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Name: Melany J. Rabideau

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Primary Care

Committee Chair: Jennifer Locraft Cuddapah, Ed.D.

Program Director: Kathleen Bands, Ph.D.

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Signed:

Melany J. Rabideau

4/12/2020

Melany J. Rabideau

Date

HOOD COLLEGE



An Exploration of the Emerging Adult Woman's Perceived Value of Primary Care

A DISSERTATION

Submitted to the faculty of the
Graduate School of Hood College
In partial fulfillment of the requirements
for the degree
Doctor of Organizational Leadership

by
Melany J. Rabideau

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2020

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Jennifer L. Cuddapah, Ed.D. (Chair) (Committee Member)	Date
--	------

Jennifer Cooper, DNP, RN, PHNA-BC, CNE (Committee Member)	Date
---	------

Elizabeth Bulette, Ed.D. (Committee Member)	Date
---	------

David Alan Loxterkamp, M.D. (Committee Member)	Date
--	------

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ABSTRACT

The healthcare industry often justifies framing patients as consumers using the fact that today's emerging adults, who assume priority of convenience over continuity, demand transactional care and are forgoing relational care. Self-guided transactional utilization has caused emerging adults to lack primary care continuity, which is problematic both for cost and quality of care. This qualitative study explores the lived experiences of emerging adult women and reveals the essence of the value of primary care purported in their individually designed ideal primary care systems. Analysis of individual interviews revealed: (1) emerging adults desire, but struggle to find, the human connection or a patient-provider relationship in primary care; (2) primary care delivered like a business reinforces emerging adults' belief that the human connection is not possible, causing transactional services to be attractive for at least their convenience and efficiency; and (3) emerging adults are asking for high touch care similar to care management services traditionally only provided to insurance-backed "high risk" patient panels. Implications of these findings are crucial to discerning how primary care practices and policies can evolve to focus on empathy and leverage transactional conveniences that reinforce rather than replace patient-provider relationships. Focused attention is needed to ensure the value proposition of the patient-provider relationship is not lost on future generations of patients through adoption of these findings in best practice models like the National Committee for Quality Assurance's Patient Centered Medical Home.

An Exploration of the Emerging Adult Woman's Perceived Value of Primary Care

CHAPTER 1: INTRODUCTION

In the United States, healthcare systems are adopting technologies and workflow efficiencies to reduce costs and remain relevant (i.e., marketable, profitable, technologically current) (Hickson et al., 2015). These innovations are often attributed to the assumption, in a consumerism market, that transactional services lead to a more patient-centric delivery model (Hernandez et al., 2013). But this is not always the case (Freas, 2020; Loxterkamp, 2015). Creating a delivery system that leads with transactional and impersonal interactions reinforces patient utilization behaviors devaluing the relational qualities of care (Healthcare Information and Management Systems Society, Inc. [HIMSS], 2019). From asynchronous telemedicine to episodic urgent care centers, healthcare has rapidly evolved to meet consumer demand for quick convenient care (Pecci, 2018). However, transactional services become a problem when they undermine the long-term provider-patient relationship (Hoff, 2017).

Primary care, focusing on the entire spectrum of patient health, exists to maintain the human-contact and relationship-building aspects of healthcare (Loxterkamp, 2015; Starfield, 2011). Primary care alternatives, such as urgent care or asynchronous telemedicine, should exist to complement, not replace, primary care (American Association of Urgent Care Medicine [AAUCM 2019]; Loxterkamp, 2015). Relationships are healthcare's core product (Gottlieb, 2013). With relationship-based care as the foundation of value-based care, leveraging transactional innovation can improve the provider-patient relationship but without the intent to replace it (Koloroutis, 2004).

Transactional healthcare has shifted the health care system to see patients as consumers (revenue sources, commodities, insurance liabilities, financial risk etc.). When a patient

establishes a relationship with a primary care provider, the patient is the one receiving care (Becker's Healthcare, 2015). Without a primary care relationship, the patient is in a consumer state, expected to navigate the healthcare system as a direct purchaser (Becker's Healthcare, 2015). The self-navigating consumer is solely responsible for their healthcare outcomes, out-of-pocket costs, and use (Becker's Healthcare, 2015). Most adult Americans lack a skill set called "health literacy" required to manage health and navigate health services (Kutner et al., 2006). A consumer-driven approach to healthcare is often lost in the complexities of navigating complicated service siloes independently (Agency for Healthcare Research and Quality [AHRQ], 2015). Unfortunately, "only 12 percent of adults have proficient health literacy, according to the National Assessment of Adult Literacy" (Kutner et al., 2006). To impact these statistics, we must first understand where and when health literacy is initially acquired through iterative learning: emerging adulthood (Arnett, 2000).

Emerging adulthood, ages 18-25, is a life stage used for independent exploration between the chasm of youth and adulthood (Arnett, 2000). It is a vulnerable period when patients form their beliefs and establish behavioral patterns (Arnett, 2000). These beliefs include how we use health services transactionally versus relationally. For the emerging adult, primary care is the optimal learning lab for the development of health literacy and for building long lasting relationships with a primary care provider (Stange et al., 1998). Continuity is not the norm at work, in love, and in healthcare for young adults. They increasingly job hop (Berger, 2016) and date around (Sumter, 2017), pushing back the average age of marriage and having children (U.S. Census Bureau, 2018). Following the same pattern, establishing a relationship with a primary care provider is at an all-time low (Kaiser Family Foundation, 2018). Many studies rationalize this behavior as an affinity for convenience rather than continuity (Advisory Board, 2017).

Regardless of the root cause, emerging adults are at high risk for not reaping the benefits of relational based care now and for future health needs as they age.

Below is an overview of the hypothetical differences in the outcomes an emerging adult example, “Jane,” would experience if she approached her healthcare utilization transactionally versus relationally:

Jane, a 21-year-old woman, is in her last of year of her community college education. When she is not in class, Jane works at a local coffee shop. Living at home with minimal expenses and access to the family car, she uses her income primarily to invest in her social life. She is looking forward to graduation and securing full-time employment to pay back her student loans. She browses social media skipping over the wedding and baby images because that’s the last thing on her mind. She dreams of moving to a big city and traveling the world. Jane has the luxury to stay on her parents’ insurance plan until she turns 26, which, to her, feels like a lifetime away.

1. Transactional: Jane has just returned home from a weekend at the beach with friends. She wakes up Monday morning and while urinating, experiences pain. Panicking, she googles her symptoms and believes she has a urinary tract infection (UTI). She finds a website offering asynchronous telemedicine – perfect because she does not have to leave her home. She completes the online visit, pays the \$25 fee, and heads down to the local pharmacy to pick up an antibiotic. Jane loved this experience so much, that she used it often over the next few months because her symptoms seemed to keep coming back now that she started dating her boyfriend. Eventually, she experienced an extreme pain in her side and ended up in the emergency room diagnosed with a kidney infection. The emergency room provider told her the antibiotic she had

been taking repeatedly had become ineffective and the infection had spread. After one week, the symptoms had not diminished. Jane returned to the emergency room.

1. Relational: Jane has just returned home from a weekend at the beach with friends. She wakes up Monday morning and while urinating, experiences pain. Panicking, she calls her primary care provider and a nurse triages her symptoms over the phone and advises her to come in that morning to get tested for a UTI. Jane is diagnosed with a UTI, receives an antibiotic, and pays her \$15 copay. A month later Jane is back in the office with another UTI. Recognizing the recurring pattern, her primary care provider talks to Jane about how to prevent UTIs because the antibiotics will not always be a quick fix. Her provider also talks to Jane about safe sex and routine Sexually Transmitted Disease (STD) screenings. Jane takes her provider's advice and does not have any reoccurring UTIs and is screened regularly with periodic treatment for STDs.

2. Transactional: A few months go by and Jane is in Walmart during flu season and decides to take advantage of the \$20 flu shot. She thinks it is a great deal and super convenient since she was there shopping anyway for her upcoming vacation. Jane is about to graduate and is going to Thailand to celebrate. She returns home from a great trip but feels very sick with a fever. She thinks her flu shot has not kicked in yet, so she waits a while before heading into an urgent care center for treatment. Urgent care treats her for the flu and advises she follow up with her primary care doctor. Confused, Jane goes home and does not get any better. Jane ends up in the emergency room where she is diagnosed with malaria, Jane had not realized she had been in a high-risk area and was unaware that preventive medication was available. Jane makes a speedy recovery. She now has a job offer requiring pre-employment health screening. Jane needs her prior medical records, including immunizations, so she has her parents call the pediatrician office. It has been many years since Jane saw the pediatrician and the only immunizations on file

are the ones she received as a baby. Her new employer requires a flu vaccination. Jane forgot about her Walmart experience and ends up getting a second vaccination. Causing a lot of stress, the majority of her first paycheck goes to paying off her urgent care and emergency room bills.

2. Relational: A few months go by and Jane stops by her primary care office for a flu shot at no cost to her. While talking with her provider, she mentions her upcoming trip to Thailand. Her provider prescribes medication to prevent Malaria. Jane returns home from a great trip and now has a job offer requiring a pre-employment health screening. Jane needs her prior medical records including her immunizations. This was easy because she had electronic access to her complete medical records through her primary care provider's portal.

3. Transactional: Almost two decades go by and Jane is now in her late 30s. She is married now and having trouble conceiving. She is also having difficulties navigating her new insurance benefits to select a fertility specialist. At the fertility clinic, she finds out she had an untreated STD in her early 20s that may be the cause of her infertility. Jane and her husband decide to stop trying to conceive and plan to adopt in the future.

One day, Jane's husband cuts his finger and Jane takes him to urgent care for treatment. A few days later, the cut has not healed, and Jane takes her husband back to urgent care. The staff cleans the area and advise him to follow up with his primary care provider. There may be other issues causing delayed healing. Worried, Jane calls around to primary care offices. She has trouble getting in because she and her husband are new patients. A week later, Jane accompanies her husband to his first primary care visit, where he is diagnosed with diabetes. The primary care provider sets up routine visits and advises Jane's husband that if any urgent needs arise, he is on call on weekends and evenings. While paying her husband's medical bills, she realizes the bill

for the primary care visit was substantially less than the urgent care and emergency room. Jane is now asking herself why it has taken so long to become a primary care patient.

3. Relational: A few years pass, and Jane is now in her late thirties. She is married and expecting her first child. She has her own health insurance and made sure her trusted primary care provider was in network. One day, Jane's husband cuts his finger, Jane takes him to her primary care provider. Because their primary care provider is actively managing her husband's diabetes, they know it is important to take extra care of the wound. They make a follow up visit the next week to ensure everything is healing properly. As Jane's family grows, she takes them to the same primary care provider for all their initial healthcare needs.

When anticipating the needs of an aging population, it is often assumed that today's 18- to 29-year-olds will fit the patient profiles of today's 65-year-olds and older as they age. The lived experiences between two extreme groups—emerging adults and those who are 65 years and older—will always be different, regardless of whether we are analyzing patients today or ones from 100 years ago. That profound difference is the essence of life. However, the difference is not in time or the inevitable life that needs to be lived that divides these two age groups. It is the evolving healthcare options that distinguish how the emerging adults of today experience health care versus how 65-year-old and above patients experienced healthcare during their emerging adulthoods – two drastically different paradigms. Understanding the snowball effect for the way today's emerging adults experience healthcare with a plethora of transactional options compared to how today's 65-year-olds and above experienced healthcare during their emerging adulthood is a blind spot for the future utilization and behavioral patterns. Eighty-five-year-olds today were 18 in 1953 and 65-year-olds today were 18 in 1973. From the 1950s to the and early 1970s, primary care was at its peak before the development of primary care alternatives. This impact on

the evolution of healthcare options is important to consider. It is not a generational difference, but rather a difference in options available. It is underestimated how the compounding effect of perceived value developed during emerging adulthood will impact future patient utilization behaviors, depending on whether healthcare options were experienced relationally versus transactionally.

Healthcare is fundamentally relational. If healthcare is about helping and our ability to think systemically, it calls for us to change the way we think about how we operate. As a system built on task, checklists, and protocol, healthcare has become a primarily transactional system. This was done with purpose, but at what cost? As the largest people-facing industry in the world (for patient and consumers of care alike) the expectations are to support the relational nature of care. As a transactional healthcare system, we have attempted to bolster our transactions with relational practices to make it feel more personal, but rather our opportunity is in creating a relational system, and then working to find the best transactions to ensure that that relational system is effective. (Wolf, 2019).

Problem Statement

With a strong patient-provider relationship, patients receive continuity of care and health literacy rates increase along with the quality of care (Mayer, 2007). However, the patient-provider relationship is not beneficial when emerging adults do not use primary care as their routine source for care. Unfortunately, only 42% of care needs are treated by a patient's primary care provider (Pitts et al., 2010). Unlike older generations, modern day emerging adults are assumed to prioritize cost and convenience over continuity (American Heart Association, 2018). Maintaining a relationship with a primary care provider develops health literacy, a skill set

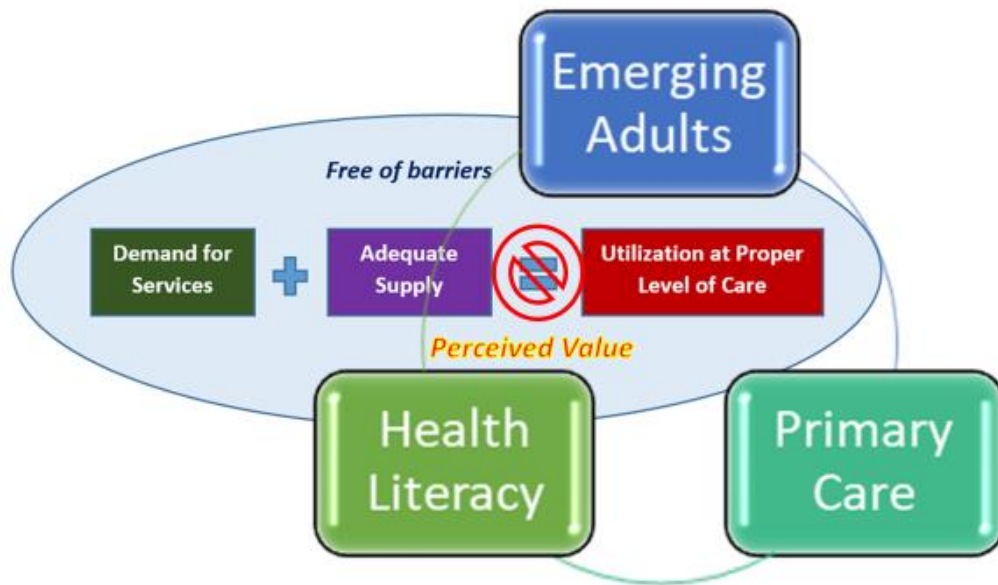
essential for navigating health services and maintaining health (Barrett et al., 2008). As a result, the phenomena of 9 out of 10 people not having this skill set is linked to an annual economic impact between \$106 billion to \$238 billion annually (Kutner et al., 2006).

Primary care is becoming irrelevant to emerging adults as alternatives capitalize on this untapped market, promoting convenience and the perception of lower costs. Conceptually, in an environment free of barriers, when demand is met with adequate supply there should be utilization at the proper level of care (John Snow, Inc., 2010). Theoretically, emerging adulthood is the life stage most essential for establishing the primary care relationship (Arnett, 2000; Starfield, 1998). The problem, shown in the figure below, is emerging adults are low utilizers of primary care at the proper level. Little research has been done to understand why this is so, including what emerging adults expect from, and how they perceive, the value of primary care to facilitate utilization of the proper level (Kaiser Family Foundation, 2018).

With models of primary care transformation such as the Patient Centered Medical Home claiming best practice, it is unknown how these efforts will impact emerging adult's utilization of primary care. With the infiltration of primary care alternatives, this paradox puts emerging adults at risk for worsening health disparities and loss of equitable care when self-navigating the healthcare system for the first time (Starfield, 1998).

Figure 1

Collaboration of Conceptual and Theoretical Frameworks with Outline of Problem Statement



Note. This figure shows the collaboration between the Conceptual Framework and Theoretical Framework, calling out the Problem Statement of lack of utilization.

Conceptual Framework

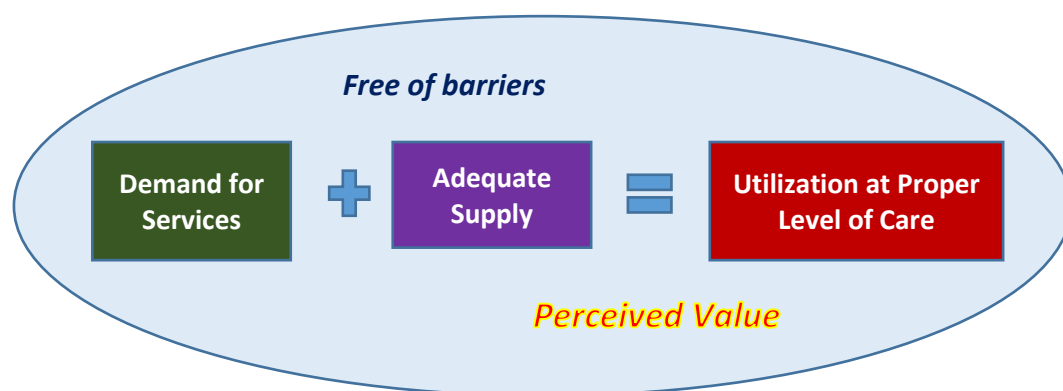
Using the conceptual framework of John Snow, Inc., “in an environment free of access barriers, the population’s need for care is fully expressed as demand for services which, when met by adequate supply, translates into use at the proper level” (John Snow, Inc., 2010). Snow’s research defines the “proper level” for care described by the conceptual framework as primary care (Starfield, 1998). Demand is defined by active patient pursuit of health services (John Snow, Inc., 2010). Adequate supply assumes the availability of health services to support use in response to demand (John Snow, Inc., 2010). Currently, 72% of emerging adults translate their pursuit of health services into utilization when met with adequate supply (Patient Centered Medical Home Resource Center [PCMHRC], 2019). However, utilization is not at the “proper level” of care because 45% of emerging adults do not have primary care providers even though

72% of emerging adults are active users of health services (PCMHRC, 2019). Accessing care is challenged with barriers to care when geographic, socio-economic, health literacy, and other factors impede a patient's ability to access health services (John Snow, Inc., 2010). The Patient Centered Medical Home model aims to identify and mitigate barriers to care through a set of core concepts and competencies. Deemed an industry best practice, PCMH strives to enhance access in support of primary care utilization as the proper level of care (NCQA, 2017). However, even with the expansion of the Patient Centered Medical Home model, low utilization of primary care still exists among emerging adults (Frederick Health, 2019).

The John Snow conceptual framework is the foundation to my research enhanced by adding the construct of perceived value (John Snow, Inc., 2010). The patient's perceived value of primary care as the proper level of care may be an influential force in the overall utilization conceptual framework to be explored throughout this study.

Figure 2

Conceptual Framework

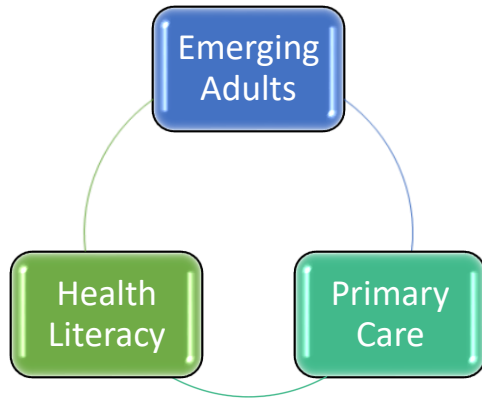


Note. This figure is based on the Conceptual Framework, showing John Snow, Inc.'s framework for utilization enhanced to include perceived value.

Theoretical Framework

Figure 3

Theoretical Framework

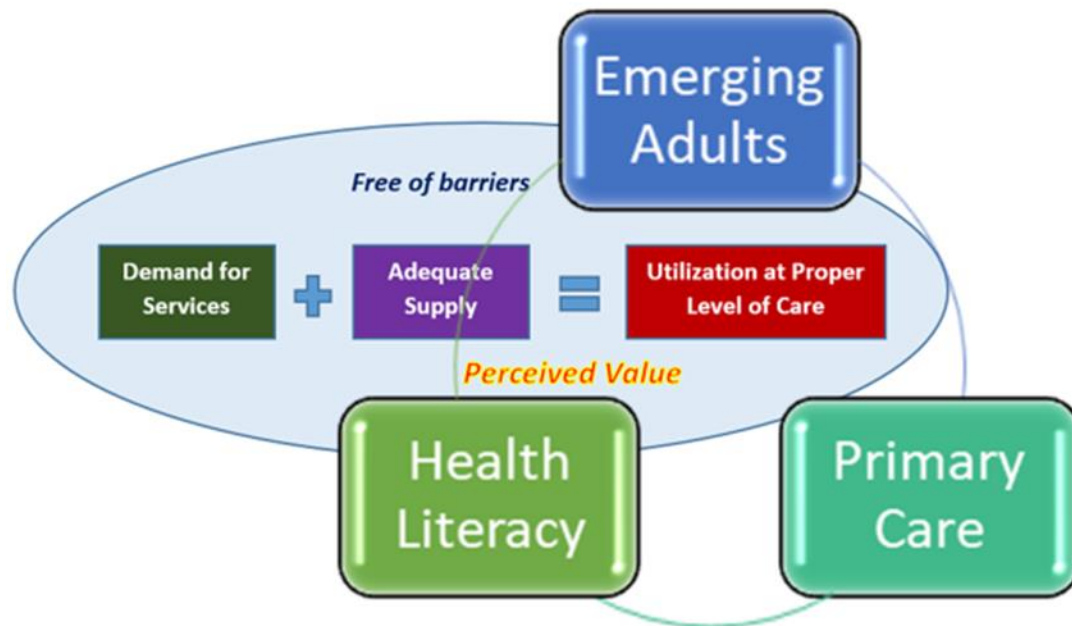


Note. This figure shows the synergy between each element of the Framework.

Primary care is the proper level of care for emerging adults when applying the iterative theories of health literacy, primary care, and emerging adulthood conceptually. Emerging adulthood is the life stage when perceived value of healthcare services is developed (Arnett, 2000; Institute of Medicine [IOM], 2004). Not only is primary care the proper level for the demand, but it is also theoretically the place health literacy should be developed and strengthened during emerging adulthood (Arnett, 2000; IOM, 2004; John Snow, Inc., 2010). Health literacy is also known to inform how patients perceive the value of healthcare and influences utilization at the proper level reinforced by the patient-provider relationship (IOM, 2004; Starfield, 1998). These interrelated theories set the tone for how a patient hard wires their perceived value of healthcare during emerging adulthood and builds the utilization muscle memory for the rest of their life (Arnett, 2000).

Figure 4

Collaboration of Conceptual and Theoretical Frameworks



Note. This figure shows the collaboration between the Conceptual Framework and the Theoretical Framework.

Primary Care

This study uses Starfield's theoretical framework with primary care viewed as the gatekeeper to the healthcare system applicable to all patient care needs. As described by Starfield, "in its most highly developed form, primary care is the point of entry into the health services system and the locus of responsibility for the care of patients and populations over time" (Starfield, 1998). Starfield's integration of acute care with primary care is backed by the World Health Organization; to effectively manage health, everyone at every life stage should be utilizing primary care services including acute care needs to maintain continuity of care (Hirshon et al., 2013). Further, "The integration of acute care with preventive and primary care completes a health-care system paradigm that fully encompasses all essential aspects of health care delivery" (Hirshon et al., 2013). There are four elements of primary care defined by Vuori: (1)

set of activities; (2) level of care; (3) strategy for organizing healthcare; and (4) philosophy that permeates health care (Vuori, 1985). This set of activities describes a spectrum of interventions which are not unique to primary care and can be transactionally furnished as acute care in many different places of service including specialty offices, urgent cares, retail minute clinics, asynchronous telemedicine, and the emergency room. These activities provide acute care services to those in need of immediate attention (Hirshon et al., 2013). Primary care alternatives are referred to in this paper as a place to seek care with only the intent to receive a set of activities but is not primary care as defined by Starfield's theoretical framework. The "philosophy that permeates healthcare" is referred to as primary care in this paper (Starfield, 1998). The "strategy for organizing healthcare" is referred to as the Patient Centered Medical Home (NCQA, 2017).

The Patient Centered Medical Home

The Patient Centered Medical Home model puts Starfield's primary care and the Institutes of Medicine's Health Literacy theory into practice as a delivery model to reinforce primary care at the proper level of care (John Snow, Inc., 2010). The Patient Centered Medical Home (PCMH) designed by the National Center for Quality Assurance is a formalized framework used in the healthcare industry to redesign the operational mechanics of primary care by leveraging patient-centric care teams expanding access to care. The value of primary care is optimized when holistic services extend beyond the traditional patient-provider relationship to solve for barriers to care. The integration of behavioral health provides a comprehensive experience with shared medical records. Convenience and continuity are core concepts of the PCMH model including expanded hours of operations, same day access, telehealth, and portal integration (NCQA, 2017). PCMH concepts and competencies including care management are

designed to only apply for certain risk segments of the patient panel. High risk patients are defined as having a behavioral health diagnosis, general cost to the system, comorbidities, social determinants of health, and/or as declared by insurance/risk-based contracts (NCQA, 2017). In effort to shift from volume to value, the PCMH model has proven to be an industry leader in achieving the quadruple aim; lower costs, better care, better health, and a greater experience (Adamson, 2011). The Patient Centered Medical Home 2017 standards and guidelines will be used for this study as the most current version at the time of this study.

NCQA PCMH Concept areas are overarching themes that make up the patient-centered medical home recognition criteria:

1. **Team-Based Care and Practice Organization (TC):** Helps structure a practice's leadership, care team responsibilities and how the practice partners with patients, families and caregivers.
2. **Knowing and Managing Your Patients (KM):** Sets standards for data collection, medication reconciliation, evidence-based clinical decision support and other activities.
3. **Patient-Centered Access and Continuity (AC):** Guides practices to provide patients with convenient access to clinical advice and helps ensure continuity of care.
4. **Care Management and Support (CM):** Helps clinicians set up care management protocols to identify patients who need more closely-managed care.
5. **Care Coordination and Care Transitions (CC):** Ensures that primary and specialty care clinicians are effectively sharing information and managing patient referrals to minimize cost, confusion and inappropriate care.

6. **Performance Measurement and Quality Improvement (QI):** Improvement helps practices develop ways to measure performance, set goals and develop activities that will improve performance.

(NCQA, 2017).

Health Literacy

The Health Literacy Framework (HLF), defined in *Health Literacy: A Prescription to End Confusion* and produced by the Institute of Medicine Committee on Health Literacy, is the guiding theoretical framework for the importance of health literacy development in primary care (IOM, 2004). Health literacy is the mediating factor between individuals and health contexts influencing how and when patients seek care. Therefore, health literacy is directly related to a patient's perceived value determining proper level of care. The HLF synthesizes three main elements of health literacy: (1) culture and society; (2) education system; and (3) healthcare system (IOM, 2004). It is within these three elements that health literacy is developed and should be the target of interventional improvements. This study focuses on health literacy as the ability to negotiate complex healthcare systems while acknowledging the importance of the patient-provider relationship (National Network of Libraries of Medicine, n.d.). Health literacy at the individual level, such as diet and exercise decision making, to enhance health and prevent disease is another way to view the application of health literacy. However, leveraging health literacy to enhance individual health outside of the healthcare system is outside the scope of this study. This is because the relationship between health literacy and preventive health behaviors are drastically different across ages groups (White et al., 2008). Younger adults are shown to have less connection between health literacy and likelihood of using preventive health practices

(White et al., 2008). Therefore, future research will need to focus on the relationship between health literacy and preventive health for emerging adults.

Emerging Adults

Emerging adults, Arnett's (2000) concept of the distinct life stage between the ages of 18 and 25, is used to ground the theoretical significance of the study population regarding health literacy development through the utilization of primary care. According to Arnett, emerging adulthood is the time to build lifestyles including health utilization behaviors. Primary care is positioned to be the ideal delivery model for emerging adults because it can solve for barriers to care and foster health literacy (IOM, 2004; Starfield, 1998). "Emerging adulthood is a time of life when many different directions remain possible, when little about the future has been decided for certain, when the scope of independent exploration of life's possibilities is greater for most people than it will be at any other period of the life course" (Arnett, 2000).

Primary Care Industry Background

The healthcare industry has accepted the top two utilization influencers as cost and convenience when navigating health service options for emerging adults (Advisory Board, 2017). Additionally, many known barriers to care exist including transportation, supply, language, and childcare (Frederick County Community Needs Assessment, 2019). Despite such barriers, most emerging adults in the United States are active utilizers of healthcare services (PCMHRC, 2019) but 45% do not have a primary care provider (Kaiser Family Foundation, 2018). Therefore, the choices emerging adults are making for healthcare are more transactional in design and less relational.

Primary care has the lowest out-of-pocket costs and the lowest utilization rates among emerging adults. Services furnished by primary care have lower copays and out-of-pocket costs

compared to primary care alternatives (BlueCross BlueShield, 2019). For example, an asynchronous telemedicine visits costs \$25, while a primary care copay may only cost \$15 with insurance (Why is My Copay Higher for Urgent Care Centers? n.d.). According to the National Center for Health Statistics, emerging adults had the highest uninsured rates among any other age group prior to the implementation of the Patient Protection and Affordable Care Act (CDC, 2020). With recent reform, emerging adults gained significant insurance benefits to alleviate the cost of care including extended eligibility under their parents' plans, Medicaid expansion, and no cost preventive services (Kotagal et al., 2014; Uberoi et al., 2016). While primary care utilization is expected to increase over the next few years, the motives driving patient demand are attributed to mainly an aging population and less from the newly insured emerging adult patients (Kotagal et al., 2014; Uberoi et al., 2016). Therefore, even with expanded insurance coverage, it is unexpected emerging adults will change their utilization patterns toward primary care which is counterintuitive to the fact that emerging adults are the most cost-conscious consumers. This may be because in complement to cost, there are other pertinent barriers to care (American Hospital Association, 2018a). A national survey in 2017 found most respondents struggled with identifying the proper care site for certain symptoms and healthcare needs (CityMD, 2017). Having the skill set to manage insurance as a resource tool and act to utilize health services at the proper level relies on health literacy (WHO, 2009).

Primary care is a societal construct to promote health literacy and more attention is needed to ensure the value proposition of primary care isn't lost on future generations of patients. Health maintenance requires active participation (WHO, 1986). To achieve optimal health, a patient must have the knowledge base to navigate the complexities of life including when, where, and how to access health services. This skill set is referred to as functional health literacy.

“Health literacy builds on the idea that both health and literacy are critical resources for everyday living. Our level of literacy directly affects our ability to not only act on health information but also to take more control of our health as individuals, families and communities” (WHO, 2009). Functional health literacy is a learned skill developed over time with experience. Healthcare has become the main learning environment where people shape their frame of understanding by receiving reinforcement or coaching through practical experiences including the patient-provider relationship (Wolf et al., 2009).

A relational approach to healthcare utilization is the foundation of value-based care (St. Martin, 2014). That relationship, especially for emerging adults, starts with primary care as the focal point in building health literacy (Hersh et al., 2015). Primary care utilization fosters a learning lab for the promotion of good health stewardship informing health literacy around relational care (Barrett et al., 2008). Primary care “integrates care when there is more than one health problem and deals with the context in which illness exists and influences the responses of people to their health problems” (Starfield, 1998). Therefore, utilization of primary care even for transactional needs serves as a teachable moment developing the emerging adult’s health literacy (Sturmberg, 2011). Because health literacy is a learned skill, patients utilizing primary care services are given the reinforcement and role modeling to enhance health literacy because “it is care that organizes and rationalizes the deployment of all resources, basic as well as specialized, directed at promoting, maintaining, and improving health” (Starfield, 1998). In addition, patients experience the value of continuity of care when “effective medical care is not limited to the treatment of disease itself; it must consider the context in which the illness occurs and in which the patient lives” (Starfield, 1998). Where people seek care and the modeling behaviors witnessed for each experience, directly informs their health literacy for better or worse (Wolf et

al., 2009). Therefore, primary care is considered the proper level of care for emerging adults to reduce health literacy inequalities (Sturmberg, 2011).

Emerging adults have been shown to typically demand transactional acute care and are forgoing relational care (Advisory Board, 2017). Emerging adulthood is the prime time to develop health literacy but is limited by a lack of familiarity with health, the healthcare system, and their role within it (Wolf et al., 2009). However, emerging adults are exercising their health literacy as active utilizers through the demand of health services comparable to other age groups (AHRQ, 2009). According to the 2009 Medical Expenditures Panel Survey, 72% of emerging adults aged 18-25 utilized health services compared to 78% of adults aged 26-44 (AHRQ, 2009). Emerging adults are susceptible to illnesses including urinary tract infections, mental health needs, injury, sexually transmitted disease (STD), and cold/flu symptoms in need of interventional treatment (Institute of Medicine & National Research Council [IOM & NRC], 2015). The Centers for Disease Control and Prevention (CDC) estimates half of the 20 million newly diagnosed STDs cases are from those aged 15-24 (CDC, 2020b). The potential to build the patient-provider relationship is a missed opportunity for undiagnosed STD cases because according to a national poll by the Kaiser Family Foundation, 45% of patients 18-29 years of age do not have primary care providers (Kaiser Family Foundation, 2018).

Emerging adults are more likely to seek transactional care at primary care alternatives compared to any other age group (American Hospital Association, 2018b; IOM & NRC, 2015). A 2015 study by PNC Healthcare found emerging adults make up 33% of patients at urgent care centers. That is twice the number of older adults at 14% and seniors at 11%. In addition, RAND Corporation found out of 1.3 million retail clinics surveyed, emerging adults account for 44% of retail clinic patients (PNC Healthcare, 2015). Since emerging adults are more likely to engage

with primary care alternatives, they are more likely to experience the illusion of value in care with the receipt of a medication or episodic intervention and forgo preventive services (U.S. Preventive Services Task Force, 2020). Primary care alternative locations use the business model of transactional care matched with convenience triggered by patient-initiated demand. When care is delivered in a transactional manner without continuity of care, the patient experience and outcomes suffer (St. Martin, 2014).

The mixed service offerings of relational versus transactional care is causing emerging adults to lack continuity, which is bad for equitable quality of care. Utilization of services at the proper level of care is contingent on the empowerment of patients to take the lead in their healthcare decision-making during the transition from childhood to adulthood (Wolf et al., 2009). By establishing a solid patient-provider relationship, the prevention of chronic illness is achieved with continuity and developed health literacy (Starfield, 1998). However, even if chronic conditions need to be managed, the provider is already familiar with the patient and their medical history, fostering better quality of care (Starfield, 1998). Emerging adulthood is the life stage primary care should be partnering with patients to build health literacy valuing primary care utilization in the context of continuity (Wolf et al., 2009). While transactional needs may be satisfied with primary care alternatives, emerging adults are not building the patient-provider relationship needed for long term outcomes (St. Martin, 2014). These utilization patterns limit emerging adult health literacy and conflict with primary care as the proper level of care (Haggerty et al., 2013). For example, a 2018 report from *JAMA Internal Medicine* linked inappropriate antibiotic stewardship to nearly half of the antibiotics prescribed by an urgent care compared to 17% seen in a primary care office for respiratory cold and flu symptoms (Palms et al., 2018). Therefore, emerging adults' affinity for transactional primary care alternatives is

reinforcing utilization behavior away from relational primary care in a demographic that prioritizes instant gratification at an impressionable life stage where health literacy skills are in development (Stanney, 2017).

Good primary care relies on connection and context, not convenience. It takes time, perspective, and team work to tackle the biopsychosocial dimensions of chronic disease. More importantly, primary care is built on trusting and caring relationships, forged over time through crises large and small that remain the best catalysts we have for fostering behavioral change. (Loxterkamp, 2015)

Purpose of the Study

This study aims to understand the lived experiences of emerging adult women to reveal the essence of primary care's value from the patient's perspective. The purpose of this study is to understand what emerging adult women want from primary care and identify the attributes that matter most to them. With low rates of primary care utilization among emerging adults, there is a sense of urgency to better understand the perceived value of primary care for patients in a community with adequate primary care supply. Convenient acute care is the tip of the iceberg in the scope of services primary care can provide to emerging adults (Barrett, 2018). Because health literacy rates are low, an effort to impact utilization of primary care by fostering demand for preventive and chronic services in emerging adults may be difficult (Scott et al., 2002). However, demand for transactional care is already present in this population serving as low hanging fruit to influence a shift in utilization behaviors toward primary care.

Primary care is adopting the Patient Centered Medical Home model as a best practice framework (Maryland Primary Care Program [MDPCP], 2018). Little research has explored how emerging adults view primary care and their role within it (IOM & NRC, 2015). This lack of

knowledge is a limiting factor in ensuring services are designed to meet emerging adult needs when deploying best practice models through health policy initiatives (IOM & NRC, 2015). While emerging adults utilize primary care alternatives at higher rates than any other age group, there is a gap in knowledge for why primary care is not their first preference – health literacy, cost, convenience versus continuity and many other factors are assumptions (IOM & NRC, 2015). Illuminating this blind spot to capture the emerging adult’s perception of primary care value will serve as an opportunity to incorporate these lessons learned into the best practice delivery models of primary care.

Overview of Research Methodology

Research Questions

I sought to understand the following questions about emerging adult women aged 18-25:

1. What prevents primary care utilization when not challenged with supply and demand?
2. What is the perceived value of the Patient Centered Medical Home?
3. What is the perceived value of the patient-provider relationship?

Methodology

Qualitative one-on-one interviews were conducted with emerging adult women living in the researched community. The study aimed to understand the lived experiences of emerging adult women who seek primary care services to determine the value of primary care from the patients’ perspective (Giorgi, 1997).

Context

In keeping with John Snow, Inc.’s 2010 utilization conceptual framework, this study controlled for adequate supply and demand for services while the participant selection process

mitigated known barriers to care. The researched community was the ideal site because primary care utilization is low for emerging adults while adequate supply of primary care services is not an issue. In addition, the community healthcare system offers primary care under NCQA's Patient Centered Medical Home model in the state of Maryland with health policy incentivizing aggressive primary care transformation (MDPCP, 2020).

Research Site

The researched community is not a Health Professional Shortage Area as defined by the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA) (HRSA, 2020). Therefore, community residents have an adequate supply of primary care providers to foster primary care utilization. The community healthcare system offers primary care services under the Patient Centered Medical Home with seven locations throughout the county currently taking new patients and accepting all major insurances including Medicaid. The state of Maryland also hosts progressive health policy reform incentivizing the utilization of primary care. The financial support of multiple pay for performance programs allows primary care investment and innovation to flourish (Maryland Total Cost of Care Model, 2019).

The researched community's healthcare system has seen high volumes of primary care treatable conditions in their emergency room. The highest volume of primary care treatable conditions is from emerging adults. Needs assessments for this community in 2016 and 2019 concluded the top barrier to care, after cost, is the knowledge to navigate the healthcare system. Studies conducted on the community's data conclude there is a large untapped emerging adult population moving to the community as the third fastest growing county percentagewise in Maryland. This finding is supported by urgent care patients with no indicated primary care provider. Out of the unique patients seen in the healthcare system's urgent care, 40% of patients

aged 20-29 did not have a primary care provider. In addition, only 8% of the healthcare system's primary care panel are emerging adults aged 18-25. The data show the researched community is not immune to the nationwide paradox of underutilization of primary care for emerging adults. However, the potential lessons learned from this study can turn the tide as Maryland leads the way with primary care practice transformation and policy reform.

Research Population

The following screening protocol for participants applied: (1) emerging adult women (aged 18-25) demanding care in the research community; (2) no children; (3) not married; and (4) active health insurance coverage. The population for the research study were emerging adult women living in the same Maryland community. This sample set ensured context of community when analyzing relevancy of primary care and utilization controlling for adequate supply. Individuals younger than 18 were outside the scope of study because parents or legal guardians make health decisions as guarantors. Individuals older than 25 introduce another financial dynamic outside the scope of this study because parental insurance coverage expires at age 26. Only participants who self-declared they have received healthcare as an adult were used for the study to control for demand.

A local community college was used as the source of the research population. In addition to an opportunistic sample base, attainment of higher education is associated with higher levels of literacy and resources mitigating barriers to care. Further, the PCMH model offered in the community promises to solve for barriers to care ensuring the "environment free of access barriers" contingency facilitating utilization (John Snow, Inc., 2010). The sample set derived from a community college in the district of the study adds a lens of attainment for higher education which is known to alleviate barriers to care and may be a confounding variable

influencing perceived value of primary care. While it is outside the scope of this study, more research is needed to understand the population of emerging adults with lower levels of education.

Researcher Positionality

Like the research scope, I fit the profile of an emerging adult women living and seeking care in the researched community. I have a self-declared high perceived value of the patient-provider relationship but have found sustaining a patient-provider relationship difficult in practice. I am a dedicated public health professional with extensive experience in diverse leadership positions supporting physician practices within large healthcare systems. My profession combines data analytics expertise and business acumen to align quality outcomes with pay for performance, backed by my Master of Public Health in Practice and Policy degree from the University of Maryland, College Park and Lean Six Sigma Black Belt certification. I have a track record for practice transformation reversing underperforming operations by improving processes, generating revenue, and ensuring optimal patient care. My personal lens, informed by interactions with emerging adults in my community, leads me to believe primary care's value proposition of relational care is diminishing among emerging adults. This is discouraging, as I see firsthand, the progress of primary care practice transformation improving cost and convenience. I fear, even with evolving health policy support emphasizing primary care as the backbone to reform, the unknowns of the emerging adult's perceived value are healthcare's biggest threat.

Boundaries

This section reviews the boundaries to the study, including participant selection criteria, scope of practice analysis, and motives for research. It was assumed participant stated demand

of healthcare services is captured through the self-declared answer of “yes” to the screening question: *As an adult (since you turned 18), have you ever needed to use healthcare services?*

The scope and frequency of use was not a selection factor.

Participants were asked to declare if they had an established primary care which was not used for selecting participants but was intended to be used to balance load the group with users and non-users of primary care. However, two out of twelve participants did not have a self-declared established relationship with primary care. It was shown through data collection, having a self-declared primary care provider was not synonymous with consistency in utilization of primary care. Many participants checked yes to having primary care because their insurance card listed a primary care doctor’s name, but they may have never met this person. This boundary is discussed in more detail in Chapters Four and Five.

Patient Centered Medical Home is a term used loosely in healthcare in many different contexts. NCQA’s Patient Centered Medical Home 2017 standards and guidelines is the model the study used for data analysis (NCQA, 2017). This approach is used because the Maryland Primary Care Program uses the NCQA PCMH to guide the program requirements for payment reform (MDPCP, 2020). Additionally, NCQA and MDPCP requires practices to formally attest to their delivery of services to claim competency in the guiding principles of primary care referred to by NCQA as concepts (NCQA, 2017). Insurance contractual programs and pay for performance Patient Centered Medical Homes are outside the scope of this study. The analytical approach to assessing perceived value for this study was based on the results of the patient’s perspective regardless of financial potential or disincentive.

Significance of the Study

A new patient acquisition strategy is just as important as a current panel management strategy. Many primary care practices are only using a ‘if we build it they will come’ new patient acquisition strategy. Primary care providers are wise to ensure their market share is strong with emerging adults to instill equitable care and navigate patients for better quality outcomes. This study should serve as an influence on primary care providers to proactively target emerging adult new patients by adopting elements they perceive as valuable.

Currently, under the pressure of pay for performance programs, many primary care providers are focused on their existing patients and high utilizers via the demands of lowering Total Cost of Care linked to readmissions and emergency room visits (MDPCP, 2020; NCQA, 2017). Primary care needs to focus on acquiring healthy patients as patients for life to mitigate the rising risk of adverse outcomes and chronic disease. High cost stems from patients only accessing health services when an issue arises, often too late and too costly for healthcare systems to continue to maintain with the prevalence of low health literacy. Solving today’s patient’s problems has become the sense of urgency for healthcare systems without a healthy balance of preventing future systematic issues. These pressures originate from pay for performance contracts segmenting patients by insurance coverage targeting patients of high risk for intervention. Failure of primary care to make themselves relevant to emerging adult women traditionally not deemed high risk from a contractual perspective will ensure the cyclical pattern of inappropriate utilization, higher costs and lower quality. This study should serve as an influence on health policy and pay for performance constituents such as the National Center for Quality Assurance to: (1) prioritize concepts relevant to emerging adults; (2) modify existing concepts to mitigate conflicts; and (3) remedy non-value-added concepts.

While there may be significant financial gains in attracting emerging adults to primary care, these do not represent the motives of this study. The findings of this study should start a national dialogue to promote equity of care through the promotion of health literacy and protecting the patient provider relationship for quality care. Since health literacy is contingent on adequate healthcare experience, healthcare systems have an obligation to be cognizant of their influence of health literacy and lead by example at every touch point reinforcing the patient-provider relationship. All roads must lead to primary care and that road starts with emerging adults.

Definition of Key Terms

Health: The World Health Organization (WHO) defines health as, “the extent to which an individual or group is able, on one hand, to realize aspirations and satisfy needs and, on the other hand, to cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living; it is a positive concept embracing social and personal resources as well as physical capabilities” (WHO, 1986).

Health Literacy: Many definitions and conceptual frameworks exist for health literacy, but the WHO definition is used for this study is, “The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course” (WHO, 2009).

Primary Care: The Institute of Medicine defines primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community” (IOM, 1994).

Acute Care: “Providing or concerned with short-term usually immediate medical care (as for serious illness or traumatic injury)” (Merriam-Webster, 2020a).

Chronic Care: “Providing or concerned with long-term medical care lasting usually more than 90 days especially for individuals with chronic physical or mental impairment” (Merriam-Webster, 2020b).

Preventive Care: “Designed or serving to prevent the occurrence of disease” (Merriam-Webster, 2020c).

Primary Care Provider: A primary care provider (PCP) is a health care practitioner who sees people who have common medical problems. This person is most often a doctor (MD/DO). However, a PCP may be a physician assistant or a nurse practitioner (U.S. National Library of Medicine, n.d.).

Patient Centered Medical Home: “The medical home model holds promise as a way to improve health care in America by transforming how primary care is organized and delivered. Building on the work of a large and growing community, the Agency for Healthcare Research and Quality (AHRQ) defines a medical home not simply as a place but as a model of the organization of primary care that delivers the core functions of primary health care” (AHRQ, 2009).

Emerging Adult: “Neither adolescence nor young adulthood but is theoretically and empirically distinct from them both. Emerging adulthood is distinguished by relative independence from social roles and from normative expectations. Having left the dependency of childhood and adolescence and having not yet entered the enduring responsibilities that are normative in adulthood, emerging adults often explore a variety of possible life directions in love, work, and worldviews” (Arnett, 2000).

Total Cost of Care (TCOC): “Maryland Total Cost of Care Model. The Centers for Medicare & Medicaid Services (CMS) and the state of Maryland are partnering to test the Maryland Total Cost of Care (TCOC) Model, which sets a per capita limit on Medicare total cost of care in Maryland” (CMS, 2020).

Asynchronous: “An exchange of information between a patient and a health care practitioner that does not occur in real time, including the secure collection and transmission of a patient’s medical information, clinical data, clinical images, laboratory results, and self-reported medical history” (Maryland Senate Bill 402, 2020).

Synchronous: “An exchange of information between a patient and a health care practitioner that occurs in real time” (Maryland Senate Bill 402, 2020).

Telehealth: “A mode of delivering health care services through the use of telecommunications technologies by a health care practitioner to a patient at a different physical location than the health care practitioner” (Maryland Senate Bill, 2020).

Summary

A relational approach to healthcare utilization at the proper level is the foundation of value-based care (St. Martin, 2014). That relationship, especially for emerging adults, starts with primary care as the focal point in building health literacy (Hersh et al., 2015). Emerging adults are shown to demand transactional care and are forgoing relational care, assuming convenience over continuity (Advisory Board, 2017). Consumer utilization is shifting with high rates of services rendered transactionally via primary care alternatives like asynchronous telemedicine, retail clinics, urgent cares, and ultimately the emergency room. Self-guided transactional utilization is causing emerging adults to lack continuity which is problematic for equitable quality of care. Primary care is a societal construct to promote health literacy and focused

attention is needed to ensure the value proposition of the patient-provider relationship is not lost on future generations of patients. Utilization of primary care is low among emerging adults even though this age group are active consumers of services that can be rendered in primary care. The Patient Centered Medical Home (PCMH) model developed by the National Center for Quality Assurance has become a best practice to redesigning primary care into hopefully a relevant and convenient place to seek care but its relevance to emerging adults remains unknown (Lipson et al., 2011). Since women are healthcare decision making influencers, it is useful to assess the perceived value of primary care among emerging adult women if the Patient Centered Medical Home model promises to be the future of primary care.

CHAPTER 2: LITERATURE REVIEW

The Institute of Medicine defines primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community” (IOM, 1994). To unpack the intended value of primary care, a better understanding of primary care’s historical and current role in the United States is essential to including the fundamental role of the patient-provider relationship and modern-day challenges. The literature review conceptual approach will provide a historical overview of the evolution of primary care in the United States. Leading into the theoretical framework, the literature applicable to NCQA’s Patient Centered Medical Home model will be synthesized for barriers and advantages. Health literacy will be defined using a meta-analysis merging WHO’s health literacy levels against NCQA’s PCMH concepts.

Evolution of Primary Care in the United States

The fundamental values of primary care had early Native American roots dating back to the 1400s (Shelton, 2004). Prior to colonization and European influence, the Native Americans governed themselves with a developed healthcare system. The National Institutes of Health identifies the Native American Traditional Health[care] System as viewing illness in the context of the whole person including “a health promotion foundation that embraces bio-psycho-socio-spiritual approaches and traditions” (Koithan & Farrell, 2010). In Native American culture, the core modality to healing is the relationship backed by the mantra “we are all related” (Koithan & Farrell, 2010).

The United States became the great nation it is today out of resiliency and resourcefulness, much how the modern-day primary care developed out of necessity in the 1800s

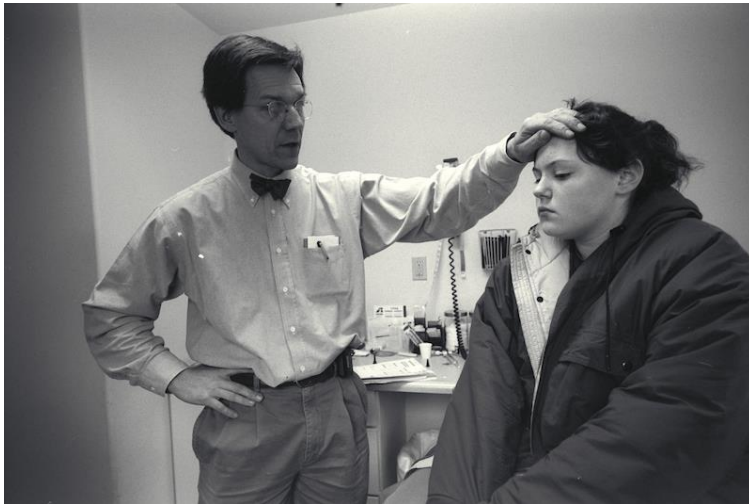
in response to an unstructured healthcare system (Canfield, 1976). Family medicine physicians attempted to fill the void to provide personalized care in a time when resources were scarce and access to quality care was for many unattainable (Canfield, 1976). With limited formalized training and schooling, most physicians crafted their skills from on the job training. Primary care physicians did their best work by providing care for entire families in the intimacy of their homes (Smith & Ritsema, 2018). The scope of practice ranged from delivering babies, the treatment of illnesses, surgery, to end of life care (Smith & Ritsema, 2018). The impactful photo essay “country doctor” followed the life of a primary care physician outlining the demands of selflessly serving a broad spectrum of community needs (Smith & Ritsema, 2018).

As the United States grew, a sense of urgency was created for physicians to organize and formalize their skills to develop standards in care (Weisz, 2006). In 1846, the American Medical Association (AMA) was formed and in 1882, the *Journal of the American Medical Association* was first published (American Medical Association [AMA], 2019). The Flexner Report published in 1910 synthesized international best practices in medical education and gave way to the development of specialty practice silos (Duffy, 2011). In the early 1900s, American Boards were formed starting with Ophthalmology in 1917 (Weisz, 2006). The cost of a medical education grew from the institutionalization and bureaucracy of a growing society with medical training forming its place as a heavily white male dominated upper-class profession (Weisz, 2006). A divide between family medicine physicians and specialists grew as the delivery of medicine became siloed (Weisz, 2006). While a family medicine physician’s scope of practice did not change much, the specialization of interventional services traditionally performed by the primary care physicians shifted the way patients utilized health care services toward more specialized care (Weisz, 2006).

In response to the weakening patient-provider relationship, the AMA requested a study on primary care that called for a physician specialization that focused on the whole person (Isaacs & Knickman, 2004). The study recommended that every person have a relationship with a primary care physician to establish continuity as a routine source for care (Isaacs & Knickman, 2004). The focus of the primary care physician was to be preventive medicine, taking into consideration environmental, emotional, and physical factors (Isaacs & Knickman, 2004). Thereafter, in 1969, the American Boards approved Family Practice as a new specialty (AMA, 2019). “Relationship continuity is the essence of primary care; accumulated knowledge is critical to the person-focused interventions over time that are unique to primary care” (Starfield, 2011). As a result, Family Medicine became the label given for the specialty of practicing primary care.

Figure 5

Example of Relational Care.



Note. This figure shows an in-person office visit between a patient and her primary care provider.

Today, Family Medicine physicians are the dominant providers of primary care (National Centers for Health Workforce Analytics, 2013). However, due to an aging and growing population, the patient demand for primary care services is anticipated to outpace the physician supply (National Centers for Health Workforce Analytics, 2013). To supplement, physician assistants (PAs) and nurse practitioners (NPs) are integrating their services into the primary care delivery system (Liu et al., 2017). About one-fourth of all primary care services are rendered by PAs or NPs (National Centers for Health Workforce Analytics, 2013). With primary care delivered by either a physician (MD/DO), NP or PA, the terms “primary care provider” and “primary care practitioner” were developed as more inclusive terminology. The Bureau of Health Workforce published *Projecting the Supply and Demand for Primary Care Practitioners Through 2020*, showing there are an estimated 98 full-time primary care providers actively engaged in patient care per 100,000 population. A range from a low of 41 full-time primary care providers per 100,000 persons aged 18-20 to a high of 172 per 100,000 persons aged 75 and above (National Centers for Health Workforce Analytics, 2013). Therefore, the primary care resources are stratified to focus mainly on the elderly and aging populations. Fewer resources are focused on younger patients building the patient-provider relationship.

Empirical research on the topic of primary care are predominantly quantitative aimed at either clinical practice or clinical outcomes. Research around expanding primary care’s scope in new areas include prevention of heat stress for existing patients resulting from climate change (Tait et al., 2018). In addition, asthma management and mental health integration for adult populations is heavily researched (Bhana et al., 2019; Yoo et al., 2019). Participants included are mainly sourced from primary care practices where the relationships are already established. There are limited qualitative studies on the patient’s perspective. Qualitative studies have

focused heavily on the providers perspective regarding clinical scope of practice and provider job satisfaction (Agana, 2017; Smeets et al., 2019). Therefore, the voice of the emerging adult from a qualitative lens on the topic of primary care is limited.

Primary Care Alternatives

In response to limited primary care provider resources, acute care has become another “specialty” service stripped away from the traditional offerings of primary care creating a competitive market to capture consumer demand (AAUCM, 2019). Many primary care alternative business models are used to increase access to acute care services including the development of urgent care and asynchronous telemedicine (Anderson & Althausen, 2016; Johansson et al., 2020). Historically, specialty services such as cardiology, neurology, and urology, developed from the need to standardize and competency a specific skill essential to proving a complex service (Ramirez et al., 2018). Transactional primary care alternatives developed in response to providing convenient acute care services when primary care fails to meet the convenience needs (AAUCM, 2019). Urgent care was one of the first primary care alternatives to hit the consumer driven market in the late 1970s (McNeeley, 2012). Insurance companies viewed urgent care as an efficient emergency room diversion strategy to reduce cost of care while healthcare systems viewed them as a threat to market share (Resnick, 2013). Healthcare systems began aggressively partnering or competing in the urgent care space in the late 1990s to prevent leakage (Resnick, 2013). Growth of the new business model was slow between 1970 and 2000 as insurance companies and competitor healthcare systems adjusted to the change (McNeeley, 2012). However, that was just a false start for profit driven transactional care (McNeeley, 2012). Over the last 20 years, primary care alternatives have seen exponential growth as an industry worth more than \$18 billion (Japsen, 2018). Most recently, telemedicine is

being discussed as an emerging specialty (Waller et al., 2019). In addition, aggressive health policy is under review in the state of Maryland proposing to remove the patient-provider relationship requirement for asynchronous telemedicine. These changes would allow asynchronous visits to scale in a direct to consumer model (Maryland Senate Bill 402, 2020).

Acute care requires the provider specialty skill set of family or internal medicine and was the bread and butter of primary care prior to primary care alternatives entering the market. Excluding the emergency room, primary care alternatives usually employ providers trained in family medicine or internal medicine to provide strictly transactional care (Amirault, 2018). Most family medicine trained providers are attracted to work in urgent care for financial and work life balance reasons (Alkon, 2018). Therefore, the interventions received in primary care alternative locations like urgent care are the same set of interventions that can be furnished in a primary care place of service. Urgent care providers do not receive additional or special training one receives as primary care provider during medical school (Alkon, 2018). However, as urgent care becomes a more distinct specialty, the *Journal of Urgent Care Medicine and a Board Certification of Urgent Care Medicine* was published in 2010 in recognition of a separate knowledge base (McNeeley, 2012). Currently, the distinct difference between primary care and primary care alternatives is continuity and comprehensiveness reinforcing relational care (Loxterkamp, 2015). According to the American Association of Physician Assistants, “while urgent care providers may also be the first to diagnosis chronic diseases such as diabetes or asthma, they generally refer patients to a primary care provider for the management of these conditions” (Smith & Ritsema, 2018). This is concerning when the transition of care for long-term health outcomes relies often on the missing link of the primary care relationship.

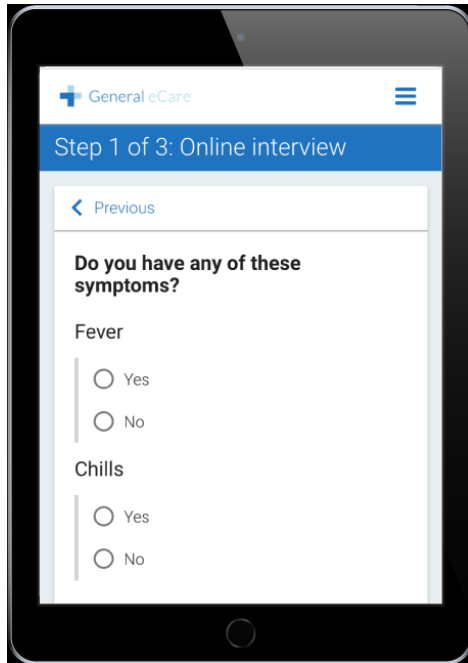
Urgent cares have outpaced traditional primary care practices in the convenience of care revolution (Alkon, 2018). “This is the age of the patient as a consumer, where fast and convenient is never fast and convenient enough,” says Richard Park, MD, CEO and co-founder of CityMD, a large group of urgent care clinics (Alkon, 2018). Video visits have become another strategy to enhance access and utilization of health services (Waller et al., 2019). Two-way interaction over a video platform connects patients directly to providers. While this interaction is void of human touch, the patient-provider relationship is strengthened through two-way real-time communication and visual contact (Krauss et al., 2018). The deployment of video visits can be used to either scale urgent care or primary care services depending on the context of the patient-provider relationship (Waller et al., 2019). For example, a primary care provider can use video visits to connect to their patients for a variety of needs including transactional acute care. On the other hand, primary care alternatives can offer video visits connecting patients to providers where no relationship is established to only satisfy the acute care need (Elliot & Shih, 2019). Video visits provide a modality of care but the intent of the two people connecting virtually defines the level of care (Starfield, 1998).

Taking transactional care to the next level, asynchronous telemedicine is now offering an even more quick and convenient option completely removing patient-provider contact (Zipnosis, 2019). This business model is often referred to as direct to consumer healthcare (Elliot & Shih, 2019). To complete an asynchronous visit, patients interact with a web-based questionnaire, as shown in the adjacent figure, and the software curates a treatment plan. This treatment plan is signed off on by a provider with usually no relationship to the patient requiring less than two minutes of the provider’s attention (Zipnosis, 2019). The treatment plan is electronically sent back to the patient without a feedback loop for patient comprehension and compliance. This

business model eliminates the patient-provider relationship as a context to understanding illness to allow scalability of provider resources for greater profit (Zipnosis, 2019).

Figure 6

Examples of an Asynchronous Experience



Note. This figure shows a Zipnosis asynchronous experience.

Empirical research on primary care alternatives are limited to mainly quantitative utilization analysis and provider resource scaling strategies (Mammel & Spalsbury, 2017; Montalbano et al., 2017). The main topic for current research on primary care alternatives is centered around antibiotic and opioid stewardship (Morris et al., 2019; Yadav et al., 2019). Clinical scope of practice research ranges from treatment of sunburn to chronic care management (Chen, 2015; Di Xia et al., 2017). Asynchronous telemedicine has limited research since it is a relatively new way to receive transactional care. There is industry attention on leveraging

asynchronous telemedicine for mental health due to the physician supply shortages and high demand (Chan, 2018). Qualitative research is prevalent on the motives of utilization for urgent care with the intent to drive volumes toward primary care alternatives as an emergency room diversion strategy (Coster et al., 2017).

Walk-in clinics raise red flags for the future of primary care. No matter how advocates spin it, walk-in clinics are no more about primary care than are emergency rooms. Fast food chains are the walk-in health centers for the appetite: they fill a niche for society on the go, providing quick service at all hours for a fraction of the cost of traditional restaurants. When they began to cut into the profits of traditional restaurants, many restaurants changed their menus, hours, and pricing to stay in business. But fast food has also changed the cultural context of eating: no longer does it connect us to family and friends, provide a relaxing break in the middle of the day, or challenge our culinary palette; it is now just a quick fix for hunger and stress. (Loxterkamp, 2015)

Patient Centered Medical Home

Without aggressive primary care practice transformation, the assumption is that demand will outpace supply and, by 2020, there will be a projected shortage of 20,400 physicians to support an aging population (National Centers for Health Workforce Analytics, 2013). The Patient Protection and Affordable Care Act includes a call to action under health reform for primary care to succeed in the competition of the transactional market (Pitts et al., 2010). Specifically, it outlines how the Patient Centered Medical Home model of care improves access for urgent needs as a potential method for success (Pitts et al., 2010). According to the Patient-Centered Primary Care Collaborative, there are over 500 PCMH initiatives across the United States redesigning primary care (NCQA, 2017).

The National Center for Quality Assurance has designed an operational framework to mobilize primary care providers to transform their practices into the Patient Centered Medical Homes. Even with the integration of PAs and NPs as supplemental primary care providers, healthcare systems are challenged to redesign and scale their services to enhance access. Often referred to as continuity of care, the partnership between patients and providers is one way of achieving healthcare reform (Gottlieb et al., 2008). Many primary care practices have undergone significant organizational changes to deliver cost effective, convenient, and comprehensive care while remaining true to its core value of continuity supporting relationships (Gottlieb et al., 2008). Primary care practices accredited as an NCQA Patient Centered Medical Home have shown competency under the core concept of “Patient-Centered Access and Continuity: Guides practices to provide patients with convenient access to clinical advice and helps ensure continuity of care” (NCQA, 2017). With the introduction of Patient Centered Medical Home, primary care now offers the same conveniences a patient would expect at a primary care alternative. This includes, same day access, 24/7 clinical advice, and often walk in availability to their primary care provider for urgent needs (NCQA, 2017). The recall process for established patients is a core element of NCQA’s PCMH (NCQA, 2017). Therefore, it can be projected through the utilization of primary care as the proper level of care for acute transactional demand, the demand for preventive care will develop (Garcia-Huidobro, 2016; Scott et al., 2002).

Practice transformation under the Patient Centered Medical Home requires substantial financial investment. Total transformation often takes over a year to achieve with extensive administrative documentation and oversight (Bresnick, 2014). For many primary care practices, the catalyst to adopting changes in alignment with NCQA’s PCMH stems from health policy initiatives investing substantially in primary care including the National Comprehensive Primary

Care Program (CPC+). Maryland is on the front lines of health reform citing primary care as the backbone to success with their new Maryland Primary Care Program (MDPCP, 2020). CPC+ and Maryland's MDPCP program are aggressively shifting the payment model for primary care from fee for service to pay for performance (MDPCP, 2020). Performance driving payment was defined using a rubric of services primary care must attest to offering to warrant payment (MDPCP, 2020). This rubric was designed in line with NCQA's Patient Centered Medical Home framework including integration of same day visits, behavioral health, and telemedicine (MDPCP, 2018). These new payment models include upfront payments to alleviate the investment burden of practice transformation under the Patient Centered Medical Home model (MDPCP, 2018). MDPCP is creating excitement by serving as one of the first case studies to test how financially incentivizing primary care providers impacts cost, quality, and access to care. The current payment model for MDPCP only applies to Medicare patients based on attributed lives, meaning patients already utilizing primary care services (CMS, 2020).

Health Literacy

Health literacy is the skill set to manage health and informs how patients engage with health services at the proper level (WHO, 1998). According to the World Health Organization lack of health literacy adversely impacts a person's ability to manage their health, access care, and comprehend information during the patient experience vital to decision making (WHO, 1998). In addition, health literacy levels have been found to directly impact health outcomes (WHO, 1998). Targeting improvement efforts to promote health literacy is a pivotal tactic in the pursuit of eradicating health inequalities (WHO, 1998). It is essential that we leverage primary care in this call to action for health equity (Wolf et al., 2009). Through continuity in the utilization of primary care health literacy would be strengthened by the patient-provider

relationship (Wolf et al., 2009). “The health[care] system – whether the setting is a hospital, doctor’s office, or community health center – should view itself as a dynamic learning environment with an educational directive” (Wolf et al., 2009). To optimize learning, an established patient-provider relationship must be at the foundation of care to build upon the patient’s healthcare schema on the journey toward self-efficacy (Wolf et al., 2009).

Health literacy can be measured in different ways with industry best practice tools. Most tools simply evaluate reading capabilities in a health care context, but other tools have evolved to measure cognitive and functional ability. RTI designed the Health Literacy Skills Instrument (HLSI) with funding from the National Cancer Institute to assess four separate domains of health literacy to ensure a comprehensive approach to health literacy measurement (RTI International, 2016). When patients self-navigate health services, it is up to their own level of health literacy to inform when, where, and how to seek care (WHO, 1998). According to the WHO, the scope of health literacy has three distinct “levels” and using Starfield’s theoretical framework, primary care puts health literacy into practice in the optimal learning environment (NCQA, 2017).

Functional Literacy

Functional Literacy consists of “[s]kills that allow an individual to read consent forms, medicine labels, and health care information and to understand written and oral information given by physicians, nurses, pharmacists, or other health care professionals and to act on directions by taking medication correctly, adhering to self-care at home, and keeping appointment schedules” (WHO, 2009). Engagement with primary care gives patients a resource team trained to gauge and teach understanding to ensure compliance with treatment plans and medication adherence. For example, Patient Centered Medical Homes are required to provide

patient education materials, use teach back methods, and have a screening mechanism for patients that need additional care coordination assistance (NCQA, 2017).

Conceptual Literacy

Conceptual literacy encompasses “[t]he wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life” (WHO, 2009). Primary care teams are designed to be multidisciplinary to increase patient access to complimentary services such as behavioral health, pharmacy, and nutrition. A dynamic team gives the patient the ability to have all angles of their health looked after. In addition, Patient Centered Medical Homes are required to share a patient’s medical record across the care team including the patient. Access to a complete medical record assists with shared decision making (NCQA, 2017).

Health Literacy as Empowerment

Health literacy as empowerment involves “[s]trengthening active citizenship for health by bringing together a commitment to citizenship with health promotion and prevention efforts and involving individuals in: understanding their rights as patients and their ability to navigate through the health care system; acting as an informed consumers about the health risks of products and services and about options in health care providers, and acting individually or collectively to improve health through the political system through voting, advocacy or membership of social movements” (WHO, 2009). Health literacy at its prime builds self-efficacy for patients to take control of their health with iterative cycles of learning through primary care utilization. Patient Centered Medical Homes are required to have a patient family advisory council to directly engage patients in the continuous improvement efforts of the services they

receive as a patient (NCQA, 2009). Empowered patients are mobilized with the mind set and skill set to be good stewards of healthcare services. The Alma-Ata declaration defines Primary Health Care through the lens of self-efficacy as “essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every state of their development in the spirit of self-reliance and self-determination” (Walley et al., 2008). It forms an integral part both of the country’s healthcare system, of which is the central function and main focus, and of the overall social and economic development of the community (Walley et al., 2008). It is the first level of contact of individuals, the family and community with the national healthcare systems bring health care as close as possible to where people live and work and constitutes the first element of the continuing health care process” (WHO, 1978). The ripple effect of empowered patients through health literacy rooted in the relationships of primary care is felt throughout the community and the catalyst for eradicating health disparities (Gottlieb et al., 2008; Michel et al., 2020).

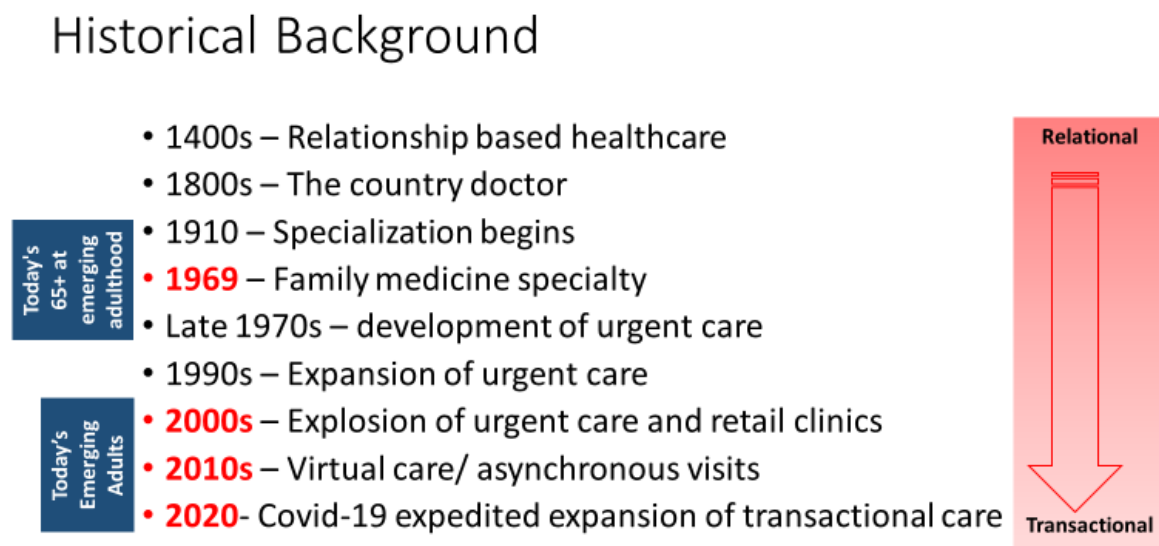
Conclusion

Empowerment of health literacy when establishing the primary care patient- provider relationship facilitates utilization at the proper level of care (WHO, 1998). Active relationships with primary care, as a routine source for care, is associated with decreased utilization of primary care alternatives such as the emergency room (Enard & Ganelin, 2013). Primary care alternatives introduce vast transactional options for patients that challenge the traditional primary care relationship compromising quality of care (Michel et al., 2020). The historical background of the evolution of primary care and with the infiltration of primary care alternatives illustrates two

distinct paradigms over time: relational vs transactional. Depending on the timeframe a patient was an emerging adult, their lived experiences involving healthcare could be drastically different. For example, today's 65-year-old and above patients were emerging adults between 1953 and 1973. This point in time was primary care's prime regarding the market share of relational care, as shown in the image below:

Figure 7

Historical Timeline of Emerging Adult Health Care Experiences



Note. This figure shows the differences between how today's emerging adults experience primary care versus how today's 65-year-olds experiences primary care as emerging adults.

Today's emerging adults are experiencing primary care alternative's as emergent specialties in direct to consumer business models. While the healthcare industry is preoccupied with internally revitalize primary care under the Patient Centered Medical Home for existing high-risk patients, there is a gap in the literature representing the emerging adult's perspective. The emerging adult's perceived need or desire for a relational model of care anchored by the patient-provider relationship remains unknown.

CHAPTER 3: METHODOLOGY

Capitalizing on the leadership and influence of women on American society's health care behaviors and decision-making, emerging adult women are the prime targets for primary care alternatives to maximize their profits and gain market share (Ayers, 2011). Primary care alternatives, such as asynchronous telemedicine, urgent cares, and ultimately the emergency room, are reinforcing solely transactional utilization behaviors devaluing the patient-provider relationship (Loxterkamp, 2015). Emerging adulthood is a life phase where lived experiences build the framework for adulthood behaviors and attitudes (Arnett, 2000).

Today's emerging adults are the first generation in America to have had consistent options for primary care alternatives since childhood. However, reinforced by a gap in the current research literature, primary care's value proposition grounded in a patient-provider relationship is challenged as transaction care scales. To ensure primary care remains relevant against primary care alternatives, this study explored the emerging adult woman's perceived value of primary care.

Chapter Three outlines the qualitative methodology used to answer the research questions, including the limitations to the approach and areas for future research. The scope of this study includes 12 emerging adult women who use healthcare in the researched community. Participant screening took place September 2019 and data collection occurred from October 2019 to January 2020.

Chapter 3 Structure

Table 1

Research Questions Chart

Research Question	Participants	Sampling & Instruments	Analysis
RQ1: What prevents primary care utilization when not challenged with supply and demand?	<i>Screening:</i> ✓ Emerging Adults, 18-25 age ✓ Female ✓ Not married <i>Adequate supply:</i> ✓ Research community Resident	Qualitative: <i>Step 1: Individual interviews</i> - Personal experiences with primary care, expectations, and limitations of current services - Ranking value exercise - Deeper dive into access and continuity concept <i>Step 2: Individual interviews</i> - Design ideal primary care	Code against ALL PCMH concepts synthesizing <i>missing</i> and <i>conflicting</i> perceived value items
RQ2: What is the perceived value of the Patient Centered Medical Home?	<i>Demand:</i> ✓ Received healthcare services as an adult <i>No known barriers to care:</i> ✓ Active health insurance coverage ✓ No children <i>Segmentation:</i> <input type="checkbox"/> Primary care utilization <input type="checkbox"/> Racial minority status		Code against ALL PCMH concepts synthesizing <i>aligned</i> perceived value items
RQ3: What is the perceived value of the patient-provider relationship?			Code against PCMH “knowing and managing your patients” & “patient centered access and continuity” concepts synthesizing the <i>missing</i> , <i>conflicting</i> , and <i>aligned</i> perceived value items

Note. This table aligns the research questions with the methodological approach.

Research Design

To fill the gap of knowledge in current research, this study aimed to reveal the essence of primary care’s value from the patient’s perspective by understanding the lived experiences of

emerging adult women demanding primary care services (Giorgi, 1997). In this qualitative study of the phenomenon of transactional versus relational care, one-on-one interviews were conducted to determine the following: (1) What prevents primary care utilization when not challenged with supply and demand?; (2) What is the perceived value of the Patient Centered Medical Home?; and (3) What is the perceived value of the patient-provider relationship?

Setting and Context

In this section, the setting and context are described. First, I explain women as healthcare decisionmakers broadly. Second, I focus my discussion specifically on emerging adults, their demand for care, and health literacy. Finally, I end with an overview of the researched community in context to where these young adult women live.

Women as Healthcare Decisionmakers

While males show lower rates of primary care utilization, emerging adult women are the target population for this study (Bertakis et al., 2000). To have the greatest systemic impact on patient behaviors, Lounsbery says that understanding the women's perceived value is essential because women serve as society's healthcare decision-making influencers (Lounsbery, 2018). Ideally, women would have the foundation of an established primary care relationship before influencing a partner's or child's health decisions because families are known to seek care together (Karazivan, 2011). Married women with children are outside the scope of this study because childcare is a known barrier to care that impacts primary care utilization (Frederick County Needs Assessment, 2016).

Emerging Adults

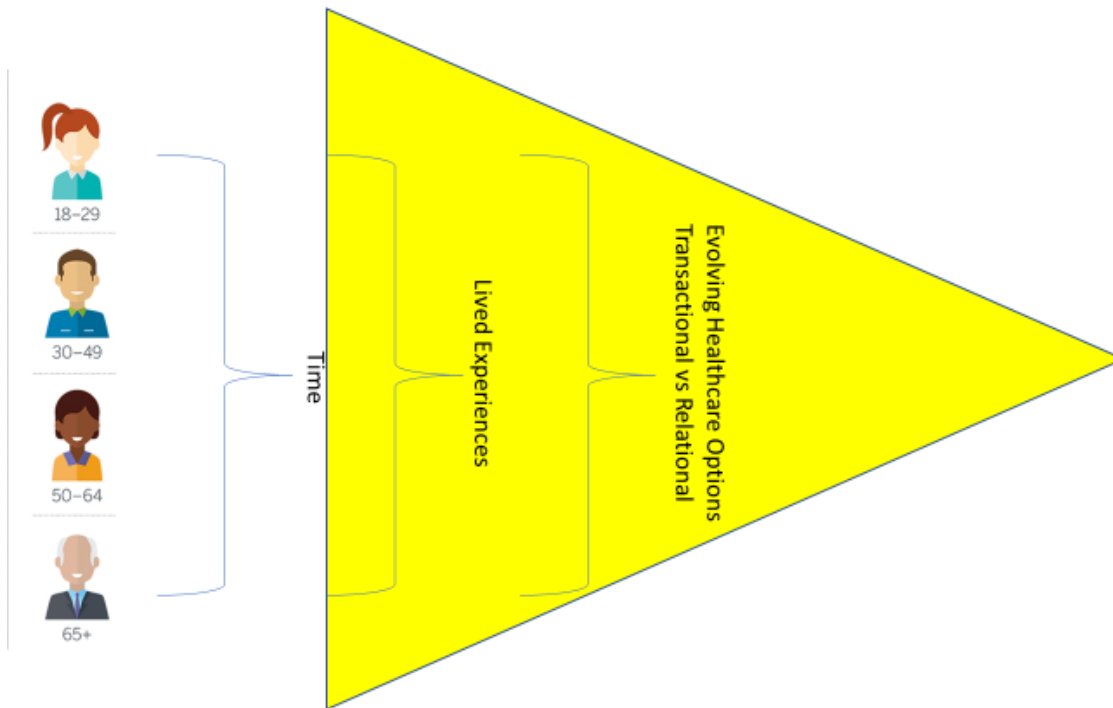
Understanding the compounding effect of the way today's emerging adults experience healthcare with a plethora of options versus how today's 65-year-olds and above experienced

healthcare during their emerging adulthoods is a blind spot for the future of healthcare. The healthcare industry segments patients by age when seeking to understand their utilization patterns and behaviors. Computing patient demand to anticipate supply is a core business practice. It is typical for the healthcare industry to track the movement of age for the population served to project future volumes. Balancing supply and demand of health care resources for an aging population often assumes that the 18-25-year-olds of today will eventually fit the patient profile of today's 65-year-olds and above. This may be a solid assumption if time were the only variable between emerging adulthood and older adulthood. However, a rapidly evolving healthcare landscape moving from relational to transactional care is an unknown force on the perceived value and future utilization patterns of today's emerging adults. Therefore, the target age group for this study is emerging adults between the ages of 18 and 25.

American society lacks a proactive format for educating patients on how to be good stewards of healthcare, which includes the value of primary care (Wolf et al., 2009). Therefore, a patient's experience with the healthcare system has become a pivotal learning opportunity to increase health literacy during emerging adulthood (Wolf et al., 2009). However, emerging adults must use health services to be given this practical iterative learning opportunity. This approach assumes patients already have the skills and knowledge to determine when and where to engage with health services. Emerging adults are shown to be active users of healthcare, as reflected in their comparable utilization rates to other age groups (AHRQ, 2009). Primary care providers have a blind spot, shown in the image below, for understanding the voice of the emerging adult patient, due to lack of exposure (Frederick Health, 2019).

Figure 8

Segmentation of Age for Health Care Experiences



Note. This figure shows the variables between the lived experiences of each age group.

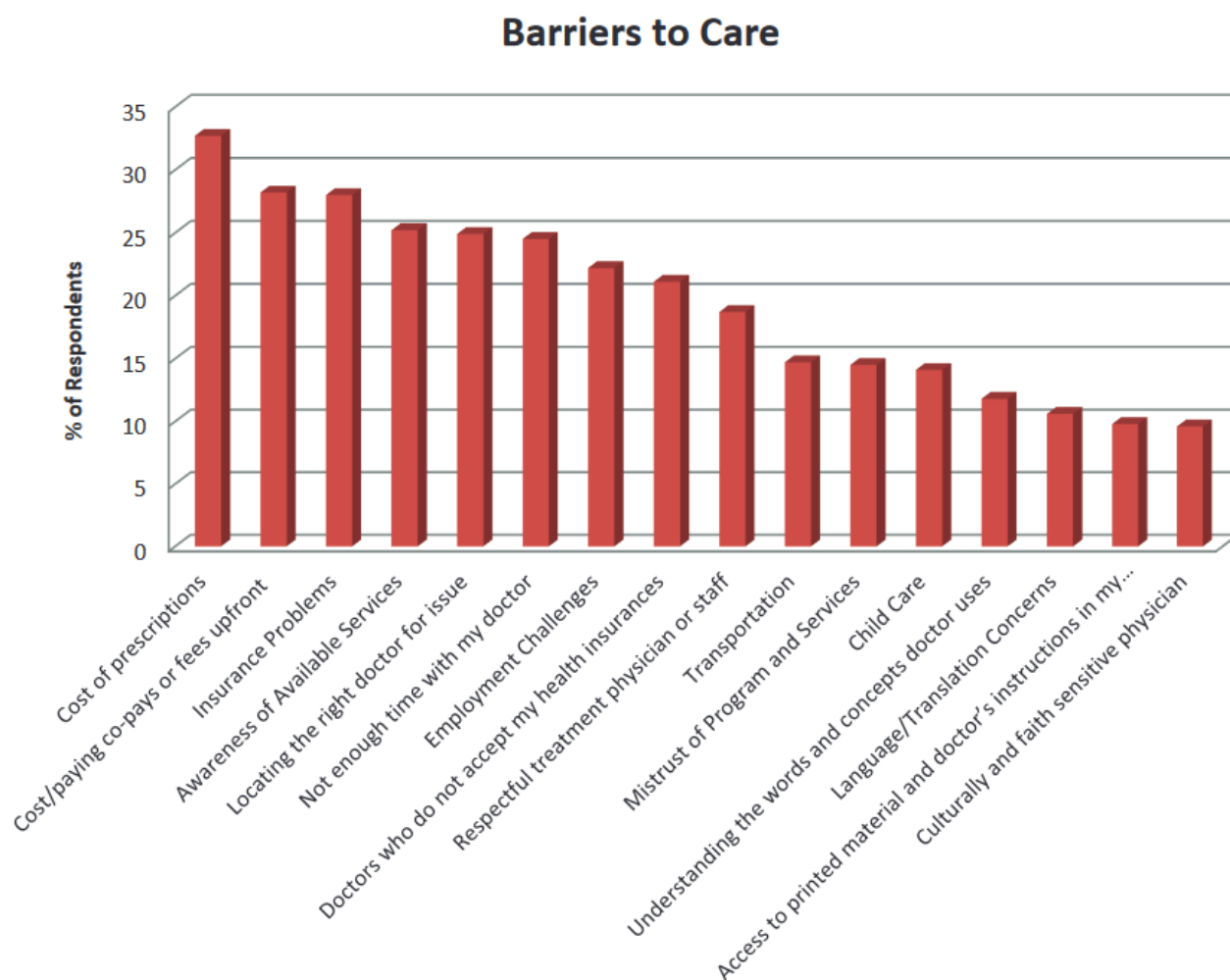
Emerging Adult Demanded Care

Although emerging adults have shown lower rates of primary care utilization than the overall population in America, they are demanding services at a comparably high rate (AHRQ, 2009). Referenced in the theoretical framework as a set of services, emerging adults are active users of care appropriate to be treated in primary care including STDs, UTIs, and cold or flu symptoms (AHRQ, 2009). In the researched community, with low use of primary care, emerging adults are high utilizers of the emergency room and primary care alternatives (Frederick Health, 2019). Emerging adults often feel the burden of coordinating their care and making unassisted decisions regarding when, where, and how to access healthcare services (Sarango et al., 2017). Care provided in primary care alternative locations is not preventive in nature. Therefore,

emerging adults often forego their preventive care when utilization of primary care is low (U.S. Preventive Services Task Force, 2020).

Figure 9

Researched Communities Barriers to Care



Source: George Washington University Milken Institute School of Public Health Survey Report on Frederick County, 2015.

Note. This figure shows the results of the Community Health Needs Assessment.

Emerging Adult Health Literacy

Areas for future research in the literature often call for efforts to understand the best way to anticipate and meet the needs of establishing primary care relationships during emerging adulthood to increase patients' familiarity with health maintenance and their role within the

healthcare system (Wolf et al., 2009). There is limited understanding on how health literacy impacts the perceived value of primary care for emerging adults. This study will seek to understand patients' perceived value of primary care as the proper level of care, which health literacy informs, but the direct analysis of a patient's health literacy is out of scope.

Researched Community

There is a single healthcare system serving the researched community. Each year, about 5% of all emergency room visits in the community could have been treated in primary care (Premier, 2019). While only a small percentage, 5% represents 3,555 patients using the emergency room for illnesses their primary care providers could have treated, which has caused over 1.2 million dollars in avoidable hospital utilization (Premier, 2019). Among such patients, emerging adults were the highest users seeking inappropriate care in the emergency room (Premier, 2019). This is not surprising, considering some of the leading barriers to care for residents include “awareness of available services” and “locating the right doctor for issue” (Frederick County Community Needs Assessment, 2016).

When not seeking care in the emergency room, emerging adults tend to use urgent care services and asynchronous telemedicine for illnesses their primary care providers could have treated (Roundtable, 2019). Emerging adults in the researched community are not supported to be good stewards of healthcare services with low rates of primary care utilization compromising the value of relational care (Lindau et al., 2006). Since the vast majority of the researched community's healthcare system's patient seek care where they live as community resident, the target population for this study will be residents of the community (Roundtable, 2019).

The researched community is experiencing rapid population growth, with more and more emerging adults calling it home. The local health care system has invested in primary care

delivered under the Patient Centered Medical Home model (Frederick Health, 2019). Many practices have redesigned primary care to ensure increased access and convenience for care (Frederick Health, 2019). Established patients with primary care have same day access to their providers, a 24/7 clinical advice line, and a walk-in clinic with a low cost of a primary care copay (Frederick Health, 2019). However, long term viability of primary care is contingent upon the ability to build continuous relationships with emerging adults amidst a market saturated with primary care alternatives (Hall, 2016).

Researcher Positionality

Given my view of primary care being more than just about cost and convenience, this study was significant to me both personally and professionally, as it caused me to reflect on the relationship between myself as the primary research instrument and research decisions throughout the research process. The lessons I learned from the participants' stories, with their innovative ideal state designs and aspirations for relational care, gave me hope for the future of healthcare.

I am a public health professional with extensive experience in diverse leadership positions supporting physician practices within large healthcare systems, stemming from my Master of Public Health in Practice and Policy degree from the University of Maryland, College Park and Lean Six Sigma Black Belt certification. My profession combines data analytics expertise and business acumen to align quality outcomes with pay for performance. My professional focus involves practice transformation reversing underperforming operations by improving processes, generating revenue, and ensuring optimal patient care. Given my professional experience with six sigma's design, the Lean six sigma methodology, I have emulated such design in the research questions and design for this study. The research questions

aimed to understand the lived experiences and expectations of emerging adults, often referred to as the “voice of the customer” in design for six sigma (Ginn & Varner et al., 2004). The voice of the customer determines the critical to quality factors essential for designing something of value as defined by the customer (Ginn & Varner et al., 2004). The interviews were structured to design a value-added primary care service that incorporated the critical to quality factors. My biggest take away was my realization of the incumbency on healthcare providers to qualitatively capture customers’ voices and design for quality based off those specifications over quantitative assumptions.

I find this study relevant to enhancing industry best practices including the Patient Centered Medical Home model of care. The recommendations include opportunities to incorporate lessons learned from soliciting the voice of the customer into the framework used to design for quality in primary care. The descriptive category codes and categorical coding matrix reflect my comfort in an organized analysis approach found in lean six sigma.

My personal lens, informed by interactions with emerging adults in the researched community, leads me to believe that primary care’s value proposition of relational care is diminishing among emerging adults. This is especially discouraging given the progress of primary care practice in areas of affordability and convenience I have seen firsthand. Additionally, my belief that my peers would benefit from a reliable patient-provider relationship as a routine source for care to reduce the stress of navigating healthcare system independently was reinforced with the findings. However, I have learned the importance of translating theory into practice, having validated the desired patient experience directly through conversations with patients. I view health as wholeness and to heal is to make whole. I believe a missing element to healing during emerging adulthood is a support system with tangible human connections, which

includes primary care. From the analysis of the findings, I learned how the structural barriers of the PCMH model prevent progress for providing this type of care to emerging adults.

Like any healthy relationship, the relationship must be mutually beneficial. I believe the healthcare industry has a clear idea of what is expected from patients, based on the industry's quantitative assumptions. As transactional options expand, and emerging adults continue to be the majority users, primary care providers will miss out on the opportunity to understanding what emerging adults want out of the patient-provider relationship. Speaking with these women enlightened and encouraged me to rethink healthcare delivery strategies with greater depth about how success is defined.

Research Questions

In terms of emerging adult women, aged 18-25, I sought understanding to the following questions:

1. What prevents primary care utilization when not challenged by supply and demand?
2. What is the perceived value of the Patient Centered Medical Home?
3. What is the perceived value of the patient-provider relationship?

Participants

The Participant Demographics

There were 12 participants that each completed two individual interviews ranging from 30 minutes to one hour long. All the participants met the eligibility screening criteria: female; aged 18-25; not married; resident of the researched community; has received healthcare as an adult; no children; and has active health insurance coverage.

The study included 12 emerging adult women who resided in the researched community, were not married, and did not have children. Participants were screened using a self-declared

survey tool to determine eligibility, which required their usage of healthcare as an adult. The full spectrum of ages 18-25 was represented. Specific ages for each participant can be found in Appendix B. A local community college and small liberal arts college offered a diverse population from which to solicit participants representative of emerging adults in the community.

The sampling procedure included on-campus solicitation inviting the opportunity to participate via fliers in common areas and campus-wide emails supported by the colleges. The sampling procedure started in September 2019 and ended in January 2020 once a balanced racial minority participant mix was achieved. Forty-two percent of the participant group represented a racial minority group. Two of the 12 participants did not report having an established relationship with primary care but have used primary care. Once a potential participant expressed interest, eligibility was determined by self-declared answers to the screening tool protocol administered on paper.

Screening Tool Filtering Logic

Interested participants were asked to confirm their age and current gender identity to determine eligibility that was limited to emerging adult women. Only emerging adult women without children and spouses were included in the study, as children are known barriers to care and thus may complicate the study's objective to understand women's perceived value before influencing family utilization behaviors. Further, only emerging adult women with active health insurance were included in the study, as cost is a known barrier to care and the number one factor individuals consider when deciding when and where to seek care. Interested participants with self-declared election for active health insurance were eligible.

Supply and demand were required to participate in the study, in line with the utilization conceptual framework. Interested subjects were asked if they identify as community residents.

Only community residents were eligible because the study defines adequate supply of primary care by seeking healthcare in the researched community, which hosts a variety of primary care practices taking new patients and is not a healthcare shortage area. To capture demand, interested subjects were asked to confirm if they have ever received healthcare as an adult (i.e., since they have turned 18), including any services from Planned Parenthood, student health clinics, emergency rooms, doctors' offices, and telemedicine.

After an interested participant was deemed eligible pursuant to the basic screening checklist, two questions were on the form to assist with group balancing and data segmentation. First, a yes or no question was asked to capture if they have an established primary care provider. Second, interested participants were asked to declare if they identify as part of a racial minority group. These two questions did not impact eligibility but provided a data point to ensure the study captured an experientially and racially diverse representation of the researched community. These data points also provided segmentation lenses when analyzing results.

The ethical procedures used to ensure no harm and minimal risk to the participants included no link to participation in the study and the student's academic status. Each participant received a \$10 gift card to Starbucks for participating in both one-on-one interviews. Participants were given gift cards in person or electronically after the study. In total, funds needed to support the incentive for participation was \$120. Funding was sponsored by the Hood College graduate fund.

Potential risks to study participants are minimal. The study methods prioritize participants' physical and emotional safety. All interviews were completed in full and successfully. If topics of discussion were to have become a distress, participants and/or researchers were empowered to stop the intervention at any time. Benefits to participants

included a learning opportunity to engage in primary research for participants' potential future academic aspirations. With the conversational qualitative-based approach, this study was also a unique opportunity for participants to allow their voices to be heard on an important topic aimed at improving the health of their own community.

Data Collection Instruments and Procedures

Instrumentation

Two instrumentation approaches were used with the same study participants at two separate times. The first approach was a structured one-on-one interview ranging from 30-60 minutes. The first phase of the interview included open-ended questions capturing each participants' prior healthcare experiences to explore individuals' perceived value of primary care as the proper level of care. The second phase of the interview was a ranking exercise using concepts from the Person-Centered Primary Care Measure and Fielding Reporting Kit developed by the Larry A. Green Center for the Advancement of Primary Health Care (Person-Centered Primary Care Measure, n.d.). The concepts of the exercise remained unmodified from the original Likert scale survey protocol but were administered as a ranking exercise because the original tool was intended to measure a patient's experience after receiving a service. Additionally, two concepts addressing cost and convenience were added to the exercise to gain insight into how such concepts compare to the relational concepts. Comparing these concepts against each other in order of importance through the lens of the participant established the fundamental perceived value of each concept versus the degree to which the concept was achieved during a service.

The second approach was a follow-up interview using open-ended questions building the constructs of an ideal primary care service. Completing the initial interviews before the follow-

up design interview was intended to give each participant context to her personal views of primary care, thereby encouraging a robust design process. The design interview questions align with NCQA's PCMH concepts to assist with data coding and analysis. These questions are also designed to cover the competencies under each concept in the NCQA PCMH model. After answering several introductory questions, participants were asked to answer questions as if they could design a primary care system that would work best for them and to describe their critical to quality factors. This questionnaire protocol was original to the study, due to lack of research in this topic area, and solicited data-rich responses conducive to the qualitative design. The structured open-ended questioning, aligned with NCQA's PCMH framework, informed descriptive category codes based on the theoretical framework.

Procedures

During recruitment, interested participants completed the screening protocol and provided their contact information. The Student Engagement Center at the community college worked directly with the researcher to socialize the opportunity to participate with via a weekly newsletter. Interested participants emailed the researcher to begin the screening process. An informed consent agreement was attached to the screening tool with an option for interested participants to sign, indicating they have read the agreement and consent to participate.

The researcher established her research relationship with the participants throughout the study by emphasizing her status as a young woman who lives in the researched community and her prior working experience in healthcare supporting the community. The researcher introduced herself as a female, a healthcare professional, a community resident, and a part-time doctoral student. The intent a scripted introduction is to leverage the researcher's position while

maintaining an unbiased research lens to establish a common ground versus a researcher-subject relationship that may be intimidating and stifle data (Maxwell, 2013).

The interviews took place on the college campuses and researcher's home office. Participants received a text reminder from the researcher on the day before each scheduled interview. Participant confidentiality was ensured throughout the study and post-interventions by not disclosing conversations among the participants. Audio from interviews were recorded, transcribed, and stored on a password-protected device. Transcriptions were outsourced to an electronic service, *Rev.com*.

Memos were captured immediately after each interview. Memos include non-verbal data elements and moments of significance. Memos served as additional data sources in combination with audio recordings for coding. The ranking exercise was conducted using flashcards; results were read aloud for audio capture and recorded in the memo.

Participants were given a lettered tag used for raw data identification to assist with coding and data analysis. The tags were associated with the participant roster, including the screening results stored in a separate secure file to ensure confidentiality. Published results were deidentified and only refer to the "participant" or "participants," since the study used a standardized screening protocol and general participant demographics were shared as an aggregate. Published content used deidentified locations and organizations. A pseudonym was given to the research site and sponsoring colleges.

Pilot Study/Pilot Testing

A pilot study was conducted on June 5, 2019 as a small-scale preparation for the major study (Polit & Beck, 2001). Two participants fitting the screening protocol criteria were used as the pilot sample sourced. Both participants had an established relationship with a primary care

provider and were not part of a racial minority group. The participants volunteered their time and had no prior relationship with the researcher (Baker, 1994). The intent of the pilot study was to: (1) trail the design instrumentation for comprehension; (2) check researcher skills in procedures; and (3) check the dependability and credibility of results (De Vaus, 1993).

The results of the pilot study highlighted the sequencing flaws in the original instrumentation approach. Modifications to the study design were made to have the introductory one-on-one interviews completed before the design interviews. Designing their ideal primary care systems required participants to discuss their prior experiences with and understandings of primary care. Having this individual prework completed in the interviews will set participants up for more detailed design interview. Therefore, the introductory interviews will take place before the design interview.

The researcher confirmed participant comfort level with the questions and sequencing. However, due to the lack of prior context from the participants regarding the researcher relationship and personal perspectives, the design questions needed to be clarified to unpack each participant's own view before the participants solved for their ideal experience. Redesigning the methods to have the individual interviews before the design interviews attempts to mitigate these issues moving forward.

The pilot study initiated discussion about the value of practice versus provider. Additional one-on-one interview questions were added to the protocol to understand the perceived value of the patient-practice relationship versus just the patient-provider relationship in a more structured method for credibility. Travel vaccines were also mentioned in the pilot study findings as a missing item. Additional questions were added to the protocol to further explore vaccine needs. Participants credited their mothers as key influencers for how they viewed

primary care, noting how their mothers' opinions were crucial to how they made health-related decisions. This insight supports the importance of the study's scope to understand women as healthcare influencers who impact family utilization behaviors.

Data Analysis

The data coding process was both pre-set and open. The data were categorized by coding for aligned, missing, and conflicting emergent themes to define the participants' perceived values. The aligned, missing, and conflicting items were measured against the a priori NCQA PCMH 2017 concepts in response to the research questions as descriptive category codes based on the theoretical framework. A categorical coding matrix was used to synthesize the data and identify themes in response to the research questions. An emergent theme analysis was used to identify missing, aligned, conflicting, and unknown themes in relation to the direct content analysis where the codes are derived from the theory (Maxwell, 2013).

- **Missing** items will be defined as concepts expressed by the participants as value added but not reflected in the PCMH model framework.
- **Aligned** items will be defined as concepts expressed by the participants as value added and reflected in the PCMH model framework.
- **Conflicting** items will be defined as concepts expressed by the participants as non-value added but reflected in the PCMH model framework.
- **Unknown** items defined as concepts reflected in the PCMH model but not explicitly discussed in the research findings will be summarized for future research and will be outside the scope of the study.

The hybrid coding process began by establishing the list of priori codes derived from the NCQA PCMH theoretical framework. This initial list served as the foundation to the code book

including the PCMH concept and description. Emergent codes were captured by reading and analyzing the data, looking for items that were different than the pre-set codes. First, an initial readthrough of the memos and transcripts identified powerful or interesting quotes. Second, the data were analyzed line by line, coding for the pre-set PCMH codes. Third, the data coded for the PCMH concepts were refined by coding for missing, conflicting, aligned, and unknown concepts. Fourth, the leftover data that did not align with the PCMH pre-set codes were analyzed for emergent codes.

Understanding what prevents primary care utilization when not challenged by supply and demand was answered by identifying the missing and conflicting items across all PCMH concepts. Understanding what the perceived value of the PCMH was answered by identifying the aligned items across all PCMH concepts. Understanding what the perceived value of the patient-provider relationship was answered by identifying the missing, aligned, and conflicting items under the “knowing and managing your patients” and “patient centered access and continuity” PCMH concepts (NCQA, 2017). While the research design attempted to limit the unknown items, unknown items will be summarized as a limitation and areas for future research. Emergent codes and themes will be analyzed to fit the data in context to answering the research questions.

Boundaries/Delimitations

This study’s scope seeks understanding of the research questions through the lens of emerging adult women in the researched community. The advantage to women led interviews is the fostering of a safe environment that allows relevant issues for women’s care to be expressed free of male influence. While the problem of underutilization of primary care exists across the United States, the results are limited in their generalizations outside of the community and the lived experiences of the study participants. The researched community is fortunate to have

adequate primary care supply represented by many primary care providers currently taking new patients. This is not representative of the United States as a whole, as many communities struggle with the supply of primary care providers across the country.

The study participants were active users of healthcare as described by their stories of healthcare experiences. A limitation of the study was that the lack of information collected outside the stories each participant told, such as self-reported medical histories, scope of healthcare use, and specific type of insurance coverage (i.e., Medicaid, parents, Obamacare, and participants' own). Five percent of the researched community goes without healthcare and is outside the scope of this study (Frederick Health, 2019). By excluding emerging adults who have never engaged with health services in their lifetimes, the study remains aligned with the conceptual framework, assuming utilization exists with supply and demand. Once the perceived value of primary care is captured through current demand, future research is needed to target emerging adults who do not currently demand care.

While the study defined demand for care in the sampling procedure as any utilization of health services, the study did define the scope of care. Future research is needed to build upon patient-provider relationships for preventive care services to achieve the full benefits of primary care. Once emerging adults are acquired in primary care, more analysis is needed to impact the lack of demand for preventive and chronic services. This is outside the scope of this study, as the research seeks to understand the key constructs required to establish a patient-provider relationship.

The scope of this study includes only the patient's perspective in a patient-provider relationship. A sustainable relationship requires engagement from both parties. Optimizing the

human connection by understanding the provider's perspective is outside the scope of this study but nevertheless relevant for future research.

Trustworthiness

To add rigor to the study, multiple design strategies were deployed to support transferability, dependability, confirmability, and credibility. To increase diversity of thought for transferability, a forty-two percent minority group mix ensured the sample set equitability represents the researched community, since fifty percent of the general population represents a minority group (Frederick Health, 2019). The ability to segment the data by racial minority mix gave confidence when confirming saturation of data.

Triangulation, feedback, and rich data were deployed for dependability (Maxwell, 2013). Individual interview data provided triangulation when synthesized with ranking activity results. Additionally, memos were written after each interview to capture data not represented in the audio transcript. The ranking exercise conducted during the one-on-one interviews provided a glimpse into participants' perceived values and were used as a dependability tool when coding the qualitative data against the PCMH concepts looking for alignment. To support confirmability, participants were not informed at any time of the PCMH model or the logic behind the categorization of the design questions. Feedback from the research committee was solicited throughout the study in addition to the lessons learned from the pilot study included in the research design. During data analysis, the committee provided guidance on the codes and themes informing the results. This collaborative approach assisted with limiting researcher bias and skewed logic when solidifying balancing pre-set and emergent codes.

Credibility was established by prolonged engagement in the field and by having more than one interaction with participants. Refining the code book using triangulation and remaining open to emergent codes ensured the codes properly fit the data without force.

Conclusion

The qualitative methodology fostered an exploratory approach to soliciting the voice of the emerging adult with a hybrid approach to pre-set and emergent coding analysis in alignment with the theoretical and conceptual frameworks. Chapter Four will outline the results of the study, including an evaluation of the priori codes and emergent themes as the analysis of the findings. The results will include supporting quotes to illustrate the critical to quality factors of primary care for emerging adult women.

CHAPTER 4: FINDINGS

The purpose of this chapter is to answer the research questions based on the collected and analyzed qualitative data reported by the participants of this study. Data were collected through semi-structured interviews and ranking of activities. Interviews were conducted in the researcher's home and local colleges. Each participant's anonymity has been protected by using a pseudonym. A priori and in vivo coding techniques and a charting matrix were used to synthesize the data and determine the findings. Participants reflected on their past primary care experiences and then designed their ideal primary care experience, as if they had a "magic wand." Participants closed the study by describing their ideal primary care in one word: oasis, personable, convenient, convenient, community, supportive, comfortable, reliable, affordable, accessible, dependable, or convenient. Chapter Four will present findings structured in response to the research questions using the PCMH concepts and competencies per the Analysis Process. The findings will be analyzed in Chapter Five.

The Analysis Process

The data were coded by organizing the transcribed responses into NCQA's PCMH concepts and competencies. The data were analyzed against NCQA's PCMH concepts and competencies, assessing for alignment and identifying emergent themes for missing concept items (Table 1).

- **Missing** items are defined as concepts expressed by the participants as value added but not reflected in the PCMH model framework.
- **Aligned** items are defined as concepts expressed by the participants as value added and reflected in the PCMH model framework.

- **Conflicting** items are defined as concepts expressed by the participants as non-value added but reflected in the PCMH model framework.
- **Unknown** items are defined as concepts reflected in the PCMH model framework but not explicitly discussed in the research findings. Such items will be summarized for future research, as they are outside the scope of the study.

Before organizing the results, the raw data were assessed by highlighted words and phrases that either aligned with NCQA PCMH or were a missing concept, such as “empathy” and “cost.” After coding the transcripts, a chart was used to assess alignment with NCQA PCMH and noted emerging themes in the Missing Concepts section (Appendix A). The chart is organized according to the research questions to confirm the findings based off the themes presented by the participants’ words. Table 2, below, shows the organization of the research questions in relation to the qualitative methods and findings:

Table 2

Research Questions Chart with Findings

Research Question	Participants	Sampling & Instruments	Analysis	Finding
RQ1: What prevents primary care utilization when not challenged with supply and demand?	<i>Screening:</i> ✓ Emerging Adults, 18-25 age ✓ Female ✓ Not married <i>Adequate supply:</i> ✓ Researched community resident	Qualitative: <i>Step 1: Individual interviews</i> - Personal experiences with primary care, expectations, and limitations of current services - Ranking value exercise - Deeper dive into access and continuity concept	Code against ALL PCMH concepts synthesizing <i>missing</i> and <i>conflicting</i> perceived value items	There is a demand for primary care, but lack of empathy and cost prevent utilization
RQ2: What is the perceived value of the Patient Centered Medical Home?	<i>Demand:</i> ✓ Received healthcare services as an adult <i>No known barriers to care:</i>		Code against ALL PCMH concepts synthesizing <i>aligned</i> perceived value items	There is a High perceived value with alignment in all concepts
RQ3: What is the perceived value of the	✓ Active health insurance coverage ✓ No children	<i>Step 2: Individual interviews</i>	Code against PCMH “knowing and managing	High perceived value with alignment in

Research Question	Participants	Sampling & Instruments	Analysis	Finding
patient-provider relationship?	<i>Segmentation:</i> <input type="checkbox"/> Primary care utilization <input type="checkbox"/> Racial minority status	-Design ideal primary care	your patients” & “patient centered access and continuity” concepts synthesizing the <i>missing</i> , <i>conflicting</i> , and <i>aligned</i> perceived value items	both concepts but hindered by the missing concept of empathy

Note. This table aligns the research questions with the methodological approach and findings.

Analysis of Findings

1. Emerging adults desire but struggle to find the human connection or patient-provider relationship in primary care.
2. Primary care that is delivered like a business reinforces emerging adults to believe that the human connection is not possible; thus, transactional services are attractive at least for their convenience and efficiency.
3. Emerging adults are asking for high touch care, like care management services traditionally only provided to insurance-backed “high risk” patient panels.

Research Question 1:

What Prevents Primary Care Utilization When Not Challenged with Supply and Demand?

The first research question addresses what causes emerging adult women to not seek primary care in a community where primary care is accessible. To answer this question, the data were coded against all NCQA PCMH concepts and competencies, looking for missing and conflicting items. Based on the participants’ responses, it was first confirmed there is a demand for primary care among emerging adults. However, lack of empathy and cost emerged as themes

preventing primary care utilization. Empathy and cost were missing concepts that emerged from the data but that NCQA PCMH does not include in its model.

Participants Reported Their Demand and Perceived Value for Primary Care.

Demand is defined by active patient pursuit of health services (John Snow, Inc., 2010).

Throughout the interviews, participants expressed their desire to establish care with a primary care provider and were clear in that they saw value in primary care utilization. Therefore, a lack of demand and perceived value of primary care is not reported as a barrier to utilization. For example, Rebecca, 22, a non-minority woman, does not currently have a primary care provider, but supported the need to establish care sooner rather than later:

If I could ideally pick somebody now and then, I'd be 32 and have the same person. That would be great. I see myself as 32, just maybe having kids, and then I'd be worried about their primary care. I'd make sure they have one, but I would just make sure I go on to establish one with mine. Earlier the better. (Rebecca)

Brittany, 21, who identifies as a racial non-minority woman, expressed her vision of ideal primary care:

I would say a community. So, I would use community as the word. So, a whole place where you feel welcome. It's your community, you can go there and see them for everything that you might need to see them for, and there's so many different resources there and you don't ever feel alone. So, I think that's a good word to describe it.

(Brittany)

Mary, 25, who identifies as a non-minority woman, described her view of primary care as the gatekeeper to navigating a complex system and identified the value of having an established relationship:

Primary care should be the center of your care. I do feel very strongly that it should be your first stop and your avenue to health care. I'd say for the masses, because navigating healthcare is very challenging for a lot. But I think in the reality, having that relationship and comfortability with your care with your primary care provider is very important.

(Mary)

When designing their ideal primary care, many participants described their desire for primary care to be from a trusted source. For example, Sarah, 18, who identifies as a non-minority woman, said, "It gives me a sense of security and feeling safe in that there's something that I can go to if something is wrong in my body." And, Brittany, a non-minority woman, stated, "I would say it's not just a person but a place that you go to for most of your health care needs, where you feel comfortable going, and pretty much just an overall sanctuary for your health. I feel it just means it's primary. So, I feel like it's your number one place that you should be able to go and feel safe." Gianna, 23, who identifies as a minority woman, described primary care as a tool for better health:

Primary care is a good resource tool to have. Just a good foundation for you to get the healthcare that you need, and if you can't get it there necessarily they have good connections for you to send you off to the right resources. I think just when I hear primary, I just think of Main. So, like the main source that you need, like the foundation of it all. I guess I just use primary care as the tool, honestly. (Gianna)

Supported by the literature review, a mother's influence in primary care utilization emerged throughout the interviews. While the way in which the participants used the advice of their mothers to make decisions about their health differed, the mother's influence was present

throughout. Some of the participants passively took their mother's healthcare advice, including Dory, 20, who identifies as a minority woman:

My mom went to him for years and then I just went to him by chance, and ever since I liked him. And he's really understanding and caring at the same time. (Dory)

Janya, 19, who identifies as a minority woman, reported:

I feel like my parents took care of most of it. It's under my dad's work insurance, so whatever my mom and dad tell me, I'm just like, Okay. I don't really care. (Janya)

Rebecca reported:

I would ask my mom because my dad does not seek any healthcare usually. He sometimes can be self-sufficient, but usually with most cases I guess or strange cases where he wouldn't know besides the emergency room probably, he would ask for guidance too. (Rebecca)

Joyce, 19, who identifies as a non-minority woman, reported:

My grandmother just told me that physical therapy doesn't actually work anyways, which I don't know. I was like, "What?" Because so many people do that, I guess. (Joyce)

Other participants understood and valued their mother's advice, including Ariel, 22, who identifies as a non-minority woman:

No. I went to a pediatrician for a good while, just because my mom was in control of it. So, she got it done, she made the appointments, she took...Even when I was 17, my mom was coming into the room with me and saying my symptoms. But it was because everyone would listen to her. No one wanted to listen to me, so I'd always take her in, because she has the credibility to back her up. (Ariel)

Chika, 18, who identifies as a minority woman, reported:

I went therapy because my mom told me to go there. She just makes the appointment for primary care. She's the one that makes the appointment and tells me where to go.

Because I've just been going to this same hospital since elementary school. (Chika)

Janya reported:

So, my mom was like, "Oh, I met her and she's really nice. I'll just put her down as yours." And I was like, "Okay." (Janya)

Dana, 25, a who identifies as a minority woman, reported:

My parents established it for me and I've just been going there because it's convenient. I already know where it is. I've been going there since I was little. My mom has mentioned some customer service issues there, so if she goes to a different place then I'll just kind of go with her. (Dana)

Sarah reported:

Yeah, so my mom helps support me in healthcare and got it set up when we were kids, and so she helps me on that. And then for me, for therapy, I set up my own schedule with my therapist. Yeah, and then she's a nurse so she knows a lot about the medical field and what medicines to take, what not to take. If I'm on prescriptions and all that stuff. (Sarah)

Participants Reported a Lack of Empathy That Prevents Primary Care Utilization and Is a Missing NCQA PCMH Concept. During interviews, participants reported feeling like their primary care experiences were more transactional than relational, which has prevented them from utilizing primary care. Dana, a minority woman, felt that her experience was impersonal and business-like:

What I'm experiencing is more of a business transaction. All right, you're here. The first question is probably, now that I'm thinking about it, "who's your insurance provider?" Not "why are you here?" "What can we do to help you" kind of thing. So, it seems more like a business transaction, and then they get you in and they get you going. All right we did this, this and this. Go to CVS, pick up your prescription, see ya. And then it's like, "but wait, how did I get this?" Just questions I have...It's very robotic. I understand they have practices and stuff, but it doesn't feel customized to me. (Dana)

Brittany, a non-minority woman, highlighted a lack of a genuine patient-provider experience:

I guess out of all the doctors that I've seen, there's not too many that are actually very there with you, if that makes sense. They might seem tired out, they might seem like they have other things on their mind. But I feel like just with the experience I've had here in [my community] it doesn't really relate to what I feel like it should be. (Brittany)

Dory, who identifies as a minority woman, noted that there is a need for an experience that encompasses both a transactional process and a genuine personal connection between each patient and provider:

I think that's something we're missing in society now, is people caring for others with compassion. I can be impatient sometimes, especially when you're sick. But when you go and meet a doctor, sometimes there is a disconnect. Like they're not very sympathetic or empathetic to your issues. And it's just like you're a business. So, you go in, you spend how much time with them? At most 15 minutes. Most of the time, five to eight minutes. They give you a quick diagnosis and then they're onto the next patient. And I feel like that is a big problem. (Dory)

Participants reported on primary care providers' inability to understand and connect with patients. Melody, 23, who identifies as a non-minority woman, recognized a power dynamic between patients and providers:

I would say something about respect. That's very important, I think. A lot of experiences I've had is a doctor is smarter than you. Of course, they know more medically but they don't have to treat you as though you're below them and not what you think about yourself or you have to say it is unimportant. (Melody)

Other participants valued providers spending more time with their patients, which they noted was just as, if not more, important than efficiency:

Just them asking questions [would make me go back] instead of just saying, "Well, you can go here and good luck," whatever it is. Them actually caring about that and just asking questions. And then when I got there, instead of just making it seem like an in and out, the doctor actually stopping and asking questions about it and getting to know me. Which made me feel more comfortable in that situation. You feel so uncomfortable. (Gianna)

Joyce reported:

I feel like in general a lot of times doctors are so flippant...you're doing something important. Try to remember that you're dealing with people...actually, listen and care about that and that should be a priority. (Joyce)

Melody reported:

My current health care provider, I've been seeing her for a long time, for years, but I feel like I'm growing more unsatisfied with her. I just feel like it's almost too quick and

doesn't listen enough to your problems like she's too quick to get you out of the room.

(Melody)

Participants reported a lack of a genuine interaction and concern for patients. Mary and Dory, who identify as a non-minority and minority woman, respectively, wanted someone to take the time to listen to them:

I was establishing with a brand-new practice. And it's interesting on the flip side, I was very drawn to the practice, it was a brand-new facility, the staff was wonderful, very nice, convenient. Quick appointment. The provider was not someone I was ever going to go back and see again because when he came into the exam room, he very briefly introduced himself, and just said like, "I'm Dr. So-and-so," and then sat down at a desk and actually faced away from me the entire time, just typing into a computer. And I felt never actually addressed, he never addressed my concerns. (Mary)

Dory reported:

You didn't do the job you were supposed to do, you just kind of made a judgment because you were trying to get [me] in quickly, you didn't really want to listen to [my] concerns and of course when did [my] concerns matter to you? (Dory)

Ariel and Brittany, both non-minority women, wanted someone to show that they cared about what patients had to say:

Sometimes my biggest challenge is finding [the right fit]. When I go to the doctor, it's not a doctor that I know, who knows me and knows that I know what I'm talking about to a degree. Usually my biggest difficulty is finding someone who will treat me the way that I think I should be treated. (Ariel)

Brittany reported:

I guess really showing concern for health and showing urgency. I feel like with a lot of the doctors, they just kind of brush it off or they'll say, "Oh well, there's nothing there." And just leave it aside. But I feel like to get me to really enjoy a doctor, want to stay [with them], they could show more interest or care in their actual patient. And just make me feel reassured. (Brittany)

When asked to design their ideal primary care experience, many participants were quick to include an empathetic connection. The participants solved for someone to take the time to listen to them:

They should treat everybody the same, as if they are a famous person walking in for the first time, and they don't know anything about them. I guess, warm, open, welcoming, and maybe better directions. (Rebecca)

Joyce reported:

My place would have people who have more experience in the field and dealing with people, more like customer service-y. Because I feel like for almost all the routine stuff, academia is not as important. (Joyce)

Chika reported:

It'd be nice if they were like, "Hey, welcome back." And talk about like my last appointment so I know that they were paying attention to what was going on, instead of just pulling up random documents. (Chika)

Dana reported:

I guess the connection I want is a more kind of attentive connection. A concern. When I...considered all factors of my health, I guess that piece would be more present in my

magic ball, and I think...kind of sort of to get the attention and the care the doctors kind of provide to patients. (Dana)

Participants also solved for someone to show that they cared about what patients had to say:

I think that's just kind of like being personable, like not treating me just like a regular, like just a plain person that comes through the door. If there was a magic wand, them knowing who I am and just keeping that fine line of respect being my doctor and knowing me. Just making you feel comfortable. (Gianna)

Ariel reported:

[My place would focus on] interpersonal relationships. I think technology is very disassociating in a sense of you can't physically hear that person sometimes, but you can't see them. You can't see the way their eyebrows raise, you can't see the way that the tears are actually running down their face when they tell you that something is wrong. Technology is very dehumanizing sometimes, and I think that the face-to-face contact is very important in the sense of medical fields. (Ariel)

Mary reported:

When you call in, for example, it's not like you're just another patient calling in. They say, "Oh, hi Mary, how are you?" And just adding that extra, like I said, homey feel to it. But that they know who they're talking with on the phone. That'd be one aspect of it. And then same thing when you're walking into the practice, it's, "Oh, hey Mary, how are you? How have things been going since we saw you last?" (Mary)

Participants Reported That Cost Prevents Primary Care Utilization and Is a Missing NCQA PCMH Concept. Although all participants had active health insurance coverage, during the interviews, participants described their confusion with health insurance benefits and billing

logistics, as well as a lack of price transparency, as deterrents for seeking care. Some participants noted that there is general confusion about price expectations:

Well, my only concern was the price and the facility [wasn't] sure how much it would be. They had to make sure it was covered through my insurance and it took a couple weeks.
(Melody)

Rebecca reported:

I think there is a difference and people should seek after primary care and I probably should too. But the only reason why I've ever gone I guess it would have to be someone that I'm comfortable with, and I'm not sure even the process and how to get a primary care doctor or what it is, how much it is even to see a copay? So, it depends. Like I said, it would depend on what the copay is every time I go to see them. (Rebecca)

Other participants said they were confused about who was the source of truth for defining prices:

I think it'll take until I'm on my own insurance for me to establish a relationship with a primary care. Being on my dad's insurance, things change all the time, or I just don't know where to go or I don't know this number that they're asking me for and I can't call him really quick on the other line and figure it out. (Ariel)

Joyce reported:

If you ask the doctor they're like, "Well, you have to talk to your insurance," and then if you talk to your insurance they'll tell you like, "Oh, hey... Yeah, an annual exam is covered," but then if your doctor bills it as something besides that then it's not covered but then if you ask, "Hey, is this going to be covered?" They say that you have to ask your insurance provider but there's no way of knowing how that's going to end up until afterwards. (Joyce)

Ariel reported:

I do think primary care is valuable, but establishing, find the doctor, making the appointment, going through the initial everything, that's what's stopping me from seeing it, is that I just haven't been able to find the time, the doctor, the coverage, the plan and figuring it out and just doing it. (Ariel)

Dana reported:

I described primary care as the place that your insurance is partnered with to go to. I was pretending urgent care wasn't around again and I guess I would just have to call Cigna and then they would have to tell me where to go, and it just seems like such a process and then you have to ask them if they're taking new patients. (Dana)

Even when prices were discernable, some participants stressed that receiving care was expensive:

Most of my friends are of minority status too, so I think they are well-versed because a lot of them come from single parent households, so they really have to know what they're spending because if they don't they're going to spend out of pocket or they're going to spend more than they expect. (Dory)

Janya reported:

I think cost is a big factor for us just because everything can be really expensive. My mom's always like, "Oh, if this procedure is covered here or not. Or maybe it's covered somewhere else." She'll always just look around first and see which one gives them the most coverage and we'll just go to that one. (Janya)

Many participants attempted to reconcile insurance confusion and price transparency in their ideal primary care scenarios to make access easier. After recognizing these problems, the

participants included in their ideal designs systems that would solve for the above categories.

Ariel, a non-minority woman, solved for confusion about price expectations in her ideal design:

My ideal if I say I have a primary care, what I would want from primary care is just having a doctor's office that isn't changing their insurance coverage policy every year or doing cuts or doing raises on copays, things like that. (Ariel)

Rebecca, a non-minority woman, solved for confusion about the source of truth for defining prices in her ideal design:

It can be with insurance, but I think...I don't know, I just feel like some people don't accept insurance, so they only accept certain insurances. I don't know obviously the process of how they choose all that, but it needs to be better equipped for people to get it. (Rebecca)

Dana, a minority woman, solved for expensive prices in her ideal design:

But when you look at your doctor's bill and you see \$300 for this, \$200 for this. You're like, "what the heck? Thank God my insurance is paying it." But what do all these mean[?] So that's in my magic world, I think things should be posted. Prices should be posted. They could be putting all the stuff that didn't happen, and what's it going to come down to, your word versus the doctor's word. So, I feel like also maybe we sign off on what treatment was done. (Dana)

General out-of-pocket costs were reported as a barrier to receiving care. Some participants revealed that cost drives patient utilization:

I really didn't have a relationship with my primary care provider until my copay was less there and more at urgent care. (Dana)

Ariel reported:

But insurance has changed since the last year, so I really haven't gone to anywhere.

Everywhere is doubled to tripled. (Ariel)

Melody reported:

I would say that the higher the copay, the less likely I am to go unless it's more urgent.

Fourth, I put, the care I get in this practice is low cost. That's important for me because I think that affects how frequently I go to the doctors. Even if I think it's important, if it's not killing me, I'm less inclined to go get care if it's expensive. (Melody)

Gianna, a minority woman, expressed that her desire to be independent as an emerging adult has been complicated by complex and costly insurance policies and processes:

I do understand why people want to push it on the back burner and be like, "Do I really need this? Can I just hold it off? Do I really want to go to the doctor?" I've been in that situation and now me actually getting a brain and being like, "why don't you just go back on your parents and stop trying to be independent when you don't have to[?]" I think it definitely made a difference for me and opened my eyes to take advantage of this now.

But then also see how important it is to have healthcare insurance. (Gianna)

Participants solved for cost barriers by describing accessible care for all:

Chika and Dana, both minority women, solved for cost-driven patient utilization:

Like why is it so expensive to the point where, if you need help, you can't go. I understand that there's other factors that into it. But I also feel like healthcare should be your priority than other things. So, we should prioritize having accessible healthcare for everyone. (Chika)

Dana reported:

Birth control should be free. I'm trying to think what else I would need. What else do I use? Just things that everyone needs. Yeah, things that we didn't choose to, for example, being a woman, we're going to get our periods. We are put on this earth to have babies or whatever. So, if people want to protect themselves and choose when they want to have a baby, then they should have that right. (Dana)

Dana, a minority woman, solved for complex and costly insurance policies and processes:

In my magic wand, no, I wouldn't pay, actually. I wouldn't pay anything out of pocket, in my magic wand. And another thing in my magic wand is whether I'm employed or not, I have health care. (Dana)

The importance of empathy and low costs was triangulated in the ranking activity. The desire for empathetic and low costs was also confirmed through the ranking activity, as “this doctor knows me as a person” and “the care I get in this practice is low cost” proved to be items of consistently high importance to the participants. Additionally, “this practice makes it easy for me to get care” included simplifying insurance coverage and logistics.

Table 3*Person Centered Care Item Chart*

Person Centered Care Item	Group Avg	Value Level
In caring for me, my doctor considers all factors that affect my health.	2	High
This doctor or practice knows me as a person.	4	High
The care I get in this practice is low cost.	4	High
The practice makes it easy for me to get care.	5	Moderate
Over time, my practice helps me stay healthy.	5	Moderate
The care I get in this practice is convenient.	6	Moderate
My doctor or practice stands up for me.	7	Moderate
This practice is able to provide most of my care.	7	Moderate
Over time, this practice helps me to meet my goals.	8	Low
The care I get takes into account knowledge of my family.	8	Low
My practice coordinates the care I get from multiple places.	8	Low
My doctor and I have been through a lot together.	9	Low
The care I get in this practice is informed by knowledge of my community.	9	Low

Note. This table shows the group average of the person-centered items ranking activity, showing high to low value items for care.

Research Question 2:**What Is the Perceived Value of the Patient Centered Medical Home?**

The second research question explores participants' perceived value of NCQA's Patient Centered Medical Home (PCMH). The terms "Patient Centered Medical Home" and NCQA were not introduced during the interviews because the interview protocol unpacked each concept and competency in general terms to keep industry jargon out of the dialog. During the interviews, the participants designed their ideal primary care experience and reflected on the pros and cons of their past experiences. The data were coded against NCQA's PCMH concepts and competencies, assessing for alignment. The findings report that NCQA's PCMH model and participants' ideal primary care experiences are closely aligned.

Table 4

Coding Matrix Result

Code Book		Competency					
Team Based Care	Results	A	B	C			
	Conflicting						
	Aligned	X	X	X			
	Unknown						
Knowing and Managing Your Patients	Results	A	B	C	D	E	F
	Conflicting						
	Aligned	X	X	X	X	X	X
	Unknown						
Patient Centered Access and Continuity	Results	A	B				
	Conflicting						
	Aligned	X	X				
	Unknown						
Care Management Support	Results	A	B				
	Conflicting						
	Aligned	X	X				
	Unknown						
Care Coordination and Care Transitions	Results	A	B	C			
	Conflicting						
	Aligned	X	X	X			
	Unknown						
Performance Measurement and Quality Improvement	Results	A	B	C			
	Conflicting						
	Aligned	X	X				
	Unknown			X			
Emergent Codes							
Empathy	Results						
	Missing						
Low Cost	Results						
	Missing						

Note. This table shows the alignment of the participants' ideal primary care systems with the NCQA PCMH concepts.

Participants Reported No Conflicting Items Expressed as Non-Value-Added

Concepts in Their Ideal Primary Care but Reflected in NCQA's PCMH Model.

Participants Reported Missing Concepts of Empathy and Low Cost Expressed as Value Added in Their Ideal Primary Care but Not Reflected in NCQA's PCMH Model. PCMH

concepts and competencies address medication and treatment options; they consider costs but do not address the need to mitigate insurance barriers and out-of-pocket costs for all care needs.

This finding is discussed in more detail under Research Question One. **Participants Reported**

Alignment with Their Ideal Primary Care Concepts and All NCQA PCMH Model Concepts.

Team-Based Care and Practice Organization (TC)

Participants Reported a High Perceived Value of Team-Based Care and Practice Organization. The intent of the Team-Based Care and Practice Organization concept is to ensure that the practice: provides continuity of care; communicates roles and responsibilities of the medical home to patients, families, and caregivers; and organizes and trains staff to work to the top of their licenses in providing effective team-based care (NCQA, 2017). This concept of team-based care was reported as value added by the participants' designs, including Mary's, a non-minority woman:

I kind of envision primary care as being this first stop to everything that you may need, I mean I would go to them first for physicals and Well Woman exams, and things like that, but also just any issue I'm having. I want to go to my primary care provider first, because if it's an issue that they're able to address, excellent, my care's still in the same place.

(Mary)

Participants reported effective care through continuity as essential. Gianna, a minority woman, reported:

Sometimes it takes me a little longer to get it out. But, I feel like she knows me and every time I come in she makes me feel welcome and she knows who I am, and we pick up where we left off. (Gianna)

Participants reported effective care with knowledgeable professionals as essential. Melody, a non-minority woman, reported:

I think I had previously talked to my primary care doctor on all birth control options. But she wasn't very helpful, I would say. She told me different things that I already knew the basic things. I think she doesn't know much about birth control. I don't think I've seen my primary care since after that. (Melody)

Competency A

Participants' responses aligned with Competency A. It is valuable for members of the practice to be committed to transforming the practice into a sustainable medical home. Members of the care team serve specific roles as defined by the practice's organizational structure and are equipped with the knowledge and training necessary to perform those functions (NCQA, 2017). Dory, a minority woman, acknowledged that achieving the task of transformation would not be easy:

Knowing what you're going through in your life, they don't need to know every single thing about you because that's even hard to display in one sitting so maybe taking more time with you instead of these five to eight minute appointments where they come in, look at you and then they bounce out because it's really hard in that ideal world because you want fast care and you want helpful care and you want care for everyone and the population is continuing to grow on this but then you still want them to pay attention to you. (Dory)

Mary, a non-minority woman, and Dana, a minority woman, reported having a comprehensive and in sync team in their ideal primary care designs:

I'm a pretty firm believer that there is no...just one little focus on what's impacting your health that day, but that you should take a whole-body approach to health all the time. I don't know if there are boundaries, I mean something like a stressor in your life, like

work or a relationship can really impact your mental health but can also really impact your physical health. So, tying that full circle. Something you're eating could really impact your physical or mental health. So, for me I don't know that there are boundaries, I would want someone to consider every factor in my life and how it's impacting me as an individual, wholly. (Mary)

Dana reported:

And then my care team is again, I would have my own personal consultant that's available 24/7. That also knows my budget, so they know my financials, and my consultant can know me personally and know everything about me. (Dana)

Dory and Joyce, women who identify as minority and non-minority, respectively, reported providers having the training and knowledge needed to ensure effective care in their ideal primary care designs:

When you have to work with someone who's different from you, you have to work with them. There are no other options so you have to learn and learn mutual tolerance and that sometimes, you can become friends or connected to people of the most unlikely backgrounds...just having more diversity and I think having more training sessions for doctors. I know they take an ethics course during school and I think maybe adding different courses, like a trauma informed care course or what do you do, what steps do you take after you misdiagnose a person or maybe even a course or ... if it's not a full semester course, just a two day course, a one day lecture, whatever, on how to separate work from life because we all need to separate work from life, no matter what we're doing but it's really important when you're dealing with people's life or death scenarios. (Dory)

Joyce reported:

Definitely [my team would be] competent. I mean, competent does have a certain amount of soft skills like being able to explain things and read the room. (Joyce)

Dana, a minority woman, and Brittany, a non-minority woman, created designs that included infrastructure that would allow patients to have governance over their care:

I mean in my ideal world I would tell the person, but of course in a business standpoint, they're probably be a person who oversees the doctors, and that's who you could talk to in person. And they truly care what you have to say. And they are the ones you would talk to them, and then they do their feedback. (Dana)

Brittany reported:

Maybe there was someone, not a doctor but someone who manages over the whole building, and I feel like you could go talk to them. And be like, "since you run the whole thing, this is how I feel." I feel like my care standards aren't being met with my doctor and I'm not sure what to do, and I don't know if they understand what's going on. And I feel like then that person who's above everyone could advocate for you and talk to the doctor specifically. (Brittany)

Joyce, a non-minority woman, also reported having a secure electronic medical record as an important design element:

Like an app, a website, you could definitely make it HIPAA compliant with health information, or at least you should be able to, that would be awesome. Then you could have all of your test results from ever just on there, and you can just like scroll through like, When's the last time I had this done? Oh hey, there it is. Yeah, that would be nice. (Joyce)

Competency B

Participants' ideal designs aligned with Competency B. It is valuable that communication among primary care staff is organized to ensure that patient care is coordinated, safe, and effective (NCQA, 2017) Gianna, a minority woman, had a high expectation of all members of the care team that she came in contact with:

It just comes with the whole entire practice. Just even down to the receptionist and the people checking you in and just knowing that they're there to help you and take care of you and make you feel welcome and invited. Even the nurses, they care, and they know what they're talking about. They know what to do. They know how to help you. They don't have to know how to fix me, but just having those trusted allies I guess. Definitely helps. (Gianna)

Ariel and Sarah, both non-minority women, wanted providers with integrity who recognized the importance of their jobs:

I think overall with healthcare, you expect to have someone who is going to hold up their oath that they're going to take care of you. So, that's overall the most important. (Ariel)

Sarah reported:

I want to be healthy. It's a primary thing when you're going to the doctor to make sure everything's okay and working properly. They were helpful and they're really secure and they make sure that you feel okay, that you're safe. (Sarah)

The value of effective, coordinated, and safe care was reported in the ranking exercise. That "[m]y provider and I have gone through a lot together" was not highly important to participants implies ineffective care, which was something participants did not want in their ideal primary care designs. Dana, a minority woman, wanted a constructive patient-provider relationship:

Like have been through a lot together, I just read that as like he or she has tried everything on me and nothing's working. (Dana)

Joyce and Rebecca, both non-minority women, wanted to feel the mutual benefit of time spent together between the patient and provider:

My doctor and I have been through a lot together? I mean, no. That sounds unfortunate. (Joyce)

Rebecca reported:

I just never put "going through a lot" as a good thing. I guess if it was a good...If it was like we've spent a lot of time together maybe that...but going through a lot, I don't think you have to go through a lot to know them. You just have to talk. (Rebecca)

Dana, a minority woman, reported having the patient included as part of the care team as essential to her ideal design:

Trust means...I think also like the control piece, the patient is in charge, the patient has kind of control and say over their house. (Dana)

Ariel and Dory, a non-minority and minority woman, respectively, reported behavioral health as an essential element to their ideal designs, including infrastructure to support behavioral health efforts:

I definitely want a relationship with these people in a sense of they know my first name, and they recognize my face. I don't so much need someone who knows my whole life story. I think a physical doctor and a mental doctor are two different things, so I don't really need my physical doctor knowing about my anxiety or about my depression cause they're not prescribing the things for it. They should know the classification of the drug that I'm taking outside of them and how they interact with what they put me on, like

regimens or whatever. But just basics. Like as long as they know their stuff, they keep things written down, and they know me. (Ariel)

Dory reported:

Mental health as more informed we are about it and a larger problem that we're seeing it is, I think primary care needs to provide for that because I feel like when it's a bruise or a scar that's in your mind, people don't...since they can't see it, they don't believe it.

(Dory)

Competency C

Participants reported their role as a patient in their ideal primary care designs, which aligns with Competency C. It is valuable that the practice communicates with and engages patients about patients' expectations and roles in the medical home model of care (NCQA, 2017). They acknowledge patient responsibility in establishing the relationship and being actively engaged in their health. Rebecca, a non-minority woman, reported that providers need to be receptive to being asked questions and giving honest answers:

In a perfect world, they still can't be mind readers. There would be something that I communicate them, whether they're, like I said, asking the questions. I'm not going to be able just to say everything, but if they ask the right questions, then they'll get to the right answers about stuff that maybe needs to know, or if it's obviously something I want them to know, then I would just say it. If maybe I don't know what to say or I don't know what I'm actually experiencing, it'd be their job to figure it out. (Rebecca)

Ariel, a non-minority woman, noted that providers are not expected to be all-knowing:

It takes being a good patient and being an honest and open and understanding that this person is here to help you and not judge you. Not judge you. But if you go in there and

you have all these scratches and these bumps and they're getting infected but you're not telling them that you're actively using drugs and not in the cleanest of situations and that's what those are, then they're just in the dark. You're not letting them in. You're not telling them that, "oh, I'm doing this, and this is the result." They have to go through all of the basic things and scratch out that idea and scratch out that idea to get that conclusion. So, it takes skipping the line and talking to the person and getting to where you need to get. (Ariel)

Mary and Sarah, both non-minority women, reported that patients need to be proactive:

[As a patient, I need to] be engaged, to ask questions and to seek answers. Because you're not going to get answers to things you don't ask. (Mary)

Sarah reported:

They have asked me about it, but I also think of it as my responsibility to bring it up if I want to care about my own health and make sure that I'm okay. (Sarah)

Knowing and Managing Your Patients (KM)

Participants reported a high perceived value of providers knowing and managing patients. That providers know and manage their patients ensures that the practice captures information about the patients and communities it serves, using such information to deliver evidence-based care that is culturally appropriate and supports population needs.

The emerging adult women participants of this study reported that having their care teams know them and provide evidence-based care as an important element of their ideal designs. In particular, Joyce and Brittany, both non-minority women, reported:

It's important that things are standardized and hopefully delivered in a manner that's like research-based, so if there's something you don't understand and be able to explain that in a way that's understandable. (Joyce)

Brittany reported:

One that's most important is that they know me as a person. So that is really important to me. I feel like if they know about you and know all your health problems and not just stuff about your health, but just about you. I think it's easier to care for someone that way. It gives you a bond, it makes you want to see that person more. So, I feel like that's really important. (Brittany)

The concept of providers knowing and managing their patients was also aligned with the ranking exercise, where “[i]n caring for me, my doctor considers all factors that affect my health” was the most important item to the participants.

Competency A

The participants' reported ideal primary care designs aligned with Competency A. It is valuable that the practice routinely collects comprehensive data on patients to understand patients' backgrounds and health risks. The practice uses relevant population information to implement interventions, tools, and support measures for the practice as a whole and for specific individuals (NCQA, 2017). Ariel, a non-minority woman, described her ideal primary care as having an up-to-date problem list:

Oh, my goodness. That'd be amazing. Like someone would come in and they would know my most recurring or current illnesses, or symptoms, or complaints, and touch base on those and be like, “How are those doing? What's the update on that?” And if it's not still an issue then I'll be like, “Oh I forgot I even come to see the doctor for that. It's

gone. It's great. I'm good. Go back to it later if it ever is recurring, but at that moment check it off the list." I think touching base, like having doctors who know you, and they're like, "Oh, let's do this for that," then it's cool. (Ariel)

Gianna, a minority woman, and Rebecca, a non-minority woman, reported ideal designs also included a comprehensive health assessment:

I think a big thing is like, obviously you have your medical history, almost like a file that travels with you, that we request. But I think them kind of touching base with you and talking to you, like having kind of, almost like an interview, but I don't like the word interview, like a conversation taking that pressure off of you just so that you can have that open space to kind of talk about certain things because certain things can change or can look on paper a different way than how they are perceived. So, I think kind of having that touch base moment with your provider, I think that's definitely something that is beneficial. (Gianna)

Rebecca reported:

Usually when you go to primary care you only talk about what is wrong. If they do some sort of check...they go in depth to check how you are, they think you're healthy, but they don't take your blood pressure because they know that you're healthy. They go in depth and they take their time to really make sure they check on you. (Rebecca)

Brittany, a non-minority woman, also reported behavioral health screenings as an important element of her ideal primary care design:

I feel like they should not just know about like all of my medical background and history. So, all my health problems or non-problems but just everything. I feel like they should also know about mental health things. Just go around the whole broad aspect of

everything with health, so not just the medical stuff. And also, to not feel like you don't have to be personal. We can be personal and talk about personal life things to. (Brittany)

Acknowledging the sensitivities of behavioral health screening and trust, Mary, a non-minority woman, included candid screening in her ideal primary care design. Trust within the patient-provider relationship is discussed in more detail under Research Question Three. Mary reported:

So just going for a routine med refill on the ADD medication, they have to ask you certain questions. And in the beginning, it was uncomfortable in some aspects. I'm like, "No, I'm fine, it's okay," and then I think as you become more comfortable, I was like, "No, maybe it's not as fine as it used to be." But no, not necessarily going in for... I guess ADD is technically considered mental health, so. Yeah, but not going in for what would have led to the questions and her having that deeper, "What's really going on?" There has to be a lot of trust before I start to disclose that information. (Mary)

Joyce, a non-minority woman, reported that her ideal design would also screen for social determinants of health:

I guess some things, like how much would your care change if someone knew that you didn't smoke, didn't drink, didn't do anything, was a nun or somebody who worked at a bar, how much would that change the care that you were receiving? I don't know how that would affect anything, but I guess any lifestyle things that would affect your care. (Joyce)

Sarah and Brittany, both non-minority women, reported providing patient education as essential in their ideal primary care designs, to be implemented through creative and discrete methods:

I would say, they would reassure me, and what is going on with my body? Explain what has happened, and maybe provide a brochure or pamphlet of what's going on. (Sarah)

Brittany reported:

Maybe also a list of places and phone numbers all over the place, that our services don't provide, but maybe some people have questions about it and are scared to speak up. So, for instance, I'd have on the wall phone numbers and places for if you needed to go see someone for housing, or if you needed to go see someone for getting a service dog.

(Brittany)

Competency B

The participants' ideal designs aligned with Competency B. It is valuable that the practice seeks to meet the needs of a diverse patient population by understanding the population's unique characteristics (i.e., language needs). The practice uses this information to ensure linguistic and other patient needs are met (NCQA, 2017). Diversity was reported as a valuable design element, including the ability to accommodate preferences for gender, race, ethnicity, and language. Dana and Gianna, both minority women, wanted an ideal design that was diverse in thought:

I would want them to be diverse, male, female, different ethnicities. I wouldn't want them to be just one race or one gender. But then I would want my female doctor to be a lady.

But then everyone else, I don't really care. Yeah. I wouldn't want just one ethnicity, one race. They don't have to speak another language. But it'd be nice if they did. I think that's cool. (Dana)

Gianna reported:

I'm all about diversity. So just having a big diverse group of people to kind of help you with your needs to have different experiences, that have gone to different places, have been through different things. I think it's definitely easy to trust somebody that you can

relate to or somebody that you feel like is not just a plain Jane I guess. If that makes sense. (Gianna)

Chika and Janya, both minority women, noted that there is a sense of comfort in being treated by someone with whom you identify:

I know my mom wanted an Asian doctor specifically...she was probably thinking like, oh, since she's Asian she'll probably agree with what I say. (Chika)

Janya reported:

And like sometimes there are things that I can't explain in English. (Janya)

Brittany and Dory, a non-minority and minority woman, respectively, wanted an inclusive healthcare environment for all, regardless of their own personal identifications:

And then you would have doctors of all types, so doctors that could speak different languages for people when you have diversity in the workforce, so different languages being spoke and then I think that's really important. (Dory)

Brittany reported:

I feel like I definitely would want not just someone who is bilingual, but maybe a few people who speak completely different languages. So, there aren't some people that don't have a language barrier that they can't go to this doctor for. (Brittany)

Competency C

Participants reported being proactive in their ideal designs, which aligns with Competency C. It is valuable that the practice proactively addresses care needs of the patient population to ensure that those needs are met (NCQA, 2017). Gianna, a minority woman, and Ariel, a non-minority woman, reported:

I have almost missed appointments and them just giving you a gentle courtesy or follow-ups or your feedback and like, “How’s everything going?” And I’ve had my doctor one time, just call me and just touch base of my medication, because I started a new one with her. And just asked two weeks, instead of me coming in, her just asking, “Is everything going okay?” We signed a consent for that, so she can do that over the phone. Her just touching base with me about that, that definitely was nice. (Gianna)

Ariel reported:

I know that electronics are consuming things very much, but I still do believe in the old fashioned going to a doctor, whether it’s inconvenient or not, really. You should find the time and the place to care for your health and be able to go there. (Ariel)

Competency D

The participants’ ideal designs align with Competency D. It is valuable that the practice addresses medication safety and adherence by providing information to patients and establishing processes for medication documentation, reconciliation, and barrier assessments, all of which were included in the participants’ ideal designs (NCQA, 2017). A strong preference for holistic medicine was reported. Janya and Mary, a minority and non-minority woman, respectively, would solve for a more holistic approach in their ideal systems:

Like herbal medicine. There’s also like exercises you can do for certain pains you had. Instead of taking pain medicine. (Janya)

Mary reported:

If it’s something where there’s opportunities to take a more holistic approach first, and you try things to see if they work, that should stay in primary care. And then if you’ve

exhausted all opportunities, then your providers should know where that level of comfortability is to step it up to the next specialist. (Mary)

Dory, a minority woman, did not want to feel as though her only option for health is a pharmaceutical answer:

In my magic wand, they would interact [with holistic medicine] well because not everything could be cured by a pill. (Dory)

As described by Joyce, a non-minority woman, offering pills as the first and only option was not ideal:

I'm pretty sure he's like a state licensed drug dealer. Like 100%. I'm like, "I'm having this issue and this issue," and he's like, "Do you want the pills?" (Joyce)

Sarah and Dory, both non-minority women, reported cost-related medication barriers as a major need for emerging adults in their ideal designs:

I come from a single mother family. And so, we have to be careful on what we spend, how much. But we also want to make sure that what we're receiving is good enough for ourselves because maybe like, we spend money on like a copay or something for an antibiotic and it doesn't work. So, we've already spent this much and we have to go back and figure out what works again. That can be the same with antidepressants or something like that. (Sarah)

Dory reported:

For instance, let's say someone needs a medicine but their insurance is not good. If you can help get them the generic medicine or find them other things that are equivalent to that, that can be phenomenal for that person because name brand and patents on medicine and through these insurance companies and it's really hard to get. (Dory)

Brittany, a non-minority woman, identified the need for providers to have access to information about controlled substances prior to prescribing such medications:

I know around the area there's a lot of opioid addiction and I feel like that would be good to know. Especially with students because it's a big problem. (Brittany)

Competency E

Participants' reported ideal designs aligned with Competency E. It is valuable that the practice incorporates evidence-based clinical decision support spanning a variety of conditions to ensure effective and efficient patient care (NCQA, 2017). Joyce, a non-minority woman, reported:

Well, see, the thing about cookie-cutter is not that you can't get it wrong, but I guess if they have all of my records on file, it's organized in a way that makes sense so that if there's something in my records that's flagged, they can then do what's appropriate for whatever's flagged. (Joyce)

Competency F

The participants' reported ideal primary care designs align with Competency F. It is valuable that the practice considers and collaborates with community resources to direct patients to needed support, which was described by participants' ideal designs (NCQA, 2017). Joyce, a non-minority woman, reported:

A system where everything is all plugged in together like that, I can't think of it right now though. Like social networks, like how you can login to everything with Facebook, so that except for healthcare. (Joyce)

Specifically, Sarah, a non-minority woman, described the importance of gender identity and sexual orientation support:

I mean I think it's good to know gender and sex and the difference so that if we're talking about the body, that we know that even though you may have gender dysphoria, that it's like known that you have a vagina right now and if you want you can transition to having male genitalia or something like that. And at least provide me resources. (Sarah)

Many participants' ideal designs also included providing free resources for women. Brittany, a non-minority woman, and Dana, a minority woman, included the following:

I think maybe always having resources for people. Especially for women, and I know you see this a lot in places like Planned Parenthood, or other special places. Always having like resources available for people who might not be able to spend a lot of money. So free pads and tampons, or free condoms, or free birth control. Or free medication that anyone could get, like ibuprofen, or Tylenol. Something really small, like a care package almost for a cold, or you have a flu, you can like take this bag and it'll have everything you need in it. (Brittany)

Dana reported:

And also, in my magic world, there's free tampons. All the different sizes. Not just that cardboard thing you get in the bathroom. Yeah, not the nose plugs, real tampons. (Dana)

Shared decision-making was an important item throughout the design interviews. Many participants described their disappointment with not being included in the decision-making process, including Melody and Joyce, both non-minority women:

Say you come in for one specific thing, you have to tell them the specific thing you're coming in for and then you're giving them other information about yourself that you think could be connected too. I feel like it's like, you don't know what you're talking about, I don't need to know this. And that it's like let's focus on the main thing that you

reported and the other things you need to come back for. Because they were dismissed when I brought them up in the first time. I'll Google symptoms that I have or if I hear about something on TV or video or something, I'll look it up and read other people's stories or what they're going through. I'll just try to make connections then suggest things. But when you suggest things to a doctor, they're not always happy with that.

(Melody)

Joyce reported:

I mean, the biggest thing that comes to mind is like what if I want to have a kid? That's just terrifying for so many reasons. I've just heard so many horror stories of people's doctors just not listening to them. Making decisions without consulting the person that is...not prepping with the person. (Joyce)

Many participants solved for shared decision-making in their ideal primary care designs, including Gianna, a minority woman, and Sarah, a non-minority woman:

I think knowledgeable people. People that have a welcoming heart, that know what they're talking about too though, so not just like cold Turkey like, "I know this, this is X, Y, Z." Like being able to kind of explain it to you to kind of teach you. I'm the type of person that I ask 5 million questions. So, I like to know what I'm getting into. I like to know what they're doing or why they're writing that or I'm very nosy. But just having kind of like them kind of teach you while they talk to you, like assign you to something or whatever it is. (Gianna)

Sarah reported:

Probably with mental health, providing medicine and alternative medicines that could help, maybe just suggesting a few and letting the patient decide or do their own research if they need it. (Sarah)

Patient-Centered Access and Continuity (AC)

Participants reported a high perceived value of patient-centered access and continuity. The concept of patient-centered access and continuity states that the PCMH model expects continuity of care (NCQA, 2017). Patients, families, and caregivers have 24/7 access to clinical advice and appropriate care facilitated by their designated clinician/care team and supported by access to their medical records. The practice considers the needs and preferences of the patient population when establishing and updating standards for access. Ariel, a non-minority woman, reported her expectations for continuity of care in her ideal primary care design:

If I could just call and say, “Hey, this is me. I want to see this doctor that you guys assigned me to in the beginning and I see regularly every time,” who can either take what I’m saying into consideration and hear me out. (Ariel)

Participants reported the value of continuity in their ideal primary care designs, including Mary, a non-minority woman:

Like an ideal world, all barriers removed, as conveniently as possible to the consumer. So, at any time that I wanted to walk in and see my provider, they were there and available. And if not them directly, someone else I still had a relationship with on the care team that was available. (Mary)

Ariel and Chika, a non-minority and minority woman, respectively, associated continuity with convenience and preferred a system in which patients would not have to spend time reintroducing themselves:

Cause that's your life, it's your life in someone's hands. Someone is physically and mentally taking care of you in a sense of diagnosis you and treating you. I think that they should be able to sit down and look at you face-to-face, and talk to you, and not just FaceTime, or email, or call, or text all the time. I think that it's convenient sometimes to be able to reach out to someone on the phone and get an answer back, but I think when it comes to the actual initial visits it's important to have that face-to-face contact. Just more modernized type of doctor's offices. I mean, like nowadays, when I take my boyfriend to his primary care they have him check in on a tablet, make the copay on the tablet with your card, you can pay cash at the receptionist if you need to, but it's more modern, it's more technology-based, it's faster, it's less complicated than having to go write your name down, wait to be called, things like that. But even in that first greeting, it's a face you see. It's not just a sign and take your number kind of thing, automated, system.

(Ariel)

Chika reported:

Just because I feel like it'd be easier, and I'll be like if it's something similar that's happened to the past, I can just be like, "Oh, remember this? It's kind of like that." And they'll know exactly what I'm talking about. They'll be like, "Oh yeah, I remember that."

(Chika)

Competency A

The participants' ideal primary care designs aligned with Competency A. It is valuable that the practice seeks to enhance access to primary care by providing appointments and clinical advice based on patient needs, which was identified in participants' ideal designs that featured same-day appointments, including Rebecca's, a non-minority woman (NCQA, 2017):

Usually if it's a sickness or an emergency, you can't wait to schedule something four days in advance. (Rebecca)

Gianna, a minority woman, and Brittany, a non-minority woman, highlighted that being sick is not something for which people can schedule and plan ahead:

I mean I like to be seen the same day. (Gianna)

Brittany reported:

I would want in an urgent kind of situation to be seen that day, but don't have to make an appointment for it. (Brittany)

Mary, a non-minority woman, and Janya, a minority woman, described how their primary care providers not having appointments outside of business hours compromised quality of care:

My primary care provider doesn't have out-of-normal business hours. So, for an emergent need, I have used an immediate care in the community, versus the primary care practice...not great. I mean, it was going in for, what I felt something simple, like a UTI. But because my primary care wasn't open I had to go to urgent care, and register completely as a new patient, all the new paperwork, here's my insurance. And then the wait time, for what, if I had gone to my primary care would have been a 15 minute, like, "All right, come in, we know what you need, give us a urine sample, here's your medication, here you go." Value taken away...It was a very brief interaction, they had

never met me before, there was no, I guess, personal aspect to it? I mean it quite literally felt like, one minute in, one minute out, and I mean, I got what I needed physically, but not the quality of care I would have gotten from my primary care. (Mary)

Janya reported:

I fractured my finger once. So, we had to go to the urgent care. I think it was like six. So, our primary care closed at four, so we had to go there, and it was the closest one nearby. It was just okay care. (Janya)

Chika, a minority woman, described how primary care is traditionally known for its limited hours:

I feel like primary care is the basic, from like 8:00 to 4:00, whereas urgent care is like, I need time afterwards. (Chika)

Therefore, many participants solved for having extended or 24/7-hour availability in their ideal primary care designs, including Mary, a non-minority woman:

Preference-wise I would always prefer to go to my primary care doctor, like if they were open 24/7 and I could see them for absolutely everything, I mean that would always be my top pick. (Mary)

Participants also included timely clinical advice via telephone in their ideal designs, including Gianna, a minority woman:

I think it'd be nice to just call somebody up and just be able to talk to them and explain it. (Gianna)

Joyce and Brittany, both non-minority women, said that they were open to conversations that would prevent the need to escalate to a physician:

Maybe if there was a centralized agency for locations, where they could connect you to a doctor's office that would have an open line of communication with you about your care and what you need. (Joyce)

Brittany reported:

I feel like that would be another thing that I would do over the phone or through text if they could do that. Because that's a situation where you're like, "I'm not sure if I need to go to get seen for this." Or, "I don't really know what's going on, so maybe I should ask a professional first before really diving in and doing all this stuff." (Brittany)

Ideal designs also included alternative appointment options outside of traditional office visits to ease access. Gianna, a minority woman, was open to video visits:

I know they have the FaceTiming that you can do the doctor thing, which I think is awesome. (Gianna)

Rebecca, a non-minority woman, was open to home care:

Primary care Uber. I mean, they have on-call, but if it was somebody that, at that point, you don't even have to have a place to have that kind of stuff. You can just have them come to you. You don't even need to have a location for people to drive, because that can just create a whole bunch of barriers. (Rebecca)

Dory, a minority woman, noted that there is an interest in asynchronous visits that would mitigate discrepancies in care based off of implicit bias:

You could type your symptoms into a computer so you could be like, "This is" ...and the computer could give the doctor multitude of results...that could be helpful but in my ideal system, you don't have any bias so I think having those two together would just be truly be magical. It would be a work of art together. (Dory)

Participants reported having electronic access to their practices and providers as an important element of their ideal designs. Mary, a non-minority woman, described how dissatisfaction with and inconvenience of her current non-electronic primary care experience:

What kind of gets to me the most with my current experience with my primary care is the convenience of that in-between care. They're a little bit behind on the technology aspect, so I have to drive 30 minutes away every month just to pick up a prescription, to then take it to the pharmacy, whereas I come from a background where I'm like, "Can you just send it in electronically for me, and let's skip the middle process?" So that is one aspect that I find important in healthcare, although it hasn't influenced my decision enough at this point, but it's been the only factor that has caused me to question switching to a new primary care provider, is the in-between inconveniences. (Mary)

This desire for two-way communication was solved for in the participants' ideal primary care designs with the following:

They're like 24-hour chat lines with doctors where they connect you. I think that's cool. My place would have that. (Ariel)

Chika reported:

I would definitely want them to pick up my calls when I'm trying to contact them, and if it's something like not as serious as I thought it'd be, they could be like, "Oh, from what you're telling me, it seems like it's this, so you don't necessarily have to go to the emergency room." They should be able to just talk to me as I'm going through it, instead of me having to wait until the next day, and then calling them and being like, "Hey, this happened last night." (Chika)

Brittany reported:

I guess not just meeting, like if I had an appointment or I went to see them, not just talking to them face-to-face, but maybe also video chatting or doing stuff over the phone because everything is really technical nowadays. And I feel like that would be easier, so if you had to update something then it'd be faster. (Brittany)

Mary reported:

I think given being a millennial, the opportunity to exchange conversation back and forth electronically has a lot of value. Because then you're not just kind of pigeonholed into the once of the year thing. If I, I don't know, I come down with strep or something, I could just send in, "Hey, I'm not feeling well." And then maybe they could provide that care conveniently, electronically or telephonically, and still know you and know what's going on in your world without you even having to step foot in the practice. (Mary)

However, Sarah, a non-minority woman, reported the value of face-to-face interactions and did not want to replace that altogether:

I've used it once. I used to go to a psychiatrist for medicine and she would occasionally just video chat. And that was okay, I think I prefer more face-to-face communication because sometimes I feel like it'll get the message maybe or you feel like they're not there for you physically. (Sarah)

As Brittany, a non-minority woman, describes, access to female doctors was also called out in the ideal designs:

I know for some, for my sister even, she really prefers to see a woman doctor and I feel like for her it's so hard. I feel like they're really less accessible than men doctors are. I feel like women can understand more because they are a woman. They understand how

your body works and sometimes they just understand everything in a different way. So, I feel like being able to meet goals or standing up for someone, or even connecting with them sometimes if you're a woman, it's just easier to talk to another woman about issues.

(Brittany)

Competency B

The participants' reported ideal designs align with Competency B. It is valuable that the practice supports continuity through empanelment and systematic access to patients' medical records (NCQA, 2017). Melody, a non-minority woman, and Dana, a minority woman, reported:

[I want] someone who remembers you. Someone who listens to everything you have to say, whether they agree with it or not. I would like to see the same person, so I don't have to explain my history over and over. Socially, they get to know you more. It just feels more comfortable opening up about your body and your health to someone that you are more familiar with than seeing a new person and trying to spill everything or what's wrong with you. (Melody)

Dana reported:

But it would be important, because they would be able to...If I've had, I don't know, three sore throats in a week, but I saw three different doctors, they might not recognize I've been there three times. Whereas someone else, it's like, "Oh let me see if it's actually this, because you've been here quite a few times." And they would take recognition to do that. I guess that's what I would kind of see. (Dana)

However, many participants described how their past experiences in selecting a physician were not the best, including Joyce and Brittany, both non-minority women:

I'm not necessarily choosing to go and see this person necessarily. I have a small pool of people and I have to pick one. It's like the worst Tinder imaginable. You know? (Joyce)

Brittany reported:

I think it's important, but I haven't followed that myself because I feel like I can never really find a doctor that I really like. But I do think it's important to have someone that you can always go to for this for everything. I think because even if you don't know them personally, I feel like you can build a trust with your doctor and you just get familiarity with them. So, you feel more comfortable sharing things with them, and they know all about you and then you won't have to switch everything around. So, I feel like that is important. (Brittany)

Brittany also reported accessibility of a personal clinician as a barrier to care:

So, they gave me a list of a few and then they told me the one that I picked, they said that they're usually more open. Whereas the other few ones we're usually busy and you'd have to wait longer for them. So, I just chose the one that was more open. (Brittany)

Sarah, a non-minority woman, reported availability of women doctors as important to the empanelment process:

Primarily I would want it to be women doctors only because that's just what I'm comfortable with. Every time I go to a place, I ask for a woman doctor because I think they know the anatomy more. And they will also understand in a way what I'm feeling if they've experienced it before. (Sarah)

Gianna and Rebecca, a minority and non-minority woman, respectively, reported having continuity of medical record information as an important design element:

I think just knowing my medical history. I think that's just a big important thing. Knowing the medications I'm on, knowing the doctors that I've seen, things like that. And just them kind of making me, giving me that reassurance that they know what they're talking about and they know me, yes, but also like what they're assigning you to, what they are, you know. I think knowledge is something that really attracts me to be comfortable and vulnerable with someone just because, I don't know, other than that it's kind of hard. It's hard to relate to somebody else if they don't really know what they're talking about. (Gianna)

Rebecca reported:

Well, they would probably have some sort of system to know a lot of my background, because it's not like I have it written down everywhere. A lot of different places probably have my history. Somewhere I can take all my history and family history and kind of put it together, and they can view that and then always look back to that, instead of having to sift through every record. (Rebecca)

Participants reported panel size review and management in their ideal primary care designs; participants' desire for continuity was not always reciprocated. Mary, a non-minority woman, reported insurance as a barrier, which dictates who a primary care provider can be:

I've noticed even at my current primary care doctor's office, sometimes they have rotating providers going through, and sometimes they don't always transparent that I wasn't seeing my original provider when I would make the appointment. So, then I'm kind of let down when I go in and someone new is completely walking in, "I'm like, Who are you? Are you my provider? Are you the student? What's going on today?" But then you do have to give your whole story of, "Why did you start, why are you here, how have

things been going?” Versus when it’s just my actual PCP it’s a pretty candid conversation and more so like a touch-base. (Mary)

Sarah and Joyce, both non-minority women, reported that their election of primary care providers was not enforced:

I see the same doctor, but occasionally I’ve seen different ones. Sometimes I can be a little bit nervous. I remember this one time I got a new person and I was nervous. (Sarah)

Joyce reported:

I feel like I don’t see [the doctor I selected] enough for it to be a primary care physician.

Like what even is that? I don’t know. (Joyce)

Dana, a minority woman, noted that this experience causes confusion, which makes patients question why they need to elect primary care providers if adherence to those selections will not occur:

Yeah. I wanted them to be my primary care physician, but I don’t think it’s up to really me as the patient. It’s probably more so up to them and their availability and what works for them, and that’s probably why I don’t know my physician because I don’t think I get the same physician every time. But it’s funny because every time I go to this primary care place, they ask me who my physician is and I’m like, “I don’t know.” And then they tell me, but then they’ll still tell me I can see another doctor. So, I’m like, “What does it matter if any physician could see me?” (Dana)

Care Management and Support (CM)

Participants reported a high perceived value of care management and support. The concept of care management and support by the practice identifies patient needs at the individual and population levels to effectively plan, manage, and coordinate patient care in partnership with

patients, families, and caregivers. Emphasis is placed on supporting patients at the highest risk. This concept emerged as one of the most valuable items in the participants' ideal designs.

Competency A

The participants' reported ideal designs align with Competency A. It is valuable that the practice systematically identifies patients who would benefit most from care management. It became clear from this study that emerging adult women should be considered as high risk because of their feelings of being alone and unsupported (NCQA, 2017): Some participants stressed that there is a lot to know and it is difficult to figure it out on your own:

It can be hard to find stuff because there's so much coming at you. And so, for example, I went to Planned Parenthood but my friend goes to Capital Women's or something like that. And you get two sides and you don't know which one to use. But I think you have to spend a couple hours really looking at it and figuring out what works for you. (Sarah)

Joyce reported:

Doctor or practice stands up for me, I don't know. I don't even know what that would necessarily look like. I feel like most of the time I navigate that myself. If somebody could coordinate everything or I could just get everything in the same spot that would be awesome. (Joyce)

Chika reported:

I mean I kind of like lean on myself. I will research everything. (Chika)

Mary, a non-minority woman, highlighted that women have complex and dynamic healthcare needs that would benefit from a collaborative patient-provider relationship:

Especially coming into that age of womanhood, where when you turn 21 you need Pap smears, and different types of lab testing, et cetera. I would have never known that on my

own. So, having that primary care relationship at that time is what guided me through my women's health, and the introduction to women's health. (Mary)

When designing their ideal primary care experiences, the participants reported the need to feel supported by care management, including Joyce and Brittany, both non-minority women:

There's a person that's responsible for me and their main job is just make sure that the doctors are aware that this is what's supposed to happen, and this is what they want and make sure you know what they want or something like that. (Joyce)

Brittany reported:

I want someone to make me feel really appreciated and taking care of knowing that someone else could advocate for me too and make me feel like not as alone so. (Brittany)

Dana and Gianna, both minority women, wanted a liaison between them and the physician at times:

I would have a consultant, I think I would think of them as a friend. But a friend in the health field. (Dana)

Gianna reported:

I want someone to make sure that I get the help I need and be vocal about what I need and if I am not sure about something, getting the questions that need answered and just kind of learning how to go about different situations or how to, I don't know, I guess just finding that tool, getting me to that tool. (Gianna)

Competency B

Participants' ideal designs aligned with Competency B. It is valuable for patients identified for care management that the practice consistently uses patient information and collaborates with patients, families, and caregivers to develop care plans that address barriers and

incorporate patient preferences and lifestyle goals documented in patients' charts (NCQA, 2017). Such efforts may be made through reports, file reviews, or live demonstration of case examples, which participants identified as valuable. Participants also reported the value of personalized care plans, including Chika and Sarah, a minority and non-minority woman, respectively:

I guess if they have a background of my information and who I am personally, my comfort levels, if they know that I'm uncomfortable with a certain thing, they know not to try but like get me to do it or convince me to do it. I feel like that would really show that it's made specifically, designed for me. (Chika)

Sarah reported:

In my ideal system, they don't discriminate, and their questions are gender inclusive, race inclusive, what your sexuality is. I would enjoy that. Some primary healthcare people don't really look into that as much. Maybe when you're a first patient, but I've been with this one primary healthcare for a while and so I don't know if they know that I go by non-binary status. (Sarah)

Mary, a non-minority woman, wanted a clear action plan delineating the provider's responsibilities, expectations of the care team, and any next steps:

Like you're having all of your needs met...it should feel like you're able to go in and have a comfortable conversation with your primary care provider. And whatever you need in health care. And then, they kind of help support what avenue you need to go down next. Or if it's just, everything you need is all within these four walls in the practice. Kind of homey, in a sense. Like you walk in, you're comfortable, you're directed to everything you need to do next. I think that's the one thing I hate, is like when you walk in

somewhere and you don't know where to go or what to do because no one's giving you direction. (Mary)

Leveraging the care plan to stay healthy was reported as an essential design element. Gianna, a minority woman, and Mary, a non-minority woman, solved for a personalized care plan:

Over time my practice helps me stay healthy, as long as they are working with you to be the best version of yourself and get the best care for yourself. That's very important to me. (Gianna)

Mary reported:

It important to know what your goals and aspirations with your own healthcare are. I mean if you're sick and you are making goals to not be sick, they know what all those things are. So, they know what direction you're moving in healthcare. (Mary)

Joyce and Brittany, both non-minority women, solved for a clear action plan:

Lifestyle coaching, so there's a lot of really great ways to make your lifestyle as a whole health[ier] and happ[ier] and [more] productive and stuff like that, that you can't necessarily see for yourself. If you were to go in and talk to someone at your doctor's office about like, "Oh yeah, I wish I was working out more or I wish I was doing this," or, "I wish I was eating more healthily," and then having them be able to be like, "Hey, here's some really great ways that you can start working towards reaching those goals. If you want to work out more and you have a hard time waking up in the mornings, try to schedule it this way, or here's a cool app that..." I don't know, some sort of action plan like that. (Joyce)

Brittany reported:

I mean, you go to the doctor to be healthy and I never know what's going on. I feel like that's so important that they can help you improve and then just stay healthy too.

(Brittany)

Some participants' designs reported having a written care plan to allow everyone to be on the same page and anticipate what should happen next, including Joyce and Brittany:

I feel like sometimes you walk out of the doctor's office and you don't know if you're supposed to check in with the people or the desk people or you get to the doctor's office and you're not sure exactly what to do or when to come back or even what to bring and stuff like that. That would be nice. (Joyce)

Brittany reported:

I guess not just write down a list of things for me to do but kind of be creative on how I can do certain things or help me find ways to meet my goals. And I guess goals for me, or that they would help me meet is like, "Keep a good diet. Exercise more to get your heart healthier." (Brittany)

Participants also reported having an in-depth assessment of patient barriers to health and understanding of patient goals. Brittany and Melody, both non-minority women, wanted their primary care providers to be effective by understanding their comprehensive barriers to care and their health goals:

I guess just take into consideration everything. Look at my past medical history, check in with my diet, check in with my mental health, just make sure that I'm doing okay. And then when you're comparing stuff, make sure that they all fit together. (Brittany)

Melody reported:

In caring for me, my doctor considers all factors that affect my health. I put that one first because I think it's important for my doctor to think about all the different symptoms I have throughout my history of my health and take it all into consideration instead of just that one visit, and being like this is what's wrong, and this is a quick fix. (Melody)

Chika, a minority woman, expressed that, without an effective primary care provider, there would be no mutually beneficial relationship:

Because if we can't stay healthy with the same person, then there's no point of us going there. (Chika)

Joyce, a non-minority woman, reported active roles in self-management in her ideal design:

To do as you're told. If they could offer me all the information I needed, and everything in like, "Here's how we keep ourselves and our communities healthy, do this and this and this," my job would be to come in and do those things, whether it's come in for a checkup or vaccine or whatever on a regular basis, or like, "Hey, if you have a fever that reaches this, come in, or, Don't go into the emergency room unless you fit these criteria," that sort of thing. (Joyce)

Brittany, a non-minority woman, reported having an integrated care team as part of her design:

I think just going back to the fact that I want to have like a big team of people. So maybe they could get an advocate person to come with them, or to help them talk through things before they meet with their doctor, or someone who can advocate for them, to be there with them. So, if they know what's going on, then they can talk to their doctor with permission about what's going on too. (Brittany)

Care Coordination and Care Transitions (CC)

Participants reported a high perceived value of care coordination and care transitions. Care coordination and care transitions ensure that the practice systematically tracks tests, referrals, and care transitions to achieve high quality care coordination, lower costs, improved patient safety, and effective communication with specialists and other medical providers. This concept was reported as value added in Rebecca and Mary's ideal systems:

In an ideal world, if all of my doctors could be in the same vicinity and I didn't have to travel to different locations, that way it's easy for care. It's not even different doctors for different things. It's the same doctor for different things. That could make it a little bit easier. (Rebecca)

Mary reported:

But a lot of times navigating healthcare is tricky. So, I'm going to them for a reason, I don't have the answers. So, I'm going to them for them to advocate on my behalf and have my best interests in mind. So, on top of making sure you're taking care of me as one whole individual, that's the second-most important thing, is that you're advocating for my most wellbeing. (Mary)

Although "the practice coordinates my care for multiple places" ranked low on the perceived value items, participants reported their desire for a better-connected primary care system; thus, it would be less important to coordinate if their ideal systems were set up with less silos. Dana, a minority woman, reported:

So, my practice coordinates the care I get from multiple places. Actually, I would probably move that into not important, because now as I'm reading it, I'm interpreting it

like it's like not efficient because it's coming from all over the place. So, it just seems like it'd be kind of chaotic. (Dana)

Competency A

The participants' reported ideal primary care designs aligned with Competency A. It is valuable that the practice effectively tracks and manages laboratory and imaging tests important for patient care and informs patients of the results (NCQA, 2017).

Participants desired to be promptly informed of their results in an easily understandable manner.

Mary, a non-minority woman, wanted to understand the relevance of certain testing options:

If you need labs or tests, your providers should be able to at least obtain the specimen right then and there. And then I shouldn't just receive a letter with a bunch of values on them that have abbreviations I know nothing about. But ideal world, your doctor calls you and says, "This is what this means. If this is low or abnormal, now you need to do this." Rather than me just going on a portal and looking and figuring it out. (Mary)

Brittany, a non-minority woman, wanted to have timely responses as to when their results were completed:

With my doctor that I have in real life, I go get blood work done and I never know when it comes back, the next time I see my doctor he tells me what they are. And I'm like, "Well, I'm in nursing school so I kind of understand what this stuff means," but if I wasn't, I wouldn't know what any of this meant. I feel like that would be something where I would have the doctor call right away and be like, "I have your results and we can either do this over the phone, or if you want to meet in person to talk about what all of this means, we can do that." So, I feel like give someone options and then explain what everything means, what the levels mean, and are they good or bad? (Brittany)

Ariel, a non-minority woman, and Gianna, a minority woman, wanted a personal delivery of results:

If it's major like, "Oh my god something is wrong with you," I'd hope they would be face-to-face. But if they're calling me like, "Hey, by the way, you have strep throat. We're going to call in a prescription for this for you," that would be convenient. That would be super cool if they can do that. (Ariel)

Gianna reported:

I think it would be nice to have the doctor or the person that's taking care of you. Yeah. I wouldn't want just a random nurse just telling me whatever it is. (Gianna)

Other participants wanted education and support for any next steps:

You know how someone would call after a test result would come in, and they would tell you about it? It'd be something beyond a brief conversation over the phone. It'd be something that you talk about how to prevent that kind of stuff, what could have caused it. I've had that kind of stuff before, but nobody ever asked, "what could have caused it," "what do you think is going to prevent it," and stuff like that. They just kind of say, "This is what it is, here's your medication, go pick it up at CVS." Someone that could go in depth, so it's kind of preventable, because a lot of things can be prevented. It's good to touch base, even if it's the little thing, like bronchitis or a UTI even. People can get them all the time, but just knowing simple ways to prevent them could probably come in handy. (Rebecca)

Sarah reported:

I think that helping someone understand and interpret results is important and that a lot of people might not know what it means. I would want them to tell me upfront but then also help me show options or guides on where to go next from that result. (Sarah)

Chika reported:

Just be very willing to answer questions that I have. If they're like, "Oh, you have like a high level of this in your blood." And I'm like, "Oh, like what's that?" And they be like, "Oh, it's this and it affects like so-and-so." Usually they'll just give you the document and then you have to look it up yourself. Half [of] the time it doesn't make sense. Because like if they explained it, like break it down without using like super big medical terms, then I feel like that'd be really nice. (Chika)

Competency B

The participants' reported ideal primary care designs aligned with Competency B. It is valuable that the practice provides important information in referrals to specialists and tracks referrals until reports are received (NCQA, 2017). Coordination between primary care practices and specialists was very important to the participants in creating their ideal systems. Some participants wanted to avoid feeling like they were the middle women relaying messages between providers:

They would talk to each other, because they're all in the same place. It's very convenient, because one thing I hate is if I see one doctor and then I'm the one communicating between the two of them. (Dana)

Ariel reported:

I feel like they should definitely bring it back to them. I mean, if I go to a specialist referred from my primary, I would hope that the specialist would send the information back as a follow-up. Like most doctors say, “follow up with your primary care in six weeks if you’re not feeling better.” I hope from that visit, they send them my diagnosis and my treatment, and tell them to either reach out and say, “Hey, don’t forget to schedule your follow-up appointment,” whatever. It’s a very good balance of personal responsibility as well as cool doctor offices communicate. (Ariel)

Mary reported:

But you need this procedure or this intervention, but then there’s a very strong communication back to your primary care. And whether they’re calling to check up on you and say, “How are things going with this doctor?” Or when you come back to primary care, they already know everything that’s happened. They can lead the conversation. (Mary)

Other participants wanted to feel like their primary care providers ultimately had their best interests in mind and would advocate for them to other physicians:

So, I feel like, I don’t know if this makes any sense, but I would have a cardiologist per se, I would have them partnered with primary care. So, if something was going on and my doctor was concerned about it, they could call my cardiologist. And depending on how serious it was, they could either make the time to come with me to another appointment, or they could video chat, or be on the phone and talk about what’s going on. (Brittany)

Dory reported:

I mean, I think if the doctor is referring me to a specialist, that they should convey why I'm being sent there, what they think I'm being sent there for. I think you know more about this and what it looks like. You should check for this [be]cause I just think. But definitely just communication. Just getting [to] talking is important. (Dory)

Janya reported:

I feel like they can do it themselves just because I feel like if I'm there, they'd be trying to help me as well as trying to talk to them. But like if I'm out of the picture, they can just throw medical terms around and be able to communicate properly. Whereas if I were there, they wouldn't be able to as much. (Janya)

Gianna, a minority woman, and Rebecca, a non-minority woman, also reported the value of using their primary care providers' judgment when making referral decision:

If you go to your primary care, you feel that's where they have a lot of knowledge on the best person to see. So, you just go off with their recommendation. (Gianna)

Rebecca reported:

It would be someone that my doctor, if I was seeing someone that was regular, I would hope that they could know me well enough and know somebody that is capable, they would just refer me. In a perfect world, I wouldn't have to search or wonder if it's something that's right, find a second opinion. It should be like, that person knows and that's the right person. (Rebecca)

In many of the participants' ideal systems, primary care providers would advocate for their patients and maintain high quality of care expectations with specialists. Dana, a minority woman, wanted her primary care provider to have her best interest in mind:

I also read it like stands up for me again, like if some...And also, if something's wrong or someone's not doing something right, I'd want to make sure I feel like that they would stand up for me if their colleagues would do something wrong or something like that.

(Dana)

Mary, a non-minority woman, described the patient-provider relationship as one that is grounded in trust:

At least in my experience with my primary care. I'm not saying that applies to all, but then, again, know the quality of care and then vice versa. If they get feedback that the quality of care may not be up to the par that they're expecting, then you can trust in your primary care provider. They're not going to send you off to that provider. (Mary)

Ariel and Melody, both non-minority women, expressed that the system should not be so complicated that it needs to be coordinated. Instead, the system should simply be about the patient from the beginning:

Well, it is necessary if you have a bunch of doctors and they're all trying to equally work together to find a diagnosis. But this one really thinks that it's more that or that this route would be even better and that these people are mistreating and doing something that's not practice worthy, that they would speak up and put their foot down. (Ariel)

Melody reported:

I think that would show a lot that they care about me receiving better care. Like if I reported to my normal doctor that, that another doctor was not very good with me and that she reached out to do something about that, I would be okay with that and I would be impressed by that. (Melody)

Behavioral health integration was also a major item reported in the participants' ideal primary care designs. Rebecca, a non-minority woman, reported:

It'd be nice if, that could be also something that a therapist or someone that's in the same vicinity, someone that's also mental health related. It's usually a whole separate system, but to integrate those some somehow, some way. (Rebecca)

Sarah and Janya, a non-minority and minority woman, respectively, reported that education as a stress factor commonality:

Goals right now is just like college and just figure out what I want to do. I feel like that could be more therapy instead of actual primary healthcare is what I was thinking of. (Sarah)

Janya reported:

I feel like mental health, like a therapist would be nice. Just because it's...especially since school is very stressful. I feel like a therapist is really important. (Janya)

As to items in the interviews that included behavior health as an aspect, "In caring for me, my doctor considers all factors that affect my health," emerged as most important to the participants. Since there are multiple layers to health, the participants wanted all of those factors to be considered when they took into account any medical recommendations or treatment plans:

In caring for me, my doctor considers all factors that affect my health. That's very important because physical health, mental health, everything goes hand in hand with each other. So, it's really important for me even looking at primary care level where they might not do stuff with mental health to still recognize the effects of that. And then for mental health to recognize the effects of physical health. So being so overall the entire

health and same thing with my emotions, everything ties together. So, I'd want to make sure my doctor understands that. (Dana)

Dory reported:

Sometimes they're just trying to treat you, but they're not treating you emotionally. A lot of times, I think with mental health becoming wider known, I think that it's getting better because people are having trauma informed care, but I think for a long-time people weren't having trauma informed care. (Dory)

Dory also reported:

Well if everyone's working together, they shouldn't really have to stand up for you because everyone's already working together. (Dory)

Since the participants did not view their health in segments, they did not want the healthcare system to deliver it in segments, evidenced by Janya and Brittany's ideal designs:

I don't want to jump around to a bunch of places. (Janya)

Brittany reported:

I would definitely have like someone that I could connect with and be a part of the team that might not be there per se. So, if I needed to reach out to someone that they would be easily available to come, or to talk on the phone, or wherever they were needed.

(Brittany)

Participants also noted the importance of considering treatment options and cost. Some participants stressed that a financial strategy needs to run parallel with any healthcare strategy and health teams need to support that:

So, my consulting basically is a doctor and is trained. I would say probably more a general kind of doctor kind of training level. But they know my financials, because

they're going to recommend what's best for me, as a person and financially. So, they know for example, I'm terrified of needles. So, they know if I ever have to get this shot, they're going to tell me not to get this shot, because they know I'm scared of needles for example. Or if they know my rent is coming up, and I guess I'm sick, but I don't know how sick I am. They will consult for me, where to go based on again my income and my symptoms, maybe. (Dana)

Brittany reported:

That's really important to me because I'm a student and so I only work part-time, but I still pay for myself. So, I have to find somewhere that's not very expensive to go.
(Brittany)

Mary reported:

I mean if there's insurance obligations, which fortunately hasn't played a role for me, but if there [were] those insurance obligations where maybe cost is a big factor of going to a specialist, they're able to provide some of that insight so that you can make an educated decision on where you're going next. Again, if the finances are a barrier. (Mary)

Competency C

The participants' reported ideal primary care designs aligned with Competency C. It is valuable that the practice connects with other health care facilities to support patient safety throughout care transitions (NCQA, 2017). That the practice receives and shares necessary patient treatment information to coordinate comprehensive patient care was important to the participants in creating a primary care experience that felt more like a one stop shop for current and future needs. Dana and Janya, both minority women, wanted all of their care physically proximal in their ideal designs:

Yeah, like the airport or for enterprise for example. Yeah, it's a one stop shop. Your car gets in an accident. So, there's Geico, there's Enterprise, and then there's the body shop all in the same place. So that's it. But everyone still is knowledgeable and specializes in their own kind of field, and their own thing. But you're only going to that one place.

(Dana)

Janya reported:

So, personally for me, the primary care that I go to, they don't have x-ray machines and stuff like that, so if I have to go to a specific radiology place, that's fine, but if it's like I have to constantly be going other places just to get basic health care, then I feel like that'd be kind of inconvenient. (Janya)

Joyce, a non-minority woman, described that, not only do care facilities need to be physically located in a convenient way, the coordination of care across the continuum also needed to be present in her ideal design:

I had to get blood work apparently to get my immunizations up to date. I don't know.

They just handed me the paperwork and were like, "Go get blood work. Have fun." I was like, "I don't know where to do that or how to do that." (Joyce)

Mary, a non-minority woman, acknowledged that her healthcare needs will become more complicated over time and that she will want these needs to be anticipated and supported by her care team:

Funnily enough, I feel like the ones that I said were not important would probably become important in five to ten years, as far as coordinating the care I get from multiple places and having been through a lot with your provider. Just because I feel like in that five to ten-year range is when you...Not you, but I would start to encroach having

children or other impacts to my healthcare, hopefully nothing bad. But things that I would need coordinated care for. Mostly probably having children. (Mary)

For unplanned hospital visits, Gianna and Mary included primary care providers that would be notified and present to support patients in their ideal systems:

In my magic system, I would like for them to be alerted. Cause I don't want that to be a responsibility for me. I don't really know how that'd be possible. But that would be nice if they were alerted and they were able to come check in on you themselves too if you were in that situation or kind of coordinate with them. (Gianna)

Mary reported:

Ideal magic world, your primary care should know the second you step foot in the emergency room, because they're probably the one that told you to go there. And then, if you're admitted or in observations, then your primary care I think is a critical member of your care even within the four walls of the hospital. So, whether they're, again, coming in to see you and part of, I don't know, rounds with the other doctors who would be providing your care. Or they're very closely intertwined electronically, telephonically, just that communication pathway. (Mary)

Participants also reported about the expectation that providers would follow up with patients post-hospitalization. Ariel and Sarah, both non-minority women, and desired to follow up with their primary care providers and wanted to know their primary care providers were just as eager to follow up with them:

I'd want them to call me like 72 hours later. (Ariel)

Sarah reported:

I'd want them to know probably why I'm in the emergency room and be open to me coming in after going to the emergency room to follow-up in case I need it. (Sarah)

Brittany, a non-minority woman, wanted their primary care providers to be proactive in their methods for reaching out to them:

If the ER says that they're going to send something to my doctor, maybe my doctor [could] reach out to me over the phone at least. Or I get [an] instruction to call them in two weeks for something, just so it is a little coordinated. (Brittany)

Further, Brittany reported a desire that their information be easily accessible and shared:

So, I would want my care place to connect easily with the ER. So, I would want them to always send them my information, like if needed, be able to update them on everything because I know how important it is for the ER to see your medical history and everything, to see if anything's going on. So, I think what I would do is while I was in the emergency room and let's say they send an update to my doctor that I need to be seen again, I would want my doctor to text me, or video call me, or just call me on the phone and say like, "Hey, what's going on? Do you want to come see us? We can make another follow-up appointment with you. We want to make sure you're okay." So, I feel like I would reach out technically first, and then in person, go to see them. (Brittany)

Dana and Dory, both minority women, also reported after-hours accommodation of acute care needs in their ideal primary care designs:

But in my magical world, they do not just work eight to five. They need to work before and after, because I'm going to work. I feel like right now I have to call out of work to go to the doctor for example, stuff like that. So, in my magic wand, the hours are more

flexible based on what my work schedule is, not what their work schedule is, and they have to pencil me in on their work schedule kinds of thing. (Dana)

Dory reported:

And in an emergency, open 24 hours in case something happens outside. I mean things happen outside nine to five. (Dory)

Participants reported having access to an electronic information exchange. Ariel, a non-minority woman, valued security:

You go on this one super-secret website, and you type in your email and password that you get when you graduate with this certain degree, and you can look up someone's name and find their entire medical history. That'd be cool. If that is how it is. I don't know what it actually looks like, but that'd be cool. (Ariel)

Melody, a non-minority woman, valued comprehensiveness:

I don't really know how it works but I would hope that it's all connected so that all the information is tracked and updated frequently. (Melody)

Chika, a minority woman, valued transparency:

It'd be nice if they all use like one system. So, like they just had one profile for me and they can just add on different documents. So, like anyone anywhere can. Not anywhere. People who need it can access it. I feel like that would be really nice instead of them having to like fax it or email it. (Chika)

Performance Measurement and Quality Improvement (QI)

Participants reported a high perceived value of performance measurement and quality improvement. The concept of performance measurement and quality improvement ensures that the practice establishes a culture of data-driven performance improvement on

clinical quality, efficiency, and patient experience, as well as engages staff, patients, families, and caregivers in quality improvement activities. While many of these activities are conducted out of patients' sight, the participants nevertheless designed elements of continuous improvement into their ideal systems. Gianna, a minority woman, designed the following system:

I think that's awesome. I think...And something I kind of learned, my sister-in-law's a physician's assistant at an urgent care, so her job is she's kind of higher up, so she has to review the reviews and people's feedback. One time I was overhearing a call that she had. Them going just over and them actually knowing that they care about their feedback, whether it's good or bad and not just pushing it off to the side, actually exploring it and coming up with solutions like, "What can we do better?" I think everybody benefits from feedback, whether it's negative, positive, whatever it is. There's always room for you to grow and I just think it's just a smart tool to have like, how else are you going to know?

(Gianna)

Competency A

The participants' ideal primary care designed aligned with Competency A. It is valuable that the practice measures to understand current performance and to identify opportunities for improvement (NCQA, 2017). The participants described how they would provide individual feedback in their ideal designs, including through anonymous and face-to-face methods. Mary and Dory, a non-minority and minority woman, respectively, wanted systems that were direct and provided real-time opportunities for improvement, pending that trust was built:

I don't know. I almost think sometimes direct feedback, again it has more impact than if you were to fill out like a survey or something. So even if there was an opportunity, like a community event where they say, "Come one, come all." We want to know how we can

provide better care for you. I think that face to face personal connection of, “Hey, this is where you guys dropped the ball. You really could do better on this.” Has way more impact. Ideal world. (Mary)

Dory reported:

I wouldn’t feel uncomfortable telling them to their face that they did something I didn’t like and most of the time, I don’t feel uncomfortable, especially while I’m getting older, especially if you’re taking my money. I don’t feel uncomfortable telling you in a respectful manner. (Dory)

Janya and Dana, both minority women, wanted a way to provide feedback after the fact and know that such feedback would be followed up on:

I probably would call them at a different time, like not necessarily just then in there, afterwards I call someone there and be like, “Hey, this situation happened, and I didn’t appreciate it.” And they’d be like, “Oh, okay, we apologize.” And they’ll be really nice and respectful. (Janya)

Dana reported:

In my ideal system, I think I would want to tell someone in person. I don’t want to do a review online, or a stupid email survey. I think I would want to tell someone in person. (Dana)

Dory reported receiving feedback from vulnerable populations as an important item in her ideal primary care design:

I think sometimes, well, on a historical note, speaking from research that I’ve even read, a lot of times black woman...that’s my ethnicity...Black women are not taken seriously when they say they’re in pain compared to people of lighter color. And then even during

births, on a separate tangent, when black women say they're in pain, they're not as well helped. And that's why you have high infant mortality or mother mortality rates. So, I feel like that's been the case with me a lot. When my friends or people that were lighter than me went in and said they were having this issue, it was immediately tackled. But then when I would go and say I was having this issue, it wouldn't be tackled. And I just felt really frustrated because I felt like my needs are not being met and I'm not being listened to. (Dory)

Competency B

The participants' reported ideal primary care designs aligned with Competency B. It is valuable that the practice evaluates its performance against goals or benchmarks and uses the results to prioritize and implement improvement strategies (NCQA, 2017). Joyce, a non-minority woman, described the importance of formalized data-driven improvement efforts:

I feel like everyone has feedback, but then it's data, right? Data can be so lost sometimes in the huge conglomeration of...you could have 500 people sending complaints about the exact same thing, but because it's in a complaint cloud of 100,000, you're never going to be able to sort through to that. Maybe if there was a team of people whose job is to continually work on things and make things better, like that was an office. Then they could find some system to organize complaints, kind of organize those so like, "Oh hey, we noticed that we have a lot of complaints about employee behavior, how the people who work here handle things, so let's find a way to handle that." Then like, "Hey, we noticed we have a lot of complaints about, I don't know, like, creature comforts, like how comfy things are. Let's try to handle that." So that they can deal with that in a specific order. (Joyce)

Competency C

The participants' perceived value of Competency C is unknown. It is unknown the value of the practice as accountable for performance. That the practice shares performance data with the practice, patients, and/or public for the measures and patient populations identified in the previous section was the only NCQA PCMH concept not addressed by the participants in their ideal designs (NCQA, 2017).

Research Question 3:

What Is the Perceived Value of the Patient-Provider Relationship?

The third research question explores the perceived value of the patient-provider relationship, a pivotal concept of NCQA's PCMH model. The results were analyzed in more detail, focusing on the patient-centric care items ranking activity, and the key PCMH concepts of knowing and managing your patients and patient-centered access and continuity. As discussed under Research Question Two, the findings show that emerging adult women value the patient-provider relationship and continuity of care as a trusted support mechanism to ensuring better primary care.

Participants reported missing concepts of empathy and cost expressed as value added in their ideal primary care designs, but these are not reflected in the NCQA PCMH model. As discussed in more detail under Research Question One, participants reported disappointment with their patient-provider relationships, including Melody, a non-minority woman:

I'm not too fond of her. I don't hate her, but I think, I would hope that there are more compassionate doctors. I'm not set on her. But the practice, I'm not set on either. I would say the relationship with both of them, it's pretty weak. (Melody)

However, it appears that emerging adult women want relationships with their primary care providers, evidenced by Rebecca's response:

I think it's a good idea to develop some sort of relationship, whether that's asking a lot of questions when the patient comes to visit, because that's how you get to know them. Not even just has them answering questions, but you get to know a lot about the person. I guess, just knowing me. (Rebecca)

Participants reported a high perceived value of the patient-provider relationship, in alignment with the NCQA PCMH concepts of “knowing and managing your patients” and “patient centered access and continuity.” Specifically, participants reported the value of a human connection. Dory, a minority woman, noted that the connection is bidirectional:

I think people forget that doctors are humans too. (Dory)

Janya, a minority woman, said that the human connection is contingent upon having a human conversation:

She's just very friendly. We'll just have conversations about normal stuff, not necessarily medical related. And she'll ask me about like what school I'm going to, because it was over the summer. It's what school I'm going to, what classes I'm trying to take, and stuff that. So, it was more of a personal level connection. (Janya)

Rebecca and Mary, both non-minority women, valued a connection with the people with whom patients interact and not necessary the brands of different organizations:

I don't have a relationship with the practice, the company that's just there. I have a relationship with the person that I'm seeing in the room. (Rebecca)

Mary reported:

I think in the ideal world the people are important. The people are what make the experience. The consistency and the relationship that you develop over time, it allows you to not be as closed off maybe, as an individual seeking healthcare and you can be more transparent about what you're seeking. Because you've established that rapport and relationship. (Mary)

Participants reported the patient-provider relationship as anchored by trust. Gianna, a minority woman, reported:

I think just because for me, just that comfortable openness that you have with that doctor and you just trust them, I think it comes down with the fundamental of having that trust with them and knowing that you're going to get the best care that you can get. (Gianna)

Janya, a minority woman, and Mary, a non-minority woman, noted that continuity over time reinforces trust:

I would want to see the same people. It's like a trust thing. Because the more you see someone, I guess the more connection, plus if I see them often and I noticed that everything's like perfect and nothing wrong. I don't see the point and seeing something different. (Janya)

Mary reported:

So, the first part, going to my primary care provider beforehand, I guess added value to me, because I was able to go in, be seen relatively quickly within the same day, and then I trust their judgment and opinion. And for her to tell me, "You need to go to the emergency room," I actually remember asking her like, "Do I need to go today, or can I still go snowboarding tonight and go tomorrow?" And she just looked at me and I was

like, “Okay, I’ll go today.” Because I had a relationship with her, so I’ve seen her for many different things over the years, and I mean, I trust her medical opinion. (Mary)

Dory and Dana, both minority women, reported that the patient-provider relationship is a security blanket to the overall mistrust of the healthcare system in general:

If I have this magic wand where I know anything that you’re saying in the tests that you give me right now, everything is going to come out as accurate and true, if we’re not best friends, then we don’t have to be best friends. If you’re not coming in and telling me about your life, I’m not coming in and telling you about my life. That’s okay as long as I’m getting good health but I think in this system that we have now, that contributes to a lot of trust because people are still biased, people are still judgmental, some doctors are money hungry so they’re trying to get as many people in, as many copays and then out of the door so you would have to change all that in order for that relationship with your doctor not to be there but to still have accurate information. (Dory)

Dana reported:

Yeah, my consultant. I would have that personal person, because I don’t understand that at all. I guess also maybe the doctors would do a better job explaining it. So, I guess as I’m going along I’m realizing that I’ve created this person that has to get all this training rather than the doctors just explaining it to me. So, I guess we can erase my consultant, and we just have more open and honest and not secretive doctors. Not that they’re being dishonest, but it’s like, I don’t know. They can talk to normal people. They have all these big words and acronyms and all this stuff, but they can just talk like regular people. But maybe that’s too hard for the doctors. (Dana)

Additionally, Melody and Mary, both non-minority women, reported the concept of family care as important to building trust:

If my family knows them and they're trusting in them then I can have some ease.

(Melody)

Mary reported:

It made me feel good, honestly, because I feel like we were talking about his history with smoking or alcoholism or something, and it made me feel good because she understood my family background without me saying anything, so she knew how it could apply. So, I liked it, I mean, I wanted someone to know my family background and how it would apply to me. So, I think for me, it doesn't come off as a superficial like, "What is your family history based off of what's here in my computer?" She truly knows my family because she also sees them in an exam room. So, I guess the value for me is the personal relationship aspect of it. (Mary)

Participants reported the overall perceived value of having a trusted patient-provider relationship as better care. Dory, a minority woman, reported that having a trusted relationship gives patients the ability to be candid, which is essential to effective care:

So, knowing you as a person and then considering factors of your health I kind of think go hand in hand as well. Think because you can build rapport with them and you can discuss your issues. And a lot of the times I feel like when you see a new doctor, each time you have to re-explain and test results can always come back differently. So, having been the same doctor analyze those results all the time is really good because they know what's going on in your body and what's going on with you. (Dory)

Rebecca and Mary, both non-minority women, noted that the provider, over time, knows his patient better than the patient knows herself and can help advise the patient when the provider feels strongly about a certain topic:

Well, I do know that the doctor or a practice knows me as a person is pretty important, but in caring for me doctors consider all factors that affect my health is I think maybe a little bit more. As a person is meaning they know who I am well enough to direct my care best for me. (Rebecca)

Mary reported:

Knowing me as a person is again, I feel like tying into taking care of me in a full spectrum for my healthcare. Because if you don't know all the factors of what's going on in my life, like maybe I'm just here for that, then it's just kind of transactional in my mind. So, for me it's super-valuable that someone knows me as a person. (Mary)

Brittany, a non-minority woman, said that having trust in the relationship and benefiting from that relationship is what makes the healthcare experience valuable:

If I was a patient there, I would want to be greeted promptly, make sure everything's on time, not have to wait too long. Just have genuine connections and conversations with them and being able to be comfortable with what I'm talking about and feel like I made a difference going there that day. (Brittany)

Chika, a minority woman, reported a desire to feel respected and heard:

I think for me it's just respect, and just the initial feelings I get from even just the first visit. As an example, the one I referenced earlier where that first visit, there was no eye contact, there was no personal interaction. Very quickly alerted to me like, No, this isn't someone I should not have care with. (Chika)

Rebecca and Melody, both non-minority women, expressed that continuity reinforces respect and the feeling of being heard, which is associated with better quality of care:

If it's someone that you're always seeing, it's good to give feedback that way, because it's not going to always be stuff that's like someone like a stranger. Feedback for a stranger, it could be friendly or nice or in-depth, but if you know that person, you could be like, Next time, ask these questions. That can always build, and you always can progress and increase better care. It would have to be the same person reading a feedback. Just having it a new person starts it all over. (Rebecca)

Melody reported:

I think it's just more comfortable to be around someone who is understanding of who you are versus someone who is more judgmental because they don't listen to you. (Melody)

Dory, a minority woman, reported that there are inequities in how people are listened to and heard based on their ethnicities, which hinders the ability to build mutual respect:

Oh, white privilege exists anywhere. And I think the more privilege you have the more doctors will listen to you. I mean, I'm a woman so we're less likely to be listened to anyways. (Dory)

Participants also reported having boundaries between patients and providers. Chika and Dory, both minority women, said that topics of religion seemed to be out of bounds for certain healthcare conversations:

I don't really want to talk about my religion to my doctor. I feel like that's just a different aspect, it wouldn't go under as like health care. (Chika)

Dory reported:

I think that's...people need to figure that out outside and they can figure out whoever they need to, I don't want to sound harsh but I don't think it's up for a doctor to come in and be like, "Oh, we got to check you for everything, do your physical and then we're going to talk about your religion and how your relationship is with god and how your relationship is with yourself." (Dory)

Joyce, a non-minority woman, wanted to feel like her provider knew her but did not want to cross the line and face any family-related conflicts of interest:

I guess it would be nice to see the same people every single time, and just like a small-town grocery store-type thing where you come in and they're like, "Oh hey, how [are] you doing?" This, that, the other thing, but then at the same time, that's not as important as for things to make sense. Even in some cases, that can be weird because you're dealing with health issues, and you don't necessarily want to have someone who knows your mom to be talking to you about, I don't know, the weird rashes that you have. Yeah. (Joyce)

Janya, a minority woman, noted that there are certain depths to a person that need to remain unknown to providers:

I mean, it would be nice, but I don't think it's important. They don't necessarily need to know my deeper self in order to give me good health care. (Janya)

Conclusion

The data presented in Chapter Four answered the research questions, finding that: (1) there is a demand for primary care but lack of empathy and cost prevent utilization; (2) there is a high perceived value of NCQA PCMH with alignment in all concepts; and (3) participants have

a high perceived value of the patient-provider relationship, which aligned with both PCMH concepts but was hindered by the missing concept of empathy.

These answers were analyzed to produce the following discussion points covered in Chapter Five:

1. Emerging adults desire but struggle to find human connections or patient-provider relationships in primary care.
2. Primary care that is delivered like a business reinforces emerging adults' belief that the human connection is not possible; thus, transactional services are attractive at least for their convenience and efficiency.
3. Emerging adults are asking for high touch care, similar to care management services traditionally provided only to insurance-backed "high risk" patient panels.

CHAPTER 5: DISCUSSION/IMPLICATIONS

Understanding the voice of the customer is essential when designing for improved quality, reduced cost, and improved access to a complex healthcare system. Through significant policy reform, health policy has made progress in improving access to insurance coverage with little impact on improving access to care. In 2010, the Affordable Care Act significantly enhanced primary care covered services while also expanding access to insurance for emerging adults (Kotagal et al., 2014; Uberoi et al., 2016). However, the ability of emerging adults to stay on their parents' insurance plans until age 26 has not impacted emerging adults' utilization of primary care services (Kotagal et al., 2014; Uberoi et al., 2016). By asking emerging adults about primary care, this study aimed to understand emerging adults' utilization of primary care services, or lack thereof, from a women's perspective. This study was conducted in a community that was not a primary care shortage area and where the participants validated that supply and demand was not a barrier to care. The findings of the study uncovered the participants' desires for primary care and establishment of a relationship with primary care providers. When designing their ideal primary care experiences, the participants made clear their value of the patient-provider relationship and want for transactional services to reinforce rather than replace the relationship.

Discussion

This chapter presents discussion of the significance of these findings, including the implications for practice, policy, and future research. It is framed to unpack the analysis of the following findings: (1) emerging adults desire but struggle to find human connections or patient-provider relationships in primary care; (2) primary care that is delivered like a business reinforces emerging adults' belief that the human connection is not possible; thus, transactional

services are attractive at least for their convenience and efficiency; and (3) emerging adults are asking for high touch care, similar to care management services traditionally provided only to insurance-backed “high risk” patient panels.

Emerging Adults Desire but Struggle to Find Human Connections or Patient-Provider Relationships in Primary Care

Cost and Empathy Defined as a Barrier to Care

In alignment with the conceptual framework, the participants have a high perceived value of primary care, but cost and a lack of empathy emerged as unanticipated barriers to care that prevent primary care utilization. All the participants expressed a demand for primary care services with a clear understanding of the potential value that establishing care would have on their health. Specifically, the participants desired primary care provided by a trusted resource and associated the patient-provider relationship with improved quality of care. Adequate supply was reinforced when the participants did not express that their lack of utilization of primary care was due to availability. Traditional barriers to care were limited with the participant selection process, but two significant unanticipated barriers to care emerged: cost and empathy. While every participant had active insurance coverage, out-of-pocket costs and general confusion about the insurance process made participants avoid receiving care, even when they recognized that they needed care. The participants were turned off by a lack of empathy experienced when trying to connect with primary care providers. While the community had an adequate supply of primary care options, it lacked empathetic options.

Primary Care That Is Delivered Like a Business Reinforces Emerging Adults' Belief That the Human Connection Is Not Possible; Thus, Transactional Services Are Attractive at Least for Their Convenience and Efficiency

Participants felt their primary care experiences were more like business transactions because providers were rushed and uninterested in what the participants had to say. Participants were disappointed with the lack of human connection in primary care and thus sought expedited primary care alternatives. All of these factors impact why emerging adults are unlikely to utilize primary care as the proper level of care.

The Theoretical Framework was reinforced throughout the study's findings regarding the Institute of Medicine's Health Literacy Framework, Starfield's theory of primary care, and Arnett's life stage of emerging adulthood (IOM, 2004; Starfield, 1998). The exploration of life's possibilities for emerging adults came forward when the participants stated their desire for independence and attributed ownership of their health as a step in becoming an adult. One participant even attempted to seek insurance coverage on her own because of her desire for independence, but quickly went back under her parents' coverage because of the cost. The participants expressed their desire for establishing their own healthcare routines, including finding primary care providers that would listen to and respect them. The literature highlights emerging adults as "option seekers" and the "least loyal," but the study's findings show this behavior can be rebranded as "least likely to settle" (Advisory Board, 2017). Participants explained how their quests to find trusted providers required them to shop around because establishing a genuine relationship was almost impossible to do. This study views an individual's iterative interactions with the healthcare system as the venue for how health literacy is informed. In other words, individuals craft their health literacy by experiencing health services directly.

This concept was reinforced in the participants' hesitation to design their ideal primary care systems, as they would often deem their designs as unrealistic or vastly different from what their current experiences would indicate possible. This unrealistic qualifier was even attached to participants' requests to be proactively addressed by name. Further, the participants' interactions with the healthcare system was synonymous with insurance providers. The participants explained that they often decided when and where to seek care based on the direction of their insurance companies when looking up covered services.

Insurance health literacy emerged as a topic that added confusion to the participants' healthcare experiences. Not knowing the out-of-pocket costs when evaluating service options made the participants skeptical of receiving care and fearsome of unanticipated bills. Future research is needed to evaluate health literacy in the context of insurance literacy. This study intentionally included women because the literature expressed women's influence as healthcare decision-makers (Lounsbery, 2018). All the participants credited their mothers as sources for informing them of when and where to seek care. This finding reinforces the significance of women in healthcare and indicates a need for future research on the mother's influence of health literacy. The participants' ideals also aligned with Starfield's theory of primary care (Starfield, 1998). When asked how they would define primary care, the participants called out the relationship value of primary care, including the relational locus of responsibility concept that was triangulated in the ranking activity. However, the participants were quick to point out that the theory of primary care does not always translate into practice.

Emerging Adults Are Asking for High Touch Care, Similar to Care Management Services Traditionally Provided Only to Insurance-Backed “High Risk” Patient Panels

This gap between theory and practice of primary care is intended to be closed by best practice frameworks, including NCQA’s PCMH. The participants were never directly informed of the PCMH framework during the study, but the analysis of the study reconciled their ideal primary care designs against the framework, assessing for alignment. The findings show that the participants’ ideal designs aligned with all the concepts and competencies of PCMH, with no conflicting items. However, the missing items of cost and empathy, which emerged as barriers to care, are not solved for in the PCMH framework. In addition, most emerging adults are not eligible for care coordination support as defined by PCMH, due to their ineligibility of being high risk. These findings show that while the PCMH framework is valuable, it is weakened by the fact that the most important items to emerging adult women are missing.

Implications

This section will define the implications for practice, policy, and future research, in alignment with the three findings discussed above: (1) emerging adults desire but struggle to find human connections or patient-provider relationships in primary care; (2) primary care that is delivered like a business reinforces emerging adults’ belief that the human connection is not possible; thus, transactional services are attractive at least for their convenience and efficiency; and (3) emerging adults are asking for high touch care, similar to care management services traditionally provided only to insurance-backed “high risk” patient panels.

Implications for Practice

Traditionally, barriers to care are framed by what a patient lacks (i.e., child care, transportation, insurance coverage, non-English speaking, etc.). Recognizing empathy as a

barrier to care places the onus on healthcare providers. When primary care lacks empathy, a barrier to care is created and causes emerging adults to lack utilization at the proper level of care. Emerging adults desire but struggle to find a human connection in their patient-provider primary care relationships and acknowledge that finding as much would lead to better quality care. The implication for practice in changing this paradigm requires that the healthcare industry look intrinsically into hiring and developing practices of healthcare providers. Even with empathy as a key qualification, many healthcare providers entered this profession with a good-natured intent to help and connect with people. Therefore, providers are functioning as designed in high productivity models that prioritize volume over value. Solutions to bring empathy into every healthcare experience must target the process upon which people function with an equity agenda. Productivity must be framed as doing more of what is important as deemed by the patients and not simply as doing more, such as, for example, balancing patient panels to allow for more time with individual patients versus expediting visits and missing opportunities for empathy. Provider compensation models must also align to incentivize this long-term change in practice.

The participants of this study indicated that empathy as the most important aspect of the healthcare experience and as something healthcare providers must take responsibility to foster. Potential solutions to fostering empathy should be rooted in medical educational curriculum and continuing education professional competency programs. Cost is another barrier to care that is usually quantified as lacking active insurance coverage. Each participant of this study had active insurance and thus, by traditional standards, should have been void of cost as a barrier to care. However, this was not the case, as out-of-pocket costs and lack of pricing transparency created a distrust between the participants and healthcare providers. Implications for the practice include prioritizing price transparency and developing solutions to mitigate out-of-pockets (i.e., copays).

Providers cannot tackle price transparency along due to complex contractual negotiations with insurance companies. For systemic change to occur, insurance companies must simplify their services not only to patients but to providers as well. Health policies, such as the Affordable Care Act, have opportunities for improvement to ensure out-of-pocket costs are minimized. The participants were progressive in their views on healthcare as a human right, as they included no cost solutions in their ideal primary care designs. Reformers of expanded healthcare benefits and other socialized healthcare concepts may use these findings to support improving access to care.

For NCQA PCMH to be relevant to emerging adults and considered a viable best practice, PCMH needs to address the barriers of cost and empathy. “Knowing and managing your patients” and “patient centered continuity” are concepts set up to be applicable to empathetic care (NCQA, 2017). However, the criteria to attest for these concepts do not address empathy in a direct and measurable way. Rather, a patient-provider relationship is only implied by superficial continuity measures and the practice of panel management. Including performance measures, such as the person-centric care items and empathy building programs in the attestation criteria, would be essential to meeting patients’ needs. The findings of this study identified the concept of Care Management and Support as highly aligned with the optional primary care design for the participants. Emerging adults are asking for high touch care, like care management services traditionally only provided to insurance-backed “high risk” patient panels. Under the current PCMH framework, the concept of Care Management and Support is intended only for patients who qualify as “high risk.” PCMH provides the practice with a list of options for defining “high risk,” such as cost, referred by insurance, and complex conditions. However, under these definitions, most emerging adults would not qualify as high risk and therefore would never receive these services that the participants of this study declared as important. The

recommendation to NCQA's PCMH is to add accommodation for emerging adults or remove the high-risk qualification altogether and provide these relational based services to all patients. PCMH only addresses cost regarding managing medication costs. While aligned with the participants' ideal systems, this is not enough to manage the burdens of out-of-pocket costs. The recommendation to NCQA's PCMH is to add evaluation of cost barriers for insured patients in addition to providing resources for out-of-pocket costs with transparent pricing practices.

First, empathy and cost must be accepted as credible barriers to care and NCQA's PCMH must adopt them into its criteria. Then, NCQA's PCMH must either remove altogether or include emerging adults in the high-risk qualification for Care Management and Support. Subsequently, this leaves the biggest implication for practice as the ability to operationalize PCMH concepts. Without primary care providers adopting these concepts into practice with payment reform support, the impact on patients is unfelt and the problem of primary care becoming obsolete to emerging adults remains unaddressed.

Implications for New Patient Acquisitions and Retention

Primary care delivered like a business reinforces the belief of emerging adults that a human connection is not possible, causing transactional services to be attractive at least for their convenience and efficiency. Primary care can provide a competitive advantage over its alternatives by mitigating cost barriers while providing empathetic care that addresses the need for care management and support for emerging adults. The ability to do this will position primary care providers to acquire patients for life, which builds relevancy to the patient-provider relationship. As pay for performance value-based models scale, a patient panel balanced with emerging adults ensures long term sustainability. Participants reported a strong influence from their mothers about how they utilized primary care. Specifically, to remain and gain relevancy

with emerging adults and future generations of patients, primary care must attract and build relationships with women.

Implications for Policy

Support for practice transformation efforts should be balanced and allow for empathetic care rather than transaction-based high production models. Maryland policy reforms, including the Maryland Primary Care program, are making progress to incentivize value over volume, but only for Medicare and high-risk populations (MDPCP, 2020). Because policy reforms are striving to ultimately control costs, “high-risk” is defined as high cost or high utilization. Policy reform efforts should not segment patients by insurance coverage or utilization, as doing so forces primary care providers to provide inequitable care. Health policies, such as the Affordable Care Act, have opportunities for improvement to ensure out-of-pocket costs are minimized. The participants were progressive in their views on healthcare as a human right, as they included no cost solutions in their ideal primary care designs. Reformers of expanding healthcare benefits and other socialized healthcare concepts may use these findings to support improving access to care.

The goal of primary care is to keep people healthy. Thus, primary care will not be successful if providers are contracted to turn a blind eye to their healthy and rising risk patients. Health policy aimed to improve care should benefit all patients regardless of insurance coverage or current cost to the system. Otherwise, to remain financially viable, primary care providers are forced to provide value-based care to one group of patients backed by contractual obligations and transactional-based care to non-contractually backed patients. From a patient perspective, insurance-based programs are behind the scenes negotiation between employers, payers, and providers. Many patients are unaware of these terms and how they drive the care they receive.

The influence of insurance was present in the participants' utilization of primary care services in their ideal designs. Future research is needed to evaluate the influence of insurance in the design and operations of primary care. Another implication for practice and policy is the need to align provider compensation with value-based care. Keeping pace with how services are reimbursed is needed for provider engagement in navigating the policy reforms transitioning from volume to value.

Implications for Further Research

Emerging adults are utilizing healthcare that prevents and compromises the patient-provider relationship because when primary care models like PCMH and payor contracts segment patients by risk, emerging adults are the least risky population by traditional qualifications (i.e., insurance coverage, DX, cost). Therefore, emerging adults are provided with transactional services, giving bandwidth for primary care to scale more resource-intense services to other demographics for cost containment. Future research is needed to align provider schedule templates and contact hour obligations with the depth of relational-based services demanded by emerging adults that are not considered high risk via traditional cost-based methods.

The core product of primary care is the relationship. Emerging adults desire patient-provider relationships and attribute the value of those relationships to better quality care. Since, this expectation has not found in their experiences, they have been led to believe that such a relationship does not exist. Future research focused on the provider perspective needed for empathy capacity building practices from a people and process perspective.

Future research is needed to evaluate the concept of community and how it impacts health from the patient's perspective. Sometimes the word "community" did not resonate with the participants and sometimes it did. Regardless, the participants could not decipher what their

community had to with their health. As such, more research is needed to understand why there is such an interrelationship and why the participants could not see it. Future research is also needed to evaluate the life stages after 25 years of age in the context of aging out of insurance coverage.

Conclusion

Studies show that patients whose providers practice empathy when interacting with them have better health outcomes (Mercer et al., 2016; Rakel et al., 2011a; Rakel et al., 2011b). Emerging adults have shown a demand for a relationship-based experience and have cautioned against removal of the human touch. Following the path paved by urgent care, telemedicine has been considered as an emerging specialty (Waller et al., 2019). Additionally, aggressive health policy is under review in the state of Maryland, including the proposal to remove the patient-provider relationship requirement for asynchronous telemedicine (Maryland Senate Bill 402, 2020). These changes would allow asynchronous visits to scale in a direct to consumer model (Maryland Senate Bill 402, 2020). The impact of this study is limited in its assumption that providers connecting with patients perceive value in patient-provider relationships above transactions. Encouragingly, positions from the Maryland Board of Physicians on Senate Bill 402 align with the voice of emerging adult women (Freas, 2020).

Afterword

During the final stages of this dissertation, the world was hit with the COVID-19 virus, which was officially labeled a pandemic on March 11, 2020. Data collection, analysis, and write up of findings and discussion were all completed just a month prior. We are living in two different paradigms now, as we get used to a new normal. While the answers to the research questions, analysis of the findings, and their implications still stand as timeless knowledge for

the healthcare industry, this Afterword takes a deeper dive into those implications for future research in the context of this unprecedented time.

In a time when healthcare has no choice but to scale its services to meet rising demands, there is value in understanding the patient's perspective in prioritizing quality relationship-based care versus on-demand transactional services to meet the needs of patients in mass quantities. Since the outbreak of COVID-19, patients have flooded emergency rooms, urgent cares, and primary care offices for needs ranging from lifesaving interventions and mild symptom management to simply looking for answers for what their futures hold. In a time when people are anxious and afraid, we have seen a massive influx of calls and walk-ins to primary care facilities by individuals looking for guidance from their trusted sources of truth. Those without primary care have turned to urgent cares but are being deferred to primary care for calming nerves and long-term symptom monitoring, something that urgent care, with its general prioritization of acute symptom management and testing, is not positioned to do. Asynchronous services have also been deferring to primary care after concluding that symptoms do not warrant prescriptions or a higher level of care, such as the emergency room. Even so, the worried well and mildly symptomatic patients are presenting to emergency departments and are being turned away with advisement to follow up with their primary care doctors. Hospitals are also concerned about sending patients without primary care home because, in so doing, such patients are left to their own devices for tracking and symptom management.

All of this is falling on the backs of primary care providers who cannot keep up with their existing patient volumes, let alone taking on new patients in a time of crisis. Plus, building a relationship takes time, which is not helpful with the heightened sense of urgency for answers from a trusted source that a pandemic such as COVID-19 presents. Primary care providers are

forced to close their panels to new patients just to keep up with existing patient demand. Having an established relationship prior to the pandemic has proven to be more important than ever. Primary care has switched to video visits almost overnight to keep a physical barrier between providers and patients while at least maintaining conversations with familiar faces. This is an example of leveraging a transaction convivence that reinforces the patient-provider relationship.

Massive policy reforms were made to alleviate out-of-pocket costs related to COVID-19 services. This helps with the barrier to care of cost but does not address access. Primary care is positioned as the appropriate level of care for the masses due to the symptomatology of the virus. Future consideration needs to be given to physician hierarchical cultural norms and payment discrepancies among specialties. However, with health literacy limiting the public's ability to determine when and where to go for care, patients are learning the hard way that primary care alternatives cannot fill the void of a trusted voice of reason. Therefore, there is no solution to scale relational care in this crucial moment when people need a sense of security and confidence in the healthcare system more than ever.

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APPENDIX

Appendix A: Coding Matrix Framework

Team Based Care	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Knowing and Managing Your Patients	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Patient Centered Access and Continuity	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Care Management Support	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Care Coordination and Care Transitions	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Performance Measurement and Quality Improvement	Results	Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
	Missing						
	Conflicting						
	Dominate						
	Unknown						
Emergent Code 1		Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group
Emergent Code 2		Interview #1	Interview #2	Interview #3	Interview #4	Interview #5	Focus Group

Appendix C: Participant Invitation Letter

Dear 18-25-year-old women living in researched community,
My name is Melany Rabideau. I am a doctoral student at Hood College's Organizational Leadership program.
I am kindly requesting your participation in a doctoral research study that I am conducting titled: An exploration of the emerging adult woman's perceived value of Primary Care.
The intention is to understand what young women want from primary care and identify the items that matter most to them.
The study involves completing (1) a basic eligibility screening tool, (2) completing a 30-minute individual interview, and (3) completing a follow up 30-minute individual interview. The interviews will take place during the fall of 2019.
Participation is completely voluntary, and you may withdraw from the study at any time. A \$10 gift card will be given to you at the end of the study to thank you for your time and valuable insights.
The study will always protect your confidentiality and your name will not be released as a participant or attached to direct quotes.
If you would like to participate in the study, please complete the attached eligibility screen tool. Please send the completed screening tool AND signed consent form to mr30@hood.edu by November 30, 2019.
Your participation in the research will be of great importance to assist in improving primary care in your community.

Please contact Melany with any questions at 301-514-3777 or mr30@hood.edu.
Thank you in advance for your time and interest.

Sincerely,
Melany Rabideau

Appendix D: Eligibility Screening Tool

Are you interested in participating in research to talk about your healthcare experiences and needs?

Eligibility Criteria	✓ Check
1. You are a researched community resident	<input type="checkbox"/>
2. As an adult (once you turned 18), you have received healthcare services (seen a doctor, went to a clinic, planned parenthood, urgent care, emergency room, etc.)	<input type="checkbox"/>
3. You are 18 to 25 years of age	<input type="checkbox"/>
4. You DO NOT have children	<input type="checkbox"/>
5. You are NOT married	<input type="checkbox"/>
6. Your current gender identity is female	<input type="checkbox"/>
7. You have active health insurance coverage	<input type="checkbox"/>
8. You are interested in attending two 30 min individual interviews during the fall of 2019.	<input type="checkbox"/>

✓ If you checked YES to **all** the above, please fill out the below items to be considered for participation:

Do you see a primary care doctor as a routine source for care (urgent care, minute clinics, and the ER is not primary care)?

- ☐ No
☐ Yes

Do you consider yourself a part of a racial minority group?

- ☐ No
☐ Yes

Name:
Email:
Phone:

Please email this form AND signed consent to Melany Rabideau at mr30@hood.edu by **October 31, 2019** or drop off at the student engagement center located on campus.

Eligible participants selected for the study will be notified no later than October 12th. A \$10 gift card will be provided as a thank you for your time and insights following successful completion of the study.

If you have any questions, please do not hesitate to contact Melany at 301-514-3777

Informed Consent

Project Title	An exploration of the emerging adult woman's perceived value of Primary Care
Purpose of the Study	<p><i>This research is being conducted by Melany Rabideau at researched Community College. We are inviting you to participate in this research project because you fit the participant profile of a young woman seeking healthcare in researched community. The purpose of this research project is to understand what young women want from primary care and identify the items that matter most to them.</i></p> <p><i>Research questions asked are about the choices being made NOT about specific illnesses or diagnoses, or anything personal about your medical history/profile.</i></p>
Procedures	<i>The procedures involve two 30 minute individual interview with open ended questions</i>
Potential Risks and Discomforts	<i>There may be some risks from participating in this research study.</i>
Potential Benefits	<i>The benefits to you include an opportunity to share your valuable insights on healthcare in a supportive forum. We hope that, in the future, other people might benefit from this study through improved understanding of the young woman's on primary care in the researched community.</i>
Confidentiality	<p><i>Any potential loss of confidentiality will be minimized by storing data in a secure location such as a password protected computer.</i></p> <p><i>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the researched Community College or governmental authorities if you or someone else is in danger or if we are required to do so by law.</i></p>
Compensation	<p><i>You will receive a total of \$10 in gift cards after completion of both individual interviews. You will be responsible for any taxes assessed on the compensation.</i></p> <p><i>If you expect to earn over \$100 as a research participant in this study, you must provide your name, address and SSN to receive compensation.</i></p> <p><i>If you do not earn over \$100 only your name and address will be collected to receive compensation.</i></p>

Right to Withdraw and Questions	<p><i>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</i></p> <p><i>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</i></p> <p style="text-align: center;">Melany Rabideau</p> <p>Mr30@hood.edu 301-514-3777 2407 Barrett Court Frederick Maryland, 21702</p>
Participant Rights	<p><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i></p> <p style="text-align: center;"> Frederick Community College Dr. Gohar Farahani Chair, Institutional Review Board 7932 Opposomtown Pike Frederick, MD 21702 E-mail: gfarahani@frederick.edu Telephone: 301-846-2451 </p> <p style="text-align: center;"> Hood College Dr. Diane Graves Chair, Institutional Review Board 401 Rosemont Ave., Frederick, MD 21701 E-mail: graves@hood.edu </p> <p><i>This research has been reviewed according to Frederick Community College IRB procedures for research involving human subjects.</i></p>

Statement of Consent	<p><i>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</i></p> <p><i>If you agree to participate, please sign your name below.</i></p>	
Signature and Date	NAME OF PARTICIPANT [Please Print]	
	SIGNATURE OF PARTICIPANT	
	DATE	

Appendix E: Interview Protocol #1

I am seeking your insights and perspectives about utilization of healthcare services. I want to know more about why or why not young women use primary care or alternatives (like urgent care, telemedicine, the emergency room). My questions are about the choices being made NOT about specific illnesses or diagnoses, or anything personal about your medical history/profile. Rather, I want to understand how the medical providers can best offer care to our demographic in the future based on what we think is valuable.

Participant Tag:

1. Describe the last time you used health services. How did you know when and where to go?
2. What are some of the challenges you experience when determining when and where to go for care?
3. Thinking about when you need care urgently, are your needs being met by your community's resources and facilities? If yes, are you satisfied with your care? If no, what more would you like to see?
4. Have you ever been to an urgent care, ER, or televisit? If yes, what made you decide to go there?
5. Is it important to you to have a regular doctor you see for care? Why or why not? If not, what is more important than your relationship with your provider when deciding when and where to seek care?
6. Do you see yourself having a stronger relationship with the provider or the practice?
7. What would make you keep a relationship with a provider? What would make you stop the relationship?
8. If your provider was to change practices would you follow this provider? Why or why not?
9. How comfortable are you with understanding your health insurance benefits? What are your primary care benefits? How does your primary care copay differ from your urgent care, ER and specialty care copay?
10. How does cost impact where you went for treatment when you are sick? Can you give me an example?

Ranking exercise: Person-Centered Primary Care Measure

11. Categorize these items into two groups: items important to you in your care and items not important to you in your care.
12. Rank the items you identified as important from what you find the most important to least important
 - The practice makes it easy for me to get care.
 - This practice is able to provide most of my care.
 - In caring for me, my doctor considers all factors that affect my health.
 - My practice coordinates the care I get from multiple places.
 - This doctor or practice knows me as a person.
 - My doctor and I have been through a lot together.
 - My doctor or practice stands up for me.
 - The care I get takes into account knowledge of my family.
 - The care I get in this practice is informed by knowledge of my community.
 - Over time, this practice helps me to meet my goals.

- Over time, my practice helps me stay healthy.
- The care I get in this practice is low cost.
- The care I get in this practice is convenient.

- 13.** Why did your top three important items stand out to you?
- 14.** What did you define as not important and why?
- 15.** Would you add anything to this list that is important to you?
- 16.** Think about the healthcare you may need in the future, what would you find valuable and/or not relevant 5-10 years from now?
- 17.** Is there anything else that you would like to share related to your healthcare experiences and expectations?

Appendix F: Interview Protocol #2

I am seeking your insights and perspectives about utilization of healthcare services. I want to know more about why or why not young women use primary care or alternatives (like urgent care, telemedicine, the emergency room). My questions are about the choices being made NOT about specific illnesses or diagnoses, or anything personal about your medical history/profile. Rather, I want to understand how the medical providers can best offer care to our demographic in the future based on what we think is valuable.

1. How would you describe Primary Care? What does Primary Care mean to you?
2. Where did you learn to define primary care this way?
3. What does Primary Care in researched community look like?

Imagine you have a magic wand. Let's pretend you were able to create the ideal primary care system to help you with all your healthcare needs as you see valuable. I am going to ask you a few questions about what that would look like and how it would work. Be creative and think about what would work best for you regardless of what you may/ may not have already experienced when receiving care. Remember you should be designing something that is all about you and your expectation that would be the most valuable to your health.

NCQA PCMH Concept 1: Team Based Care

4. Describe what type of things you would want care for. What would be out of scope and why? How important are vaccines (travel)?
5. How would you describe your ideal care team? These would be the people taking care of you when you needed them.
6. How do you see yourself interacting with these team members and what is your role?

NCQA PCMH Concept 2: Knowing and Managing Your Patients

7. What does personalized care look like to you?
8. What information is important for your care team to know about you to ensure you receive the best care? How would they get this information?

NCQA PCMH Concept 3: Patient Centered Access and Continuity

9. What would be the ideal way to access the care you needed?
10. How would you describe convenient care?
11. Think about a time you may have felt alone in trying to solve a problem related to your health. What did you do and who did you go to for help? How would your ideal system support you?
12. If all your needs were met with convenience and a great experience would you want to see the same people every time you needed care? Why or why not?

NCQA PCMH Concept 4: Care Management Support

13. Do you think there are certain things maybe a doctor wouldn't traditionally help you with but you would still like help with because it impacts your health? If so, what would they be?
14. Are there any areas in your life beyond your physical health you would want your care team to assist you with?

NCQA PCMH Concept 5: Care Coordination and Care Transitions

15. Would it be helpful to have assistance coordinating and understanding tests results?

16. If you needed to see a specialist how would you start that process and how would you want help from your care team?

17. If you were in the emergency room and the hospital, what type of help and support would you need?

NCQA PCMH Concept 6: Performance Measurement and Quality Improvement

18. Would you want to give the people providing you care feedback on how good of a job they are doing? How would you like to do this?

19. How would you ensure they kept up to date on what you wanted out of your care as your expectations and ideas may change?

Closing

20. Anything else you would like to see in your new primary care system to support your needs?

21. What is one word you would use to describe this new primary care system we just designed together?

Appendix G: Participant Roster Log

Tag	Name	Email	Phone	Minority Staus	PCP Est?	Interview Date	Focus Group #	Focus Group Date
100	Melany	mr30@hood.edu	301-514-3777	No	Yes	17-Oct-19	1	1-Nov-19
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"What we grieve for is not the loss of a grand vision, but rather the loss of common things, events and gestures. Ordinarity is the most precious thing we struggle for, what the Jews of the Warsaw Ghetto fought for. Not noble causes or abstract theories. But the right to go on living with a sense of purpose and a sense of self-worth — an ordinary life."

(Irena Klepfisz on the 45th anniversary of the Warsaw Ghetto Uprising)