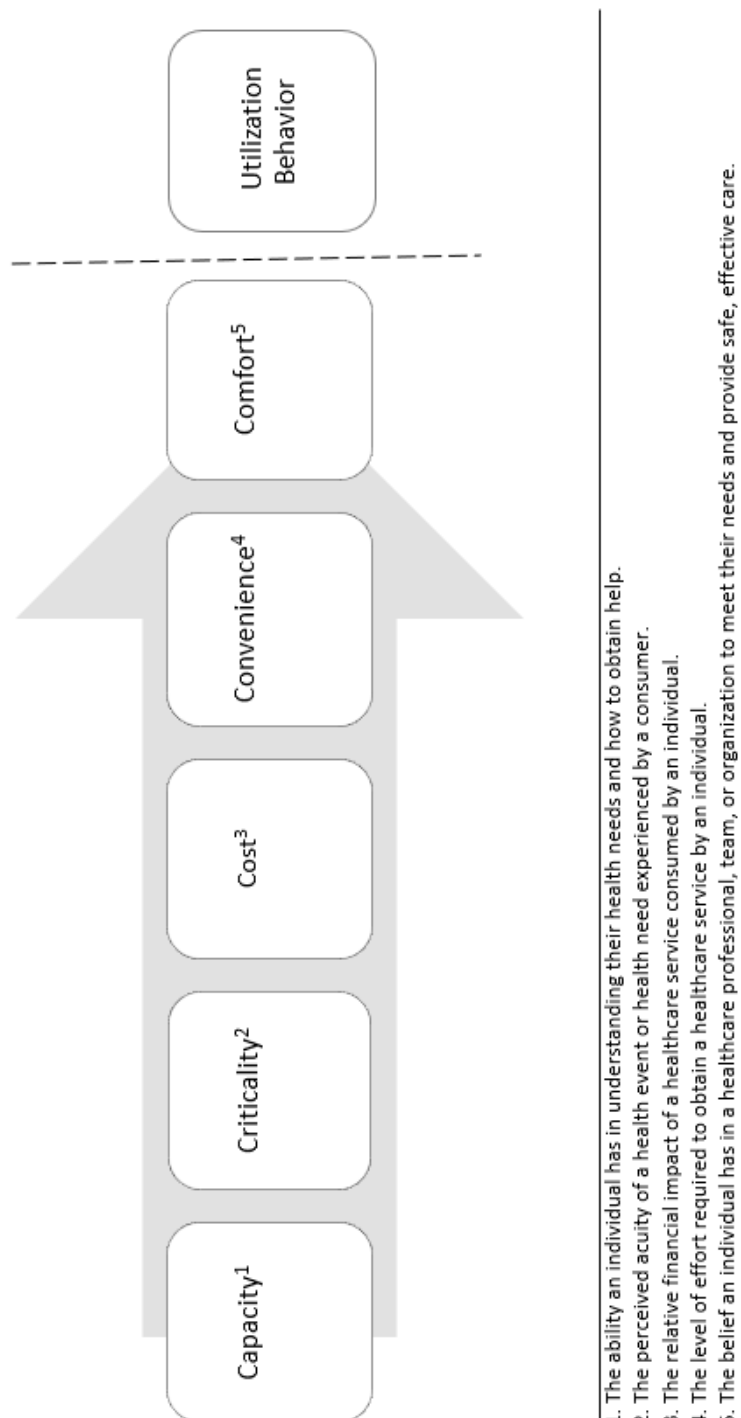
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**Figure 1.** Consumer Model of Utilization





**Table 1.** Characteristics of survey respondents

	Critical Access Hospitals (n = 45)	Rural-serving clinics (n = 47)
Gender		
Female	27	38
Male	18	9
Age in years	26 - 70	28 - 73
Position		
Administrator	30	24
Adv. Practice Prov.	7	17
Registered Nurse	4	2
Physician	0	3
Prefer not to say	4	1
Number of years in profession		
≤ 5years	9	13
6 to 10 years	11	8
11 to 20 years	12	12
> 20 years	13	14
RUCA code		
4 - Micropolitan	5	10
5 - Micropolitan	1	5
6 - Micropolitan	0	0
7 - Small town	20	10
8 - Small town	0	1
9 - Small town	0	0
10 - Rural area	19	21
Meat Packing Facility		
Yes	9	15
No	36	30
Did not say		2



**Table 2.** Access changes by rural organizations during the COVID-19 pandemic

Total Orgs (n = 80)	Total # Changes Reported (%)	# of orgs. report at least one change (%)	Average Change per Organization (M)	Changes per Org. Range (SD)
Financial Changes	21	16 (20.0)	0.26	0 – 2 (0.50)
<i>Accept new patients without upfront payment</i>	3 (3.8)			
<i>New flexible payment plans</i>	6 (7.5)			
<i>Expanded charity care</i>	4 (5.0)			
<i>Other</i>	8 (10.0)			
Changes to appointments	173	65 (81.3)	2.16	0 – 6 (1.75)
<i>Reduced hours of operations</i>	15 (18.8)			
<i>Patient flow changes</i>	52 (65.0)			
<i>Only accept certain patients at specific times</i>	23 (28.8)			
<i>Provide curbside appointments</i>	23 (28.8)			
<i>Offer telehealth*</i>	56 (70.0)			
<i>Other</i>	4 (5.0)			
Anticipated permanent changes to appointments	58	34 (42.5)	0.73	0 – 4 (1.06)
<i>Reduced hours of operations</i>	3 (3.8)			
<i>Patient flow changes</i>	15 (18.8)			
<i>Only accept certain patients at specific times</i>	5 (6.3)			
<i>Provide curbside appointments</i>	2 (2.5)			
<i>Offer telehealth</i>	31 (38.8)			
<i>Other</i>	2 (2.5)			
Changes to visitor policies	196	62 (77.5)	2.45	0 – 4 (1.17)
<i>Minor patients</i>	49 (61.3)			
<i>Active Labor Patients</i>	31 (38.8)			
<i>Altered mental/unresponsive</i>	36 (45.0)			
<i>Actively dying</i>	48 (60.0)			
<i>Non-English speaking</i>	32 (40.0)			
Anticipated permanent changes to visitor policies	35	10 (12.5)	0.44	0 – 3 (0.83)
<i>Minor patients</i>	8 (10.0)			
<i>Active Labor Patients</i>	5 (6.3)			
<i>Altered mental/unresponsive</i>	7 (8.8)			
<i>Actively dying</i>	7 (8.8)			
<i>Non-English speaking</i>	8 (10.0)			
Patient Information Outreach	94	50 (62.5)	1.18	0 – 3 (0.94)
<i>Letter explaining safety or services</i>	13 (15.2)			
<i>Org. webpage/phoneline**</i>	38 (47.8)			
<i>Local Media (T.V., newspaper, social media)</i>	38 (47.8)			
<i>Personal phone calls</i>	5 (3.3)			
Safety and Social Distancing Measures	382	73 (91.3)	4.78	0 – 7 (2.26)
<i>Increased signage</i>	68 (87.0)			
<i>Symptom and temperature screening</i>	70 (89.1)			
<i>Hand-washing stations</i>	51 (58.7)			
<i>Social distancing directions while in facility</i>	53 (65.2)			
<i>Mandatory masks for all patients</i>	71 (90.2)			
<i>Mandatory masks for all visitors</i>	63 (78.3)			
<i>Other</i>	6 (6.5)			

\*Organizations offering telehealth prior to the pandemic (n = 17)

\*\*Organizations offering information in at least two languages: phoneline (n = 15), website (n = 33)



**Table 4.** Correlations of rurality and COVID-19 confirmed cases and deaths (per 10k residents)

Variable	n	M	SD	1	2	3	4	5	6	7	8
1. Rurality <sup>a</sup>	93	3.12	0.94	-							
2. # Ag Facilities	93	0.68	1.32	-.18	-						
3. # Hospital	93	1.27	1.44	.30**	-.02	-					
4. # Hosp. Beds	93	27.78	27.14	.10	-.02	.86**	-				
5. 2020 Death	79	11.81	7.82	.143	-.18	.12	.11	-			
6. Q4 Deaths	77	9.43	6.83	.26*	-.17	.05	.01	.77**	-		
7. 2020 Confirm	77	153.92	223.13	-.48**	.30**	.04	.16	-.00	-.22*	-	
8. Q4 Confirm	93	601.93	143.46	-.24*	.25*	.18	.17	-.20	.18	-.73**	-

\*p &lt; 0.05. \*\*p &lt; 0.01

<sup>a</sup> - RUCA Codes grouped: 1 = Urban, 2 = Micropolitan, 3 = Small Town, 4 = Rural area

## CHAPTER V: Discussion and Conclusion

### Discussion

This dissertation adds to the understanding of access to care in the United States and how facilitators and barriers to care influence utilization choices in special populations. Chapter I provided an introduction describing background, key concepts, significance, and purpose of the dissertation. Gaps in the literature including the siloed approach of studying access domains and a lack of studies examining the potential dynamic relationship of access barriers and utilization were identified. Additionally, para-pandemic access strategies and COVID-19 health outcomes in rural Nebraska were recognized as not previously studied.

Major components of this study used to address the Aims included: an integrative review of the literature on the influences of consumer choices in healthcare locations for non-emergent care needs; a secondary-data analysis of appointment behavior in a chronic disease population; and a descriptive and relational assessment of access strategies and health outcomes of rural Nebraskans during the 2020 COVID-19 pandemic. The specific aims in this study were:

**Aim 1: To evaluate how patient decisions to use healthcare for non-emergent needs are shaped by access to care barriers and facilitators in U.S. ambulatory healthcare locations.**

Chapter II presented an integrative review on facilitators and barriers to care among U.S. adults. The purpose of the review was to explore factors in healthcare service location choice for non-emergent care needs in the U.S. using the Penchansky and Thomas (PT) access model. Evidence from the review suggests multiple consumer-based reasons, with complex intra-variable relationships, may influence reasons for choice in health service locations. Along with the five concepts of PT (accessibility, availability, affordability, accommodation, acceptability), the review also identified perceived acuity, health system knowledge, and the

concept of convenience. As such, results from the study support expansion of access domains beyond the concepts of the PT access model and suggest a new comprehensive model may be needed to more fully explore access and utilization of ambulatory health services. Findings from this integrative review informed the consumer utilization concepts and theory development explored in Chapter III and the categorization of access strategies in Chapter IV.

**Aim 2: To examine saliency of consumer-driven healthcare utilization concepts that influence appointment behavior among a chronic disease population.**

In Chapter III, appointment behavior for routine visits among emerging adults with type 1 diabetes was explored and addressed the question of Aim 2 of the dissertation. Results identified convenience of services, comfort with health care providers and facilities, capacity to make a health-related decision, and perceived criticality of their disease process as both facilitators and inhibitors. Cost of services was identified solely as an inhibitor. Findings from the study support further investigation of cost, convenience, comfort, criticality, and capacity as part of an explanatory model, the Consumer Model of Utilization, to explain utilization of services.

**Aim 3: To identify and explore adaptive access strategies and health outcomes in rural Nebraska, specifically as a result of the COVID-19 pandemic.**

In Chapter IV, a description of a statewide survey of health system and provider behaviors related to increasing patient access and utilization during the COVID-19 pandemic are laid out and address the third aim of the dissertation. Results were categorized into cost, convenience, comfort, and capacity organizational adjustments. The most common strategies used by organizations were comfort (safety) measures such as mask mandates and limited accompanying visitors. The second most common changes addressed convenience and were primarily adjustments to appointment strategies. Capacity was addressed through frequent

expansions of patient education sources to increase the ability of individuals to make informed decisions regarding the pandemic. The least common strategy involved changes to cost of services. Additionally, rural organizations experienced a rapid uptick in telehealth adoption as a substitute to in-person appointments. However, many organizations remain unclear on their plans for long-term adoption of telehealth technologies.

Additionally, to satisfy Aim 3, specifically addressing health outcomes, associations between confirmed COVID-19 cases and deaths were examined against levels of rurality, hospital density, hospital bed density, and meat packing facility density. Despite lower incidences of the disease, COVID-19 deaths in the Q4 2020 were positively associated with rurality. Confirmed cases showed relationality to agriculture facilities in a county. Confirmed cases were inversely associated with rurality, indicating that greater spread occurred in urban centers. Findings suggest that rurality, a known inhibitor to access, was associated with poor outcomes to COVID-19.

### **Limitations**

Like with many other facets of life over the past year, the COVID-19 pandemic played a role in shaping the trajectory of this dissertation. Due to organizational limitations on in-person research as result of the pandemic, different populations were utilized for each aim of this study. As a result, generalizability beyond the specific populations and settings used in Chapters III and IV may be limited. Additionally, due to limitations of in-person data collection during the pandemic, organizational access strategies were utilized as proxies for community access. While this design provided meaningful data on organizational response, the data collected restricted the ability to understand access during the pandemic from a consumer perspective. Moreover, the novelty of the COVID-19 pandemic limited the use of valid survey tools. Steps to provide vetted questions were taken, however the questions may not have performed as intended.

Although the shift away from in-person studies created limitations, the COVID-19 pandemic became an opportunity not lost. The rapid and evolving adjustments made in healthcare allowed for the opportunity to examine how a crisis could lead to adaptive strategies in access – showing the potential robustness of the framework.

Next, specific to Chapter II, the use of the PT access terms as part of the integrative review search strategy may have biased the retrieved journal results. Along with potential search strategy bias, alternative models, such as Andersen (1995), could have been used for grouping and may have influenced final synthesis of the literature. Despite this limitation and potential for alternative frameworks, the PT model was viewed as an adequate theoretical base for the purposes of the integrative review with the model encompassing both consumer and system-level access concepts.

Finally, the secondary data analysis used the derived consumer utilization concepts from the integrative review as an a priori schema for content analysis. While the intent of analysis was to perform a proof of concept within an ambulatory population, the validity of using a secondary data analysis of qualitative work has been debated (Ziebland and Hunt, 2014). A more standardized method for collection and analysis could have added greater validity beyond the limited scope used for this dissertation.

### **Implications**

Findings from Chapter II and III provide insight into the dynamic nature of access and how multiple drivers, both facilitators and barriers, may affect access to care and patient utilization choices. Healthcare professionals and organizations that wish to alter patient appointment behavior and location choices should consider results from this dissertation; that patients do not make utilization decisions in isolation. Further, access traits of an ambulatory location may be either facilitators or barriers depending on the consumer utilization traits of

each individual patient. Organizations may glean insight into patient behavior based on the preliminary data gathered in this study.

Access was significantly disrupted during the pandemic. Organizational responses that altered access, while necessary, may have created barriers to care. Application of the consumer utilization components formulated in this dissertation could help future responses. Ambulatory locations that look to understand the drivers that facilitate, or hinder health consumers use of services, may help them better serve their patients, and their bottom line.

### **Future Studies**

The studies in this dissertation provide preliminary evidence that consumer utilization concepts may provide insight into health consumer utilization of services. Future studies should focus on expanding the concepts of cost, convenience, comfort, criticality, and capacity and their role in using, or not using ambulatory services. A qualitative grounded design focused on general ambulatory populations along with rural individuals whose access was affected by the COVID-19 pandemic could be instrumental in advancing our understanding of facilitators and barriers in healthcare and the core concepts that drive utilization.

A future study for the development and validation of a healthcare utilization survey tool is needed. Creation of a tool to help assess individual consumer facilitators and barriers in a precise way could have significant impact in addressing delayed care of both cost sensitive and affluent patients. Establishment of a utilization tool would also allow for directional relationships among consumer concepts to be studied and utilization explanatory models to be developed in order to develop and test effective strategies to improve access and utilization to health care. Given the multivariate nature of consumer access and utilization behavior, ultimately an electronic algorithm might be an ideal tool for assisting patients to make good choices on health care.



Findings from Chapter II showed a dearth of literature on facilitators and barriers in rural populations. Therefore, opportunities to explore rurality and healthcare consumer choices could shed light on access and utilization issues such as the rural bypass phenomena, where rural consumers choose to circumvent nearby healthcare for similar services further away. Additionally, understanding rural access in during the COVID-19 pandemic could help develop strategies to increase access when future community, regional, or world health events occur.

As noted, rural residents in Nebraska experienced a “rural penalty” when contracting COVID-19, with more deaths per capita than urban-dwelling Nebraskans. Although hospital and hospital bed density in rural countries were not significantly correlated with deaths, other access and utilization issues not studied in this dissertation such as availability of specialty care, or more broadly utilization of preventative ambulatory services, may have been a contributing factor to the observed outcomes. Future studies exploring consumer preferences and access facilitators and barriers using the consumer model of utilization may be helpful to better understand health outcomes like those observed during the COVID-19 pandemic.

### **Conclusion**

A lack of access and underutilization of high-quality, low-cost care is well established as an issue in the United States. Expanding our understanding of access and use of services through consumer utilization concepts explored in this dissertation may add significant insight into the choices individuals make when choosing to use or not use ambulatory services. Utilization decisions are complex. The ability to increase use of high-quality services relies on the ability to address facilitators and barriers in dynamic ways. Continued development of the consumer utilization concepts visited in this dissertation is a necessary step to advancing the understanding on access and improving outcomes.

Future research should focus on the development of the consumer utilization concepts, creation and validation of an access survey tool, and exploration of concept relationality.

Additionally, much work is needed in rural access research. Better understanding of access and choice through the consumer utilization concepts is warranted with specific application of the concepts to rural bypass and telehealth adoption needed. The results of this dissertation support further examination of cost, convenience, comfort, criticality, and capacity as facilitators and barrier to care.

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## APPENDIX A

Search Strategy Example for Query Terms, Limiters and Expanders

Query	Limiters/ Expanders
<p>(( (MM "Health Services Accessibility+") OR MM "Patient Acceptance of Health Care" OR MM "Health Services+/UT" OR TI ((healthcare OR "health care" OR care OR help OR service*) AND (utiliz* OR utilis* OR use OR accept* OR Refus* OR seek* OR access OR prefer* OR choos* OR select* OR elect*)) ) AND ( (MH "Ambulatory Care+") OR (MH "Primary Health Care+") OR (MH "Physicians, Primary Care") OR (MH "Primary Care Nursing") OR (MH "Concierge Medicine") OR (MH "Continuity of Patient Care+") OR "ambulatory care" OR "outpatient care" OR "outpatient clinic" OR "outpatient clinics" OR "primary care" OR "family practice" OR "family physician" OR "family physicians" OR "general practice" OR "general practitioners" OR "general practitioner" OR "internal medicine" OR "personal physician*" OR concierge OR "family nurs*") AND ( (MH "Patient Preference" OR MH "Consumer behavior" OR MH "Choice behavior" OR MH "Attitude to Health" OR TI (attitud* N3 health*) OR TI (barrier* OR obstacl* OR impediment* OR hinder* OR hindrance OR hurdle* OR roadblock* OR dislik* OR distast* OR avers* OR disfavor* OR disapprov* OR disapprobat* OR hostile* OR animos* OR antipath* OR antagon* OR consumer* OR choic* OR decision* OR decisiv* OR decid* OR explain* OR explan* OR factor* OR reason* OR rational* OR "account for" OR "accounted for" OR prefer* OR choos* OR favor* OR why) ) ) NOT ( (MH "Adolescent" OR MH "Child+" OR MH "Infant+") NOT MH "Adult+" ) ) NOT ( (MH "Geographic Locations+" NOT MH "United states+" ) ) NOT ( (MH "mental disorders+" OR MH "substance-related disorders+" OR TI mental*) ) NOT TI ( (Anxiety OR behavior* OR behaviour* OR eating OR borderline OR personality OR dysmorph* OR developmental* OR combat* OR communication* OR compulsive OR obsessive OR conversion OR disruptive OR impulse OR conduct OR dissociative OR mental OR mood OR panic OR paranoid OR attachment OR affective OR learning OR speech OR "traumatic stress" OR "post-traumatic stress" OR "posttraumatic stress") N3 (disorder* OR illness* OR disease* OR syndrom*) ) NOT TI (gambl* N3 compuls*) NOT TI ( (substance OR amphetamine OR opioid OR cocaine OR food OR gambl* OR inhalant OR marijuana OR morphin* OR narcotic* OR opium OR heroin OR Phencyclidine OR PCP) N3 (disorder* OR addict* OR abus*) ) NOT TI ( "Adjustment Disorder*" OR "Affective Disorder*" OR "Attention Deficit" OR "Battered Child" OR addict* OR Agoraphobi* OR Alcohol* OR Anorexi* OR Antisocial OR Asperger* OR Autis* OR Bing* OR Bipolar OR Bulimi* OR Capgras* OR Catatoni* OR Cyclothymi* OR Delusion* OR Depression OR Depressive OR detox* OR Dyspareuni* OR Dysphori* OR Dyssomni* OR Dysthymic OR Exhibitionis* OR Factitious OR Fetish* OR "Food Addiction" OR Histrionic OR Hoarding OR Hypochondria* OR Hysteri* OR Intoxic* OR Korsakoff* OR Masochis* OR Morgellon* OR Munchausen* OR Mutism OR Neurastheni* OR Neurotic OR Obsessive-Compulsive OR Paraphil* OR Parasomni* OR Pedophil* OR Phobi* OR Psychiatr* OR Psycholog* OR "Psychological Trauma" OR Psychoses OR Psychosis OR Psychotic OR pyromani* OR Sadis* OR Schizoid OR Schizophreni* OR Schizotypal OR Somatoform OR Trichotilloman* OR Voyeurism OR withdrawal OR "substance use" OR PTSD ) NOT ( (MM "Wounds and Injuries+") OR (MM "Chemically-Induced Disorders+") OR (MM "Occupational Diseases+") OR (MM "Immune System Diseases+") OR (MM "Endocrine System Diseases+") OR (MM "Nutritional and Metabolic Diseases+") OR (MM "Skin and Connective Tissue Diseases+") OR (MM "Congenital, Hereditary, and Neonatal Diseases and Abnormalities+") OR (MM "Hemic and Lymphatic Diseases+") OR (MM "Cardiovascular Diseases+") OR (MM "Female Urogenital Diseases and Pregnancy Complications+") OR (MM "Male Urogenital Diseases+") OR (MM "Eye Diseases+") OR (MM "Disorders of Environmental Origin+") OR (MM "Nervous System Diseases+") OR (MM "Otorhinolaryngologic Diseases+") OR (MM "Respiratory Tract Diseases+") OR (MM "Stomatognathic Diseases+") OR (MM "Digestive System Diseases+") OR (MM "Musculoskeletal Diseases+") OR (MM "Neoplasms+") OR (MM "Parasitic Diseases+") OR (MM "Virus Diseases+") OR (MM "Bacterial Infections and Mycoses+") ) ) NOT ( TI (infect* OR cancer* OR HIV OR orthop* OR cardiac OR cardiol* OR specialty OR specialties OR neonat* OR newborn* OR infan* OR baby OR babies OR child* OR pediat* OR paediat* OR end-of-life OR hospice OR reproductive OR</p>	<p>Limiters - English Language; Date of Publication: 20080101-; Publication Type: Addresses, Autobiography, Bibliography, Biography, Case Reports, Clinical Conference, Comment, Congresses, Consensus Development Conference, Consensus Development Conference, NIH, Dictionary, Directory, In Vitro, Interview, Lectures, News, Newspaper Article, Patient Education Handout, Periodical Index, Review Search modes - Boolean/Phrase</p>

Query	Limiters/ Expanders
<p>"terminally ill" OR "advance care" OR "nursing home*" OR pain) ) NOT ( (MM "Surgical Procedures, Operative+") OR ((MM "Therapeutics+") NOT (MH "Patient Care+")) ) NOT ( (MM "Pathological Conditions, Signs and Symptoms+") OR (MM "Bacterial Infections and Mycoses+") )</p> <p>(( ( (MM "Health Services Accessibility+") OR MM "Patient Acceptance of Health Care" OR MM "Health Services+/UT" OR TI ((healthcare OR "health care" OR care OR help OR service*) AND (utiliz* OR utilis* OR use OR accept* OR Refus* OR seek* OR access OR prefer* OR choos* OR select* OR elect*)) ) AND ( (MH "Ambulatory Care+") OR (MH "Primary Health Care+") OR (MH "Physicians, Primary Care") OR (MH "Primary Care Nursing") OR (MH "Concierge Medicine") OR (MH "Continuity of Patient Care+") OR "ambulatory care" OR "outpatient care" OR "outpatient clinic" OR "outpatient clinics" OR "primary care" OR "family practice" OR "family physician" OR "family physicians" OR "general practice" OR "general practitioners" OR "general practitioner" OR "internal medicine" OR "personal physician*" OR concierge OR "family nurs*" ) AND ( (MH "Patient Preference" OR MH "Consumer behavior" OR MH "Choice behavior" OR MH "Attitude to Health" OR TI (attitud* N3 health*) OR TI (barrier* OR obstacl* OR impediment* OR hinder* OR hindrance OR hurdle* OR roadblock* OR dislik* OR distast* OR avers* OR disfavor* OR disapprov* OR disapprobat* OR hostil* OR animos* OR antipath* OR antagon* OR consumer* OR choic* OR decision* OR decisiv* OR decid* OR explain* OR explan* OR factor* OR reason* OR rational* OR "account for" OR "accounted for" OR prefer* OR choos* OR favor* OR why) ) ) ) NOT ( ( (MH "Adolescent" OR MH "Child+" OR MH "Infant+") NOT MH "Adult+" ) ) NOT ( (MH "Geographic Locations+" NOT MH "United states+" ) ) NOT ( (MH "mental disorders+" OR MH "substance-related disorders+" OR TI mental*) ) NOT TI ( (Anxiety OR behavior* OR behaviour* OR eating OR borderline OR personality OR dysmorph* OR developmental* OR combat* OR communication* OR compulsive OR obsessive OR conversion OR disruptive OR impulse OR conduct OR dissociative OR mental OR mood OR panic OR paranoid OR attachment OR affective OR learning OR speech OR "traumatic stress" OR "post-traumatic stress" OR "posttraumatic stress") N3 (disorder* OR illness* OR disease* OR syndrom*) ) NOT TI (gamb* N3 compuls*) NOT TI ( (substance OR amphetamine OR opioid OR cocaine OR food OR gamb* OR inhalant OR marijuana OR morphin* OR narcotic* OR opium OR heroin OR Phencyclidine OR PCP) N3 (disorder* OR addict* OR abus*) ) NOT TI ( "Adjustment Disorder*" OR "Affective Disorder*" OR "Attention Deficit" OR "Battered Child" OR addict* OR Agoraphobi* OR Alcohol* OR Anorexi* OR Antisocial OR Asperger* OR Autis* OR Bing* OR Bipolar OR Bulimi* OR Capgras* OR Catatoni* OR Cyclothymi* OR Delusion* OR Depression OR Depressive OR detox* OR Dyspareuni* OR Dysphori* OR Dysomnia* OR Dysthymic OR Exhibitionis* OR Factitious OR Fetish* OR "Food Addiction" OR Histrionic OR Hoarding OR Hypochondria* OR Hysteri* OR Intoxic* OR Korsakoff* OR Masochis* OR Morgellon* OR Munchausen* OR Mutism OR Neurastheni* OR Neurotic OR Obsessive-Compulsive OR Paraphil* OR Parasomni* OR Pedophil* OR Phobi* OR Psychiatr* OR Psycholog* OR "Psychological Trauma" OR Psychoses OR Psychosis OR Psychotic OR pyromani* OR Sadis* OR Schizoid OR Schizophreni* OR Schizotypal OR Somatoform OR Trichotilloman* OR Voyeurism OR withdrawal OR "substance use" OR PTSD ) NOT ( (MM "Wounds and Injuries+") OR (MM "Chemically-Induced Disorders+") OR (MM "Occupational Diseases+") OR (MM "Immune System Diseases+") OR (MM "Endocrine System Diseases+") OR (MM "Nutritional and Metabolic Diseases+") OR (MM "Skin and Connective Tissue Diseases+") OR (MM "Congenital, Hereditary, and Neonatal Diseases and Abnormalities+") OR (MM "Hemic and Lymphatic Diseases+") OR (MM "Cardiovascular Diseases+") OR (MM "Female Urogenital Diseases and Pregnancy Complications+") OR (MM "Male Urogenital Diseases+") OR (MM "Eye Diseases+") OR (MM "Disorders of Environmental Origin+") OR (MM "Nervous System Diseases+") OR (MM "Otorhinolaryngologic Diseases+") OR (MM "Respiratory Tract Diseases+") OR (MM "Stomatognathic Diseases+") OR (MM "Digestive System Diseases+") OR (MM "Musculoskeletal Diseases+") OR (MM "Neoplasms+") OR (MM</p>	

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<p>"Parasitic Diseases+") OR (MM "Virus Diseases+") OR (MM "Bacterial Infections and Mycoses+") ) NOT ( TI (infect* OR cancer* OR HIV OR orthop* OR cardiac OR cardiol* OR specialty OR specialties OR neonat* OR newborn* OR infan* OR baby OR babies OR child* OR pediat* OR paediat* OR end-of-life OR hospice OR reproductive OR "terminally ill" OR "advance care" OR "nursing home*" OR pain) ) NOT ( (MM "Surgical Procedures, Operative+") OR ((MM "Therapeutics+") NOT (MH "Patient Care+")) ) NOT ( (MM "Pathological Conditions, Signs and Symptoms+") OR (MM "Bacterial Infections and Mycoses+") ) ) NOT S1</p>	
<p>(( (MM "Health Services Accessibility+") OR MM "Patient Acceptance of Health Care" OR MM "Health Services+/UT" OR TI ((healthcare OR "health care" OR care OR help OR service*) AND (utiliz* OR utilis* OR use OR accept* OR Refus* OR seek* OR access OR prefer* OR choos* OR select* OR elect*)) ) AND ( (MH "Ambulatory Care+") OR (MH "Primary Health Care+") OR (MH "Physicians, Primary Care") OR (MH "Primary Care Nursing") OR (MH "Concierge Medicine") OR (MH "Continuity of Patient Care+") OR "ambulatory care" OR "outpatient care" OR "outpatient clinic" OR "outpatient clinics" OR "primary care" OR "family practice" OR "family physician" OR "family physicians" OR "general practice" OR "general practitioners" OR "general practitioner" OR "internal medicine" OR "personal physician*" OR concierge OR "family nurs*" ) AND ( (MH "Patient Preference" OR MH "Consumer behavior" OR MH "Choice behavior" OR MH "Attitude to Health" OR TI (attitud* N3 health*) OR TI (barrier* OR obstac* OR impediment* OR hinder* OR hindrance OR hurdle* OR roadblock* OR dislik* OR distast* OR avers* OR disfavor* OR disapprov* OR disapprobat* OR hostile* OR animos* OR antipath* OR antagon* OR consumer* OR choic* OR decision* OR decisiv* OR decid* OR explain* OR explan* OR factor* OR reason* OR rational* OR "account for" OR "accounted for" OR prefer* OR choos* OR favor* OR why) ) ) NOT ( (MH "Adolescent" OR MH "Child+" OR MH "Infant+") NOT MH "Adult+" ) ) NOT ( (MH "Geographic Locations+" NOT MH "United states+" ) ) NOT ( (MH "mental disorders+" OR MH "substance-related disorders+" OR TI mental*) ) NOT TI ( (Anxiety OR behavior* OR behaviour* OR eating OR borderline OR personality OR dysmorph* OR developmental* OR combat* OR communication* OR compulsive OR obsessive OR conversion OR disruptive OR impulse OR conduct OR dissociative OR mental OR mood OR panic OR paranoid OR attachment OR affective OR learning OR speech OR "traumatic stress" OR "post-traumatic stress" OR "posttraumatic stress") N3 ( disorder* OR illness* OR disease* OR syndrom*) ) NOT TI (gamb* N3 compuls*) NOT TI ( (substance OR amphetamine OR opioid OR cocaine OR food OR gamb* OR inhalant OR marijuana OR morphin* OR narcotic* OR opium OR heroin OR Phencyclidine OR PCP) N3 (disorder* OR addict* OR abus*) ) NOT TI ( "Adjustment Disorder*" OR "Affective Disorder*" OR "Attention Deficit" OR "Battered Child" OR addict* OR Agoraphobi* OR Alcohol* OR Anorexi* OR Antisocial OR Asperger* OR Autis* OR Bing* OR Bipolar OR Bulimi* OR Capgras* OR Catatoni* OR Cyclothymi* OR Delusion* OR Depression OR Depressive OR detox* OR Dyspareuni* OR Dysphori* OR Dyssomni* OR Dysthymic OR Exhibitionis* OR Factitious OR Fetish* OR "Food Addiction" OR Histrionic OR Hoarding OR Hypochondria* OR Hysteri* OR Intoxic* OR Korsakoff* OR Masochis* OR Morgellon* OR Munchausen* OR Mutism OR Neurastheni* OR Neurotic OR Obsessive-Compulsive OR Paraphil* OR Parasomni* OR Pedophil* OR Phobi* OR Psychiatr* OR Psycholog* OR "Psychological Trauma" OR Psychoses OR Psychosis OR Psychotic OR pyromani* OR Sadis* OR Schizoid OR Schizophreni* OR Schizotypal OR Somatoform OR Trichotilloman* OR Voyeurism OR withdrawal OR "substance use" OR PTSD ) NOT ( (MM "Wounds and Injuries+") OR (MM "Chemically-Induced Disorders+") OR (MM "Occupational Diseases+") OR (MM "Immune System Diseases+") OR (MM "Endocrine System Diseases+") OR (MM "Nutritional and Metabolic Diseases+") OR (MM "Skin and Connective Tissue Diseases+") OR (MM "Congenital, Hereditary, and Neonatal Diseases and Abnormalities+") OR (MM "Hemic and Lymphatic Diseases+") OR (MM "Cardiovascular Diseases+") OR (MM "Female Urogenital Diseases and Pregnancy Complications+") OR (MM "Male Urogenital Diseases+") OR (MM "Eye</p>	

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