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University Students' Experience With Primary Care During Their High School Years and the Impact on Transition to Adult Primary Care

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UNIVERSITY STUDENTS' EXPERIENCE WITH PRIMARY CARE DURING THEIR HIGH SCHOOL YEARS AND THE IMPACT ON TRANSITION TO ADULT PRIMARY CARE

by

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ABSTRACT

Focus: PC is associated with positive health outcomes and reduced costs. Estimates of adolescents who transition from pediatric PC to adult PC is low; yet it is reported those who have positive experiences with PC are more likely to access PC as adults. Studies describing adolescents' HS experience with PC and how it affected transition to adult PC are lacking. The purpose of this study was to describe university students' experience with PC during their HS years and the impact on transition to adult PC.

Methods: This study is a descriptive, non-experimental design whereby students reported their HS PC experience and how it affected transition to adult PC once in college through an anonymous online survey. The survey included the Person-Centered Primary Care Measure and questions created by the principal investigator. Data were also collected from students without a PC in HS.

Results: 210 participants received PC in HS, 16 did not. Reasons for lack of PC included no local PC sites (31%), family did not believe in PC (18%), and no health insurance (18%). In lieu of PC, urgent care was ranked as 1st and 2nd choice (100%), emergency room care 2nd and 3rd choice (78%), and school health center 3rd choice (53%). Participants who received PC reported easy access to care (92%). Only 66% reported the primary care provider (PCP) knew them as a person, 67% felt the PCP would stand up for them, and 48% felt the PCP had knowledge of their community.

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CHAPTER I

INTRODUCTION AND LITERATURE REVIEW

Introduction

When choosing a topic for my honors thesis, I knew that I wanted to focus on factors that affect healthcare utilization or quality of healthcare. Healthcare is such a broad topic, so I decided I wanted to focus on an aspect of healthcare that I had personal experience with. As a traditional college student, I experienced the transition from high school to college recently, and experienced changes relating to how I experienced healthcare. I saw many peers confused about where to receive healthcare after making the transition to college, and I wondered if the majority of college students also shared that experience. Many students move away from "home" for the first time during freshman year of college, and this may have effect on many aspects of their lives, including how they experience and access healthcare. If students have a primary care provider, they may be physically too far from the practice to get regular care, and it can be difficult to make appointments during busy winter or summer breaks when college students are typically on break. If students need care, they need to decide whether they are going to seek this out, possibly without guidance from their parents or other adults in their lives. This may lead to emergency department or urgent care trips.

Emergency departments and urgent care centers offer almost immediate care when a health problem comes up, but they do not allow a provider to build a connection with each patient or offer opportunities for preventative care. As a nursing student, I know how important preventative care is, which is at the center of primary care. College students are in a formative

stage where forming health habits is important, so why or why not are they pursuing primary health care (PHC)?

Literature Review

Definition of Primary Healthcare

Primary healthcare (PHC) is a philosophy of healthcare established internationally in 1978 during a global conference in Kazakhstan (Rifkin, 2018). This philosophy was documented in the Alma Ata Declaration and signed by 134 "national government members of the World Health Organization (WHO)" (Bhatia & Rifkin, 2010, p.1). According to the WHO, the current international definition of PHC is a whole-of-society approach to organize and strengthen national health systems in order to bring services for health and wellbeing to communities. There are three components of primary care according to the Alma Ata Declaration: (1) integrating healthcare services to meet needs across the lifespan, (2) addressing determinants of health through policy and (3) empowering individuals, families, and communities to take ownership for their health (WHO, 2023).

History of Primary Healthcare

The impetus for primary healthcare, culminating with the Alma Ata Declaration, began in the 1920s with the "Dawson Report" first published by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF). It was implemented in the United Kingdom in 1978 establishing three levels of healthcare, the first level being primary healthcare centers (Frenk, 2009). In the 1940s, South Africa and India began to utilize the concept of PHC introduced in the Dawson Report by creating clinics that served rural populations with preventative, curative, and rehabilitative care (Frenk, 2009). In the 1960s, Chinese "barefoot doctors" established residence in communities to promote health, and focused on preventative

methods, which would soon be at the heart of PHC (Cueto, 2004). The most influential event that established the concept of PHC was the "Alma Ata Declaration" which was a global conference that emphasized the importance of PHC and set global goals that were to be met by 2000 (Catton, 2018). The mission of the Alma Ata was to encourage governments to promote healthcare at the primary level as a "health system model that acted on the social, economic, and political causes of poor health" (Catton, 2018, p. 472). Alma Ata highlighted that healthcare should focus on the overall "condition of life" rather than only treating a condition and providers should be proactive to help meet the health needs of their populations (Frenk, 2009). The purpose of PHC is to facilitate overall good health by focusing on physical, psychosocial, and political factors that impact health; what we term to date as social determinants of health (WHO, n.d.).

Benefits of Primary Healthcare

Primary healthcare has been demonstrated to decrease healthcare costs and improve health and life expectancy by decreasing infant mortality, overall morbidity, hospitalizations, and health disparities (Calma et al., 2022). Preventive measures such as immunizations provided in PHC, results in decreased personal cost for the individual, decreased overall expenditure of healthcare dollars for society, and decreased personal suffering (Van Weel, 2018). When individuals have optimal health, they are less likely to experience chronic health conditions that increase costs and personal suffering. For example, immunizations prevent infectious diseases that can cause lifelong disability. Hepatitis B, a routine vaccine administered during a PHC visit, is an example of a vaccine preventable disease. Individuals who are not immunized and contract hepatitis B can have long-term liver damage (Ellis et. al., 2022). When hepatitis B is left untreated, between 15% and 25% of adults will die from liver cirrhosis, liver failure necessitating

liver transplant, or liver cancer (CDC, n.d.). Treatment for chronic hepatitis B consists of antiviral medication therapy and can last years with a cost of $8,040 per person for a year (Mukhtar et al., 2021).

Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations (CDC, n.d.). According to Healthy People 2030, primary care is critical to improve population health and reduce health disparities by addressing barriers that may interfere with access to primary care, such as lack of transportation (Office of Disease Prevention and Health Promotion, n.d.).

PHC can also reduce the incidence of low birth weight and infant mortality. Infant mortality is the rate of infant deaths per 1,000 live births before the first birthday. It is a key indicator of the overall health of a society (CDC, n.d.). Countries that implement PHC insured under universal healthcare have reported decreased infant mortality rates. In Brazil, it has been reported that "an increase of one primary care physician per 10,000 population was associated with 7.08 fewer infant deaths per 10,000 live births" (Russo et. al., 2019, p. 7). Women who receive primary care have overall better health. Subsequently, when they make the decision to become pregnant, they have fewer complications during pregnancy, delivery, and in the postpartum period because of general overall good health prior to conception (Healthy People 2030, n.d.). Also, they are more likely to get prenatal care either from the PCP or get a timely referral for obstetrical services. Prenatal care allows for early recognition and treatment of maternal and fetal complications thus reducing maternal and infant morbidity and mortality (Lockwood & Magriples, 2022).

PHC can reduce healthcare costs and decrease hospitalizations. Research analyzing continuity of care demonstrates that increased continuity of care, meaning that the primary care provider (PCP) has ongoing responsibility for the patient, results in decreased emergency care and hospitalizations and reduced mortality (Bazemore et. al., 2018; Loren Oh et. al., 2022). In a study of individuals with dementia, people who visited a PCP at least twice a year were more likely to live in a rural setting, were younger, and used more health services throughout their lives. In this population, visiting a PCP decreased hospitalizations, 30-day hospital readmissions, and emergency department visits (Godard-Sebillotee, et. al., 2021).

PHC can foster a positive relationship between the patient and the provider. Adults in countries with universal healthcare who are established with a primary care practice, are more likely to have a longstanding relationship with their PCP (Fitzgerald et. al., 2022). Adults who have long standing relationships with PCPs have been reported to have improved health (Kamimura et. al., 2020). Countries such as Germany, Italy, Brazil, the Netherlands, and the United Kingdom with universal health care have the highest percentage of people who have been with their PCP for more than five years (Fitzgerald et. al., 2022).

In the United States, a country that does not have universal healthcare but does have PHC, positive health outcomes have been reported in individuals who do have access and utilize PHC. An increase in primary care physician density was associated with lower mortality in the United States (U.S.), and greater PCP density had a higher impact on life expectancy than specialist physician density (Russo et. al., 2019).

Factors that Influence Access and Utilization of Primary Healthcare

PHC has been associated with positive health outcomes, hence it is important to look at factors that influence access and utilization of PHC in the United States (Calma et al., 2022). With an understating of these factors, solutions can be considered. Factors that influence access and utilization of PHC can be categorized as external and internal.

External Factors. External factors that impact access and utilization of PHC are those variables that exist in society and not within the individual persona. External factors that may influence access to primary include availability of health insurance, income, geographical proximity of PHC, systemic implicit bias, and personal time constraints (Gabrani et al, 2020; Sabin, 2022). According to the WHO, universal healthcare is defined as "all people having access to the full range of quality health care services they need, when and where they need them, without financial hardship" (WHO, 2023, para 1).

In the U.S., universal healthcare is not available. This can impact access and utilization of PHC in a variety of ways. Individuals who do not have health insurance or have health insurance with high deductibles might not access PHC because the cost is prohibitive (National Academies of Sciences, Engineering and Medicine, 2018). According to the Commonwealth Fund, the U.S. ranked last place in the category "equity" among the 11 countries studied. (Fitzgerald et. al., 2022). People with below-average incomes are less likely to visit a physician when sick, to get a recommended test, treatment, or follow-up, or to purchase prescriptions when needed. Thirty-three percent of low-income adults go without care when it is needed because of costs (Fitzgerald et. al., 2022).

The Commonwealth Fund conducted a study in 2020 comparing the U.S. to other major industrialized nations (i.e., Australia, Canada, France, Germany, the Netherlands, Norway, Sweden, United Kingdom) in terms of various components of PHC (Fitzgerald et. al., 2022). Overall, the U.S. ranked last for access, care coordination, safety, administrative barriers, avoidable emergency room use, and duplicative medical testing (Fitzgerald et. al., 2022). Many Americans said that they were most likely to have access problems due to cost. The Affordable Care Act, enacted in the U.S. in 2010, has improved access to PHC and lowered the number of uninsured people to an all-time low, especially reducing disparities among low-income people and people of color (Blumenthal et. al., 2020).

Geographic proximity to PHC providers can impact access and utilization of PHC. If PHC providers are not available locally patients are less likely to be able to access PHC. Additionally, geographic accessibility to PHC is associated with avoidable hospitalization and decreases preventable deaths (Daly et. al., 2018; Gunta et. al., 2022). According to a fact and statistic sheet published by the Agency for Healthcare Research and Quality, 72% of nurse practitioners (NPs), 75% of physician's assistants (PAs), 77% of family physicians, and 91% of general pediatrics providers practice in urban settings (AHRQ, 2012). This leaves less than 10% of general pediatric providers in remote rural or frontier areas, creating a large disparity between people who live in rural versus urban settings.

In the U.S., PCPs consistently have lower pay than providers in different areas of healthcare, and they also have lower job satisfaction, reducing the numbers of providers particularly in rural areas (Jin et. al., 2019). Many individuals in rural areas struggled with transportation. Time constraints are another reason that people avoid healthcare (Taber et. al., 2015). Many people report they are too busy to go to the doctor, for example, unable to take time

off from work or to get childcare, while others fear medical treatments, medical professionals, or are afraid that they are going to have an embarrassing, body-shaming experience (Boykin, 2022).

Logistics of scheduling an appointment is another factor that was found to influence access and utilization of PHC. Making appointments proved to be too difficult to some, and this made them avoid making an appointment with a PCP. Some reasons for difficulty making appointments include long wait times, unable to make appointments at the time of a problem, the office being too busy, and "general hassle," as well as not wanting to be around sick people at the office (Taber et. al., 2015).

Race is another factor that influences American's relationships with primary care. African Americans are less likely to use a PCP as their usual source of care. Data collected shows that medical distrust between providers and African Americans is the reason that many African Americans wait until they are so ill that they need to visit the emergency department instead of seeking care earlier with a PCP (Arnett et. al., 2016). According to a study published in 2022, overall cancer screenings such as mammograms, pap smears, and colorectal screenings are lower among Black, Hispanic, Asian, and American Indian & Alaska Native populations (Tong et. al., 2022). Black women when compared to white women with breast cancer believe that their concerns were dismissed by a provider due to their race (Anderson et. al, 2021).

Gender is another factor affecting PHC usage and quality of care. Women are more likely to report that their concerns are dismissed by PCPs (21%) than men (10%); however, they are still more likely than men to go for an annual checkup. Seventy-three percent of women surveyed had a visit with a PCP, or a "check-up," within the past 2 years. In another survey, only 50% of men said that getting an annual check-up was important to them (Buggey, 2019).

Discrimination against LGBTQ+ individuals also affects utilization of PHC. Fourteen percent of LGBTQ individuals who experienced discrimination in 2017 avoided medical care because of the negative experiences they have had with a provider (Mirza & Rooney, 2018). Nineteen percent of transgender people specifically avoided visiting a provider because of discrimination (Mirza & Rooney, 2018). According to current literature, pediatricians have limited knowledge about LGBTQ+ issues, and they do not address sexual orientation or gender identity during visits (Stern, 2021). However, asking these questions is important, particularly for pediatric providers, because they often follow their patients from birth through adolescence, and have opportunities to build trust with their patients, which is important when discussing issues such as LGBTQ+ care (Stern, 2021).

Internal Factors. Internal factors are those variables that exist within the individual persona, characteristics that shape identity (e.g., age, gender), specific health conditions, personal experiences, and beliefs and values. In a study by Taber et al. (2015), many individuals believed they did not have a need for PHC as their problems would resolve on their own. Others reported only seeking PHC if they were ill and did not see the value in routine visits. Some individuals relied on spiritual healing, natural remedies, or attempted to self-cure with over-the-counter medications (Taber et. al., 2015).

Some individuals were scared and avoided visiting a provider because of fear of receiving bad news or a worsening condition. Many people did not want to hear that they needed to make lifestyle changes, for example, weight loss, smoking, or diet advice (Taber et. al, 2015). Those who claimed that they are going to be ridiculed for being overweight, smoking, using drugs, or using alcohol used this as a reason to avoid primary care (Chan Carusone et. al., 2019).

Children with chronic illnesses such as cystic fibrosis are also more likely to access and utilize PHC; however, for these children transition to adult primary care is more difficult. Many adult PHC providers feel ill-equipped to care for young adults with childhood conditions as they transition into adulthood (McLaughlin et al., 2014; Schraeder et al., 2022).

However, overall healthy children have higher utilization of PHC than adults. Childhood immunizations often required for public school entry are an impetus for parents to seek PHC for their children. Parents often place the needs of their children before their own and seek PHC to help maintain the child's health, as they have a parental duty to provide medical care in order to protect their child from serious harm (Scott et. al., 2018). According to the CDC, in 2021, 89% of children under 18 years old had a well-child checkup and 97.3% of children under 18 had a usual place of care (CDC, n.d.).

Past personal experiences with healthcare can impact utilization of PHC as it influences an individual's belief system. Many individuals reported they did not like the way that physicians communicated with them, and they did not like the manner that physicians provided advice. A smaller percentage of people explained that they do not trust providers. They felt that they were made to "feel stupid," that providers were impersonal, did not believe that they truly care, and reported a general mistrust towards providers. A frequent complaint about the quality of healthcare included not having confidence in their physician's expertise (Taber et. al., 2015).

In PHC, trust between providers and patients is essential so that patients embrace recommended health promotion behaviors (Sadeghi Bazargani et. al., 2020). For example, evidence supports that vaccines prevent disease, reducing morbidity and mortality (CDC, n.d.). According to a study published in 2022, higher levels of trust between patients and providers was

correlated with a more positive attitude towards vaccination, as well as higher vaccination levels against H1N1 influenza (Borah & Hwang, 2022).

Personal experiences can also positively impact utilization of primary health care. The Person-Centered Primary Care Measure (PCPCM) is an 11-item, patient-reported measure that is used to assess an individual's experience with their PCP. Capturing the individual's experience with PHC experience can be used to improve the quality of PHC, population health, equity, and sustainable healthcare expenditures. The PCPCM is a survey, allowing patients to rank different aspects of their care. These 11 items address accessibility, comprehensiveness, integration, coordination, relationship, advocacy, family and community context, goal-oriented care, and disease, illness, and prevention management (The Larry A. Green Center, n.d.).

Transition of Care from Pediatric to Adult Primary Healthcare

In the natural process of human growth and development children progress through developmental stages concluding with the period of adolescence. Adolescence marks the last developmental stage before transitioning to young adulthood. This developmental period is a time when an individual is transitioning to independence and will be assuming responsibility for their own health and healthcare. Adolescents' experience with PHC may be one factor that influences whether an adolescent when transitioning to young adulthood accesses and utilizes PHC (Tagher & Knapp, 2020).

Transition from pediatric primary care to adult primary care has been associated with improved health outcomes which includes decreased emergency room visits and hospitalizations (Bring et al., 2018, Guzman et al., 2021). It has been reported that adolescent patients who have positive experiences with PHC are more likely to access PHC as adults (Toomey, 2016). Yet

the literature tells us that young adults are less likely to have a PCP and to utilize primary healthcare services. A precise account of the number of adolescents who transition to adult PHC is difficult to establish as this population is frequently lost to care during this time of transition. However, it has been reported that young adults account for 43% of emergency room visits suggesting that primary care has not been established (Graves et al., 2019).

There have been some studies of factors that contribute to positive PHC experiences for healthy adolescents but how these experiences impact transition to adult primary care is lacking. Factors reported to impact the adolescent primary care experience include maintaining confidentiality, welcoming office staff, wait-time, patient-centered care, health insurance coverage, and availability of PCPs (Anderson et al., 2007; Christensen et al., 2016; Healthy People 2030, 2020; Nordin et. al., 2010; Ye et al., 2016). However, this does not describe the experience of adolescents with their PCP or PHC and how the experience affected the choice of PHC in young adulthood. Much of the literature on factors that influence adolescents' transition from pediatric primary care to adult primary care is focused on adolescents with chronic diseases (Schraeder et al., 2022). The purpose of this study is to describe university students who do not have a chronic illnesses experience with primary care during their high school years and the impact on transition to adult primary care.

CHAPTER II

METHODS

Study Design

This study is a descriptive, non-experimental design (Creswell & Creswell, 2018). An online anonymous survey was administered through Qualtrics ® intended to allow healthy university students to report their experience with PHC during their high school years and how the experience with PHC affected their choice of PHC once enrolled in a university. Faculty who teach General Education and major specific entry level courses (38) were asked to share a link for a survey on Qualtrics® in a notification to the class on Brightspace®. They were asked to do the first posting the second week of classes and to post a reminder notification during the fourth week of classes. A notification script was provided to faculty who agreed to make students aware of and share the link to study (Appendix C).

The survey included questions from the Person-Centered Primary Care Measure (PCPCM) and questions created by the principal investigator to determine how participants' high school experiences affected the choice of PHC in young adulthood (Appendix A). Participants were also able to comment on any of the 11 PCPCM questions. Questions regarding demographics were included in the survey but were optional.

After students consented to participate in the study they were asked if they had a PCP when they were in high school. The full panel of survey questions were provided for those participants who responded in the affirmative. Students who agreed to participate in the study but responded that they did not have a PCP in high school, were not allowed access to the rest of the survey. This cohort however, was provided with three additional questions: (1) What were the

reasons that you did not have PCP? (2) If you needed a complete physical such as a sports physical, where did you go for care? (3) If you were sick, where would you go for care?

Instrument

Data were collected using a survey that contained questions from the Person-Centered Primary Care Measure (PCPCM). The PCPCM assesses persons' perceptions of 11 domains associated with person-centered primary care: accessibility, advocacy, community context, comprehensiveness, continuity, coordination, family context, goal-oriented care, health promotion, integration, and relationship (Appendix B; Etz et al., 2019). "Cronbach α reliability statistics >0.8 and Rasch item reliability statistics >0.9 represent excellent internal consistency reliability for both" (Etz et al., 2019, p. 223-224). The PCPCM is available in the public domain and does not require special permission for use.

Sampling

Convenience sampling was used for the study. A convenience sample is a group of subjects selected based on being accessible and expedient (McMillan & Schumacher, 2010, p. 137). Eligible participants were young adults 18 years or older enrolled in general education or major specific entry level courses who attend the University of Maine. Students enrolled in the General Education and/or 38 major specific entry level courses received a link to the survey in the Brightspace®.

Ethical Conduct of Research

To protect the rights of human subjects, the study was approved by the University of Maine Institutional Review Board (IRB). The consent form was the first document in Qualtrics® (Appendix D). By initiating the survey, participants were attesting to be 18 years of age or older

and consenting to the study. Qualtrics® uses Transport Layer Security encryption for all transmitted data. The data from this survey is stored in the Qualtrics® database which is a secure electronic platform. It was downloaded by the principal investigator on a personal laptop with a secure password.

Data Analysis

Data generated from the survey were analyzed using IBM Statistical Package for the Social Sciences (SPSS®) 29.0. Although not a qualitative study, comments were organized into themes to enrich the quantitative data. The principal investigator and the faculty advisor for the principal investigator who is an expert in PHC categorized the comments into themes.

CHAPTER III

RESULTS

Sample

6780 students enrolled in the General Education and/or major specific entry level courses received a link to the survey in the Brightspace® notification; however, some students may have been in multiple classes hence, they may have received the link to the survey more than once. 336 (5%) students agreed to participate in the survey. Of those who agreed to participate 237 (3%) fully completed the survey. Of the 237 who completed the survey, 27 had a chronic illness hence their data sets were not included in the analysis. The final number of completed surveys for data analysis was 210 (3%).

There were 16 participants who did not have a PCP in high school. All 16 participants completed the three additional questions in lieu of the PCPCM.

Demographics

Participants were asked to report demographic data; however, this was optional. Of the 210 participants, 209 (99%) reported their gender; 132 (63%) were female, 66 (32%) were male, and 11 (5%) were classified as other. The gender category of "other" was created after data collection as participants in this group were dispersed among transgender women, transgender men, nonbinary, genderqueer, or genderfluid individuals. Of the 210 participants, 197 (94%) reported their race; 185 (94%) were white and 12 (6%) were non-white. Of the 210 participants, 184 (88%) reported their age; 175 (95%) were between the ages of 18 and 21 and 9 (5%) were

between the ages of 22 and 26. Demographics were not collected on the 16 participants who did not have a PCP high school.

Survey Responses

There were 210 completed surveys by participants who had a PCP in high school. There were 16 participants who did not have a PCP in high school and completed the three additional questions in lieu of the PCPCM. Of the 16 participants who did not have a PCP in high school, 5 (31%) reported that there were no local PHC sites, 3 (18%) reported that their family did not believe in PHC, and 3 (18%) reported they had no health insurance; 5 checked the category of other but provided no explanation of why they did not have a PCP in high school. In lieu of PHC, urgent care was ranked as 1st and 2nd choice (100%), emergency room care 2nd and 3rd choice (78%), and school health center 3rd choice (53%).

Of the 210 participants who received PHC, 193 (92%) reported easy access to care. A total of 33% (70) of participants responded "somewhat" and "not at all" to the item, "The primary care provider that I saw knew me as a person." A total of 32% (67) responded "somewhat" and "not at all" to the item, "My primary care provider would stand up for me." Fifty-two percent (109) of participants responded "somewhat" and "not at all" to the item, "The care I received in my primary care practice was informed by knowledge of my community." Seventy-nine percent (166) of participants responded "definitely" and "mostly" to the item, "Over time, my primary health care practice helped me to stay healthy." Responses to all 11 questions on the PCPCM are specified in Appendix E.

For all items on the survey, there was no statistically significant difference between groups based on age, gender, or race except for gender for the item indicating that participants

felt the PCP "would stand up for them." For this item, participants who identified as "other" reported "somewhat and not at all" more frequently when compared to those participants who identified as male or female with a statistically significant p value of 0.02199 using the Pearson Chi-square test.

Themes from Comments

Although this is not a qualitative study, analysis of participants' comments enriches the data. Participants had the opportunity to comment on any of the 11 items from the PCPCM and for two additional questions: (1) Please describe how your experience with primary care when you were in high school affected your choice of primary care now that you are in college and (2) Please write other comments about your experiences with healthcare below.

There were 254 comments dispersed throughout the 11 items from the PCPCM. Participants often commented in each of the 11 items on topics that were not specific to the item, hence analysis of the comments was performed in totality. The comments enrich the understanding of participants' experience with PHC but do not represent the exact number of participants who commented as a participant may have commented multiple times. For the two additional questions that were not a part of the PCPCM, there were 126 comments for question one and 40 comments for question two. The total number of comments for analysis was 420.

Themes that emerged from analysis of the comments focused primarily on access to care, the provider-patient relationship, health promotion, healthcare costs, and transition of PHC from high school to college. Although 92% of those surveyed reported easy access to PHC, the comments shed light on potential barriers for those who did not experience easy access to PHC. Twenty-one comments mentioned long wait times for appointments, high provider turnover, and

long distances to PHC sites as barriers to access to care. Fifty-two percent (109) of participants responded "somewhat" and "not at all" to the item, "The care I received in my primary care practice was informed by knowledge of my community." Although this item is not related to access to care, it does raise the question as to whether the PCP was invested in the community. Community disengagement could potentially result in high provider turnover. When providers do not perceive themselves as part of the community, they may be less committed to remaining in that community. Comments for this item only confirmed the quantitative response and did not provide further explanation.

Of those surveyed, 33% responded "somewhat" and "not at all" to the item, "The primary care provider that I saw knew me as a person" and 32% responded "somewhat" and "not at all" to the item, "My primary care provider would stand up for me." This may reflect the provider-patient relationship. Twenty-one participants specifically commented that their PCP was supportive and advocated for their healthcare needs. Out of those 21, ten specifically commented on receiving support for mental health issues. For example, one participant noted "going through a dark time" and the PCP was supportive and helped secure counseling. In contrast, 15 participants recounted negative experiences with their PCP. These comments reflected feeling rushed (e.g., "just wanted to get you out of there as soon as possible"), that concerns were dismissed (e.g., "didn't seem to believe me" and "more attentive to my mother's concerns"), and lack of trust (e.g., "I never told her I was LGBT"). Seventy-nine percent (166) of participants responded "definitely" and "mostly" to the item, "Over time, my primary health care practice helped me to stay healthy" and five participants gave the specific example of vaccination as a primary health promotion intervention.

Participants' experience with transition of PHC from high school to college was reflected both quantitatively and qualitatively. Eighty-four percent (176) of participants reported that they still have a PCP in college. Of those who reported still having a PCP in college, 87% (153) still had the same PCP from high school. Sixteen percent (34) of participants reported no longer having a PCP in college. These 34 participants ranked Walk-in-Care as the number one source of care and the health clinic on campus as the second choice.

For the question allowing participants the opportunity to describe how their experience with PHC in high school affected their choice of PHC once in college, 126 responded (126/210; 60%). Seventy percent (56) reported having the same PCP as when in high school. Dissatisfaction was a prominent theme expressed in the opportunity to write comments about the healthcare experience. Fifty percent (20) of the 40 comments for this question addressed misdiagnosis/treatment, lack of trust, and cost of healthcare in the U.S. This is documented in Appendix F along with all the comments regarding the cost of healthcare in the U.S., as these were profound.

CHAPTER IV

IMPICATIONS FOR PARCTICE, POLICY, AND RESEARCH

Implications for Practice

Long wait times for appointments, high provider turnover, and long distances to PHC sites are barriers to access to care cited in the literature (Ansell et al., 2017). Long wait times and high provider turnover can impact the provider-patient relationship. The amount of time PCPs are provided for each patient encounter can impact both patient and provider experience. The patient may perceive the provider is simply interested in getting the patient "out of there as soon as possible" yet, the provider may be pressured by inadequate time allocated for each patient visit. Consequently, this can result in providers leaving the practice from burnout translating into high provider turnover. According to a study done in 2017, the average length of a primary care exam is 18 minutes (Neprash et. al., 2021). Another study analyzed visits, and how many minutes were spent. The average well-visit with a physician was 15 minutes in this study. The median patient talk-time was 5.3 minutes, and the physician talked for a median of 5.2 minutes. The time when both were silent was 1 minute. These visits covered an average of 6.5 topics, leaving very little time for each topic (Tai-Seale et. al., 2007). The amount of time per visit is dependent on the number of patients providers are scheduled to see in one day. In one study, it was reported that providers who work in a private practice must average 25 patients in an 8-hour period and those in a hospital-affiliated practice must average 15 patients in an 8-hour period to cover office expenses. The number of patient visits, complexity of each visit, and accurate documentation by the provider of visit complexity and clinical decision making determine the amount of reimbursement by the insurance company (American Academy of Professional

Coders, 2023). The higher the remuneration the more likely that cost of operations will be covered, which includes overhead, salaries, and benefits (Schimpff, 2014).

Potential solutions to ensure a longer appointment with a provider is for patients to call the office to schedule an appointment as early as possible. Practices allocate a variety of appointment lengths during an 8-hour period such that there is a limited number of longer appointment times. Shorter appointments can be made using "open access scheduling," closer to or on the date of the needed appointment, in order to maximize appointment slots for more urgent issues instead of patients having to go to walk-in-care centers or emergency departments (Ansell et. al., 2017).

Panel size is another issue in primary care. Panel size is the number of patients that are under the care of one provider. While reducing panel size may be difficult, there are some solutions that may optimize the amount of time that providers have for patient care. One solution to increase the amount of time a provider has with a patient is to create provider teams who co-manage a panel of patients (Margoulius et. al., 2018). This facilitates timelier care and increased face-to face time for each patient. Also, a multidisciplinary team which may include nurses who take calls, may reduce the need for in-person visits when they are not needed, allowing more time for patients who need face-to-face time with their providers (Margoulius et. al., 2018).

Provider-patient relationships may also be impacted by lack of trust and an unwelcoming office environment. These can be considered separately but may also be intertwined. For example, did the participant who reported "I never told her I was LGBT" lack trust in the provider because the environment was unwelcoming? Creating a safe environment for LGBTQ+ individuals involves several different accommodations. Some visual cues include displaying brochures about LGBTQ+ health concerns, posting a non-discrimination statement, and

displaying posters or flags from LGBTQ+ organizations (American Medical Association, n.d.). It is key for providers who are caring for adolescents and young adults to be open and accepting of the LGBTQ+ population. If providers are accepting, they will share their identity with their provider, allowing them to identify risks that specifically affect their population, as well as needs they may have. Better patient outcomes are achieved when caring for this community if providers are aware of different gender identities and sexualities, and what risks or needs patients who identify as a certain gender or sexuality may have (Bass & Nagy, 2022). It is important to use gender-neutral language, for example asking if the patient is dating *anyone* rather than asking if they have a *boyfriend*.

Participants noted difficulty finding a new PCP once enrolled in a university. Some participants stayed with their childhood provider, and some remained without a provider, seeking care at urgent care centers and emergency rooms. Facilitating the transition from a patient's childhood PCP to a new PCP as a young adult may be helpful to increasing satisfaction in the sampled age group. Though the population in this study was considered generally healthy, primary care is key for adolescents as they learn to form healthy or unhealthy habits. Adolescents and young adults are among the least likely to access preventative healthcare and have the lowest rate of primary care of any age group in the U.S. (Adelman et. al., 2016). They are also at risk for sexually transmitted infections, and therefore are at risk for premature morbidity and mortality if they do not understand the importance of healthcare (Awang et. al., 2019). When PCPs assist with transition of care early on, adolescents and young adults may have improved uptake of adult-oriented services, increased knowledge and education regarding conditions and care, as well as continuous care during transition (Schraeder, 2022).

Implications for Policy

Many participants reported that lack of health insurance was affecting their access to primary care. In America, universal healthcare does not exist. This may be a possible solution to the problem of lack of access, but it is not the only option. While programs like Medicare and Medicaid exist, they are only for certain populations. In other countries, like Japan, all residents are required to enroll in the universal health insurance system, which is supported by payroll taxes and self-employed individuals who pay premiums (Ruggles et. al., 2019). Ambulatory services are included in Japan's healthcare system. In the U.S., different insurance programs are available based on state and employer, making it so that not everybody is eligible for the best programs. Also, ambulatory care is very expensive in the U.S. Implementing a healthcare program like Japan's may ensure that ambulatory care is always provided when needed, as well as preventative care, which would decrease the need for ambulatory care.

The Affordable Care Act allows Americans who do not have employer-sponsored insurance to access healthcare coverage at a sliding-scale rate based on their income and family size. It is important for insurance companies to provide greater transparency in terms of their plans so that people can have an optimal choice of providers and have greater options (Doonan & Katz, 2015).

Implications for Research

Additional research might include focus groups to understand the PHC experience more fully, especially among individuals who had negative experiences with healthcare in order to better clarify problems and create solutions. Additionally, this is a sample of university students. Creating and completing a similar survey among non-university experience, for example, young

adults who work full-time or attend trade or vocational schools, would provide a more complete idea of PHC experience transition from adolescence to young adulthood. Replicating this study among a group of 26–28-year-olds may provide data including more information about young adults experiences with HC insurance, since once a person turns 26, they are no longer eligible to be covered by their parent's healthcare insurance plan. Identifying job specific insurance options and whether PHC is included within that option may provide additional insight. This could tell us more about the difficulty of accessing healthcare based on insurance status and financial status.

The University of Maine is a predominantly white university. As mentioned earlier, racial minorities are less likely to receive several preventative services and are more likely to feel dismissed by a provider. Studying other universities would allow for a more diverse sample, particularly looking at historically black colleges and universities (HBCUs), tribal colleges, and colleges in more urban settings. This more diverse sample would provide a more complete picture of what high school to college PHC transition looks like, and barriers that certain groups may be more likely to face.

CHAPTER V

LIMITATIONS, SUMMARY, AND CONCLUSION

Limitations

Limitations included a convenience sample, small sample size, and a lack of diversity of participants. A convenience sample is an accessible population but not necessarily a representative population of all young adults. Young adults may include those who are in postsecondary programs other than the university setting, working, or unemployed. The study was sent out to the target population, but the response rate was low: 210 out of approximately 6780, which equates to about 3%. Also, due to lack of population diversity, racial and ethnic minorities' experiences with primary care were unable to be compared to those of the white, non-Hispanic population, the latter of which made up the majority of the respondents. Diversity of gender was also not represented.

Summary

What are high school students' experiences with PHC, and how does this translate into their PHC experience during university? PHC is linked to positive health outcomes, therefore, it is key while adolescents and young adults are forming health habits that may impact quality of life throughout their lifespan. During this transition period, adolescents are gaining independence and their parents or guardians may be taking a step back and allowing the student to manage their own health in a new way. The data collected via the Qualtrics® anonymous survey provided a snapshot of a population of university students' experiences with PHC during high school and included topics such as their relationship with their provider, their perception of their health, and their ability to receive needed care. Participants were asked about where they

received their care now that they are in college, and how difficult or easy this experience was. The results from this survey revealed that participants believed their provider may not stand up for them due to the provider's relationship with a parent. LGBTQ+ individuals felt that their provider would not stand up for them due to their gender identities. Many participants also stated dissatisfaction with the healthcare system in the U.S., and how expensive receiving care can be. Some of those concerned about the price of care or insurance have been unable to get a PCP now that they are in college. Some students reported lack of information about transitioning to a new PCP, as well as feeling satisfied with their current provider, causing them to stay with their current high school PCP. In order to increase utilization in this population, making the transition from adolescent to adult PHC easier by HCPs providing adolescents with guidance, which may ensure that individuals continue to receive PHC throughout their adult life, reducing disparities. It will be important for providers to make their practices welcoming to LGBTQ+ individuals so that they feel safe enough to receive care. Implications from this research also involve continuing to make U.S. healthcare more affordable, as numerous participants were concerned about affording healthcare due to their insurance status.

Conclusion

My honors thesis was a project that took place over one and a half years. It followed me through half of my college experience! The honors thesis allowed me to grow in many ways. I wrote a complete literature review, learning how to find articles that are reliable and that apply to a certain topic, as well as how to embed them in a cohesive review. I learned how to submit and amend a proposal with the IRB, which taught me all the elements that go into conducting ethical research. I conducted research for the first time, and also put together a survey, learning how to find a reliable tool to ask questions with and amending it to allow for comments. Learning how

to target a specific audience was an important part of this project, because I had to find out how to get this survey out to as many relevant possible participants as possible. For example, I reached out to professors of one course for every major that first-year students take at this university during the second week of school, a time when students are generally checking their emails frequently. After the survey was completed, I worked with a statistician and learned about terms like “reliability” and “statistically significant”, and how they were relevant to my research. I learned how to interpret evidence, make conclusions, and come up with ideas about how to solve problems presented during the research process. Overall, this process took commitment, communication, and collaboration, and I am proud of the outcomes it has had.

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APPENDICES

APPENDIX A

Survey

Survey: University Students' Experience with Primary Care during their High School Years and the Impact on Transition to Adult Primary Care

What is a primary care provider?

A primary care provider (PCP) may be a family doctor, a pediatrician, nurse practitioner, or physician's assistant. Your PCP is someone you would visit for a "check-up" or if you had non-emergent symptoms or issues that you needed to get checked out.

I had a primary care provider that I visited during high school.

Yes No

If No:

What were the reasons that you did not have a primary care provider? (Select all that apply)

• There were no primary care providers close to where I lived.

• My family did not believe in primary care.

• I did not have health insurance.

• Other (explain)

If you needed to go for care for a complete physical exam such as for a sport physical, where did you go?

• A Walk-In-Care or Urgent Care

• The school nurse

• Other (describe):

If you were sick, where did you go for care?

• A Walk-In-Care or Urgent Care

• The emergency room

• The school nurse

• Other (describe):

If Yes:

Do you have a chronic health condition such as heart disease, cystic fibrosis, or kidney disease

that required you to go to a medical specialist?

If Yes:

Demographics questions but no other questions

If no:

PCPCM with comment box (see Appendix B)

Now that you are in college, do you have a primary care provider?

Yes No

If Yes: (check one of the following)

I still go to my primary care provider back home.

I have a new primary care provider.

If No:

If you need to go for care for a complete physical exam such as for a sport physical, where do you go?

• A Walk-In-Care or Urgent Care

• The school nurse

• Other (describe):

If you are sick, where did you go for care?

• A Walk-In-Care or Urgent Care

• The emergency room

• The school nurse

• Other (describe):

Please describe how your experience with primary care when you were in high school affected your choice of primary care now that you are in college?

Other comments:

Demographics

What is your age?

What is your current gender identity? (Check all that apply.)

• Male

• Female

• Transgender female / trans woman (or Male-to-Female (MTF) transgender, transsexual, or on the trans female spectrum)

• Transgender male / trans man (or Female-to-Male (FTM) transgender, transsexual, or on the trans male spectrum)

• Non-binary, genderqueer, or genderfluid

• Gender identity not listed:

• Prefer not to reply

What is your sex assigned at birth?

• Male

• Female

• Intersex

• Not Listed:

• Prefer not to reply

What is your sexual orientation?

• Heterosexual/Straight

• Gay/lesbian

• Bisexual

• Pansexual

• Not listed:

• Prefer not to reply

Race Demographic

• American Indian or Alaskan Native

• Asian

• Black or African American

• Native Hawaiian or Other Pacific Islander

• White

• Some other race, ethnicity, or origin

• Prefer not to reply

Ethnicity Demographic

Are you of Hispanic, Latino/a/x, or of Spanish origin? (one or more categories may be selected)

• No, not of Hispanic, Latino/a/x, or Spanish origin

• Yes, Mexican, Mexican American, Chicano/a/x

• Yes, Puerto Rican

• Yes, Cuban

• Yes, Another Hispanic, Latino/a/x or Spanish origin

• Prefer not to reply

APPENDIX B

Person-Centered Primary Care Measure

How would you assess your primary care experience when you were in high school?	
The practice I went to made it easy for me to get care.	Definitely Mostly Somewhat Not at all Comment box
The practice I went to was able to provide most of my care.	Definitely Mostly Somewhat Not at all Comment box
In caring for me, my primary care provider considered all factors that affected my health.	Definitely Mostly Somewhat Not at all Comment box
The practice I went to coordinated my care from multiple places.	Definitely Mostly Somewhat Not at all Comment box
The primary care provider that I saw knew me as a person.	Definitely Mostly Somewhat Not at all Comment box
My primary care provider and I had been through a lot together.	Definitely Mostly Somewhat Not at all Comment box
My primary care provider would stand up for me.	Definitely Mostly Somewhat Not at all Comment box
The care I received took into account knowledge of my family.	Definitely Mostly Somewhat Not at all Comment box
The care I received in my primary care practice was informed by knowledge of my community.	Definitely Mostly Somewhat Not at all Comment box
Over time, my primary care practice helped me to stay healthy.	Definitely Mostly Somewhat Not at all Comment box
Over time, my primary care practice helped me to meet my goals.	Definitely Mostly Somewhat Not at all Comment box

APPENDIX C

Script for Brightspace® Notification

Initial notification:

You are invited to participate in a research study to learn about college students' experience with primary care during their high school years. The research is being conducted by Grace Finley Undergraduate Nursing Student and Dr. Mary Tedesco-Schneck Associate Professor in the School of Nursing. You must be at least 18 years old to participate.

• Studies have shown primary care is important to promote health.

• You are being asked to submit an online survey to help learn about the experience of healthy young adults with primary care.

• The survey will take approximately 15 minutes to submit.

• The study is anonymous.

• Your decision to participate in this study is completely voluntary. If you decide to not participate in this study, it will not affect your grade in this course.

• For more information about the study please click the link to access the Consent Form and the Survey LINK HERE.

A reminder notification will be sent in 2 weeks.

If you have any questions, please feel free to contact me at grace.finley@maine.edu.

Reminder notification:

This is a reminder of the invitation to participate in a research study to learn about college students' experience with primary care during their high school years. The research is being conducted by Grace Finley Undergraduate Nursing Student and Dr. Mary Tedesco-Schneck Associate Professor in the School of Nursing. You must be at least 18 years old to participate.

• Studies have shown primary care is important to promote health.

• You are being asked to submit an online survey to help learn about the experience of healthy young adults with primary care.

• The survey will take approximately 15 minutes to submit.

• The study is anonymous.

• Your decision to participate in this study is completely voluntary. If you decide to not participate in this study, it will not affect your grade in this course.

• Here is the link to the survey: LINK HERE.

If you have any questions, please feel free to contact me at grace.finley@maine.edu.

APPENDIX D

Consent Form

Informed Consent University Students' Experience with Primary Care during their High School Years and the Impact on Transition to Adult Primary Care

You are invited to participate in a research project conducted by Grace Finley, an undergraduate student, and advised by Mary Tedesco-Schneck in the Department of Nursing at the University of Maine. The purpose of this research is to learn about University students' experiences with primary health care during their high school years and how the experience with primary care affected the choice of primary care once in college. You must be at least 18 years old to participate. By completing this survey, you are consenting to participating in the study and that you are 18 years of age or older.

What Will You Be Asked to Do?

If you decide to participate, you will be asked to take an anonymous survey. It should take you approximately 15 minutes.

Risks

Except for your time and inconvenience, there are no risks to you from participating in this study.

Benefits

While this study will not have a direct impact or benefit to you, your response will help us learn more about adolescents' experiences with healthcare, and which aspects of primary health care are appealing or deterring to adolescents. This will allow us to figure out how to make primary healthcare accommodating to adolescents.

Confidentiality

This study is anonymous, do not include your name on the survey. The data is anonymous and there will be no records that link you to the data you provide. Qualtrics data is protected on a password-protected computer.

Voluntary

Participation is voluntary. You may skip any questions you do not wish to answer. You may stop this study at any time if you decide not to take part in it.

Contact Information

If you have any questions about this study, please contact me at grace.finley@maine.edu. You may also reach the faculty advisor on this study at mary.tedescoschneck@maine.edu. If you have any questions about your rights as a research participant, please contact the Office of Research Compliance, University of Maine, 207-581-2657, or email umric@maine.edu.

APPENDIX E

Response to the PCPCM

N = 210

How would you assess your primary care experience when you were in high school?	Definitely & Mostly	Somewhat	Not at all
The practice I went to made it easy for me to get care.	193 (92%)	16 (7%)	1 (1%)
The practice I went to was able to provide most of my care.	193 (92%)	16 (7%)	1 (1%)
In caring for me, my primary care provider considered all factors that affected my health.	181 (86%)	25 (12%)	4 (2%)
The practice I went to coordinated my care from multiple places.	143 (68%)	44 (21%)	23 (11%)
The primary care provider that I saw knew me as a person.	140 (67%)	48 (23%)	22 (10%)
My primary care provider and I had been through a lot together.	64 (30%)	63 (30%)	83 (40%)
My primary care provider would stand up for me.	148 (68%)	52 (25%)	15 (7%)
The care I received took into account knowledge of my family.	159 (76%)	40 (19%)	11 (5%)
The care I received in my primary care practice was informed by knowledge of my community.	101 (48%)	67 (32%)	42 (20%)
Over time, my primary care practice helped me to stay healthy.	166 (79%)	35 (17%)	9 (4%)
Over time, my primary care practice helped me to meet my goals.	116 (55%)	64 (31%)	30 (14%)

APPENDIX F

Response to Impact of PHC Experience in High School on Present Choice of PHC

	I have the same PCP that I had in high school.	I have a new PCP now that I am in college.	I do not have a PCP now that I am in college.	I would like to have a PCP, but I can't find one.	I would like to have a PCP, but I don't have insurance.
Please describe how your experience with primary care when you were in high school affected your choice of primary care now that you are in college.	56/80 70%	7/80 9%	7/80 9%	8/80 10%	2/80 2%

	Misdiagnosed or mistreated an issue	Felt unable to trust provider or invalidated by provider	It is too expensive, or the American healthcare system is broken
Please write other comments about your experiences with healthcare below.	4/21 (19%)	8/21 (38%)	9/21 (43%)

Comments have been written out below to show the extent to which the population surveyed is dissatisfied with the American healthcare system. This data could not be represented with numbers or percentages.

1. “It’s expensive and they often say they can’t do anything to help”
2. “way too expensive. should be free”
3. “American healthcare is awful. Super slow and expensive. My mom is from France, so when I got an ear infection while we were there, I got a same day appointment. And the total cost for the appointment and the antibiotics..... $5.00. They even gave my mom a paper to fill out if she wanted to be fully reimbursed. My French grandmother also suffered from breast cancer three times and never paid a single penny for anything. She even got free taxi rides to every appointment. America should really have universal healthcare.”
4. “it's all about money”
5. “great care with some shocking price tags”
6. “I think it’s well known that the U.S. has awful healthcare. The pain to my wallet might be much worse than the physical pain I am experiencing if I go to the hospital”.
7. “Our healthcare system sucks”
8. Even a checkup is expensive, and if you have a bigger issue they find, that means more money spent.”
9. “It is pricey.”

AUTHOR'S BIOGRAPHY

Grace Finley is a graduate from the University of Maine. She earned a Bachelor of Science in Nursing. Grace is from Kittery, Maine and in her free time, she likes to spend time reading and relaxing on some of Maine's more quiet beaches, as well as taking her family's dogs for walks by the beach. She love cats, and has an almost 15-year-old cat named Princess. She loves being with her family, who have been her biggest support system throughout her life and college, especially. This summer, Grace plans on waitressing at her summer job, which she love, as well as applying for nursing jobs. She is hoping to work in an Emergency Department in or around Boston. She has loved her time at the university and in the honors college, and is looking forward to everything else life has to offer in the future!