Spring 2021

Barriers to Relational Continuity of Care for Undergraduate College Students in Southeastern South Dakota

Laura E. Nelson
University of South Dakota

BARRIERS TO RELATIONAL CONTINUITY OF CARE FOR UNDERGRADUATE COLLEGE STUDENTS IN SOUTHEASTERN SOUTH DAKOTA

by

Laura Nelson

A Thesis Submitted in Partial Fulfillment of the Requirements for the University Honors Program

_____

Department of Biology

The University of South Dakota

May 2021

The members of the Honors Thesis Committee appointed

to examine the thesis of Laura Nelson

find it satisfactory and recommend that it be accepted.

_____

Louisa Roberts
Assistant Professor of Anthropology & Sociology
Director of the Committee

_____

Gerald Yutrzenka
Associate Dean, Diversity and Inclusion (Emeritus)
Associate Professor (Emeritus)
Sanford School of Medicine

_____

Dawn St. A. Bragg
Dean of Medical Student Affairs
Professor of Pediatrics
Sanford School of Medicine

ABSTRACT

Barriers to relational continuity of care for undergraduate college students

in southeastern South Dakota

Laura E. Nelson

Director: Dr. Louisa Roberts, Ph.D.

In health care, the patient's relationship with his or her provider serves as a foundation upon which health care decisions are guided and health outcomes are addressed. Relational continuity of care refers to the presence of a sustained (long-term) relationship between a primary care provider (PCP) and a patient. Such continuity of care has been linked with improved health outcomes, reduced mortality, lower health care costs, increased patient satisfaction, and increased delivery of preventative services. Relational continuity of care tends to be low amongst young adults, especially college students. The reasons for this – and the salient barriers to relational continuity of care within the college student population – are as yet incompletely understood. This research project investigates why, focusing specifically on decision making processes, the role of parents, and the relative importance of different barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota. I conducted preliminary interviews with area health experts to better understand barriers to continuity of care in the southeast South Dakota region. Following this, fourteen interviews regarding relational continuity of care were conducted, with seven junior and senior undergraduate students attending the University of South Dakota, as well as separate interviews with the mother of each student. Since mothers have been found to play a strong role in young peoples' health-related decision making, they may in some cases be better able to speak to the influence of some relevant factors. The undergraduate student population at a four-year

university in southeastern South Dakota, the University of South Dakota (USD), was also surveyed to better understand what barriers students faced. Through interviews with and a survey of undergraduate students attending USD, it was found that main barriers to relational continuity of care in this population were: 1) PCP location and a long distance to travel to see PCPs; 2) college students' perception of having good health and the related lack of emphasis that they place on routine preventative care; 3) college students' lack of preparedness and comfort in assuming responsibility for their own health care; 4) college students' lack of familiarity with and knowledge of USD Student Health Services; 5) the absence of a facilitated transition from a pediatric PCP to an adult PCP; and 6) college students' schedules, which limit their amount of time available to receive routine health care. By using the University of South Dakota as a case study, I seek to advance our knowledge of barriers to relational continuity of care that are faced by undergraduate college students in general. It is hoped that, by improving our understanding of the barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota, this study will contribute to efforts to both reduce these barriers and provide quality health care for this population.

KEYWORDS: Relational continuity of care, Primary Care Provider (PCP), college students, undergraduate college student population, emerging adults, southeastern South Dakota, University of South Dakota (USD), USD Student Health Services, health care

TABLE OF CONTENTS

Acknowledgements

I would like to extend a huge thank you to my thesis committee, Dr. Louisa Roberts, Dr. Dawn Bragg, and Dr. Gerald Yutrzenka. Your support and encouragement for my project is greatly appreciated. Dr. Roberts, thank you for serving as the director of my committee and for being by my side throughout this entire process. I have learned so much from you, and your kindness and excellent writing skills are something I will always aspire to exemplify. Dr. Bragg and Dr. Yutrzenka, it has been an absolute joy to learn from you throughout my four years at the University of South Dakota. I am looking forward to the next step of my educational journey, which is something that you helped make possible. Thank you so much.

I. Chapter One: IntroductionRelational Continuity of Care

Relational continuity of care can be defined as the relationship of trust between a health care provider and a patient that results when the patient establishes a relationship with a primary care provider (PCP) and maintains this relationship over time (Haggerty et al., 2003; AAFP, 2017). The American Academy of Family Physicians (AAFP) views continuity of care as rooted in these long-term patient-physician partnerships, and they describe continuity of care as the "hallmark and primary objective of family medicine" (AAFP, 2020a). Others have described continuity of care as the "cornerstone" or "essential element" of primary care medicine (Freeman et al., 2003, as cited in Gulliford, Naithani, & Morgan, 2006, p. 248). Three main components are needed for relational continuity of care to exist. These are: the consistency of the patient's relationship with a specific healthcare provider, the frequency of visits, and the quality of the consultation experience (Waibel et al., 2018).

This study will examine rates of relational continuity within the American college student population, using as a case study the undergraduate student population at a four-year university in southeastern South Dakota, the University of South Dakota in Vermillion. The study identifies what barriers interfere with relational continuity of care within this population. It is hoped that, by improving our understanding of the barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota, this study will contribute to efforts to both reduce these barriers and provide quality health care for this population.

Why is relational continuity of care valuable to patients? To answer this question, it may be helpful to start with the role played by PCPs. Primary care medicine includes preventative medicine, health maintenance, patient education, health promotion, and the diagnosis and treatment of acute and chronic conditions in a wide variety of settings (AAFP, 2020b). The AAFP defines a PCP as a medical provider who provides care at the point of first contact in healthcare and takes continuing responsibility for providing the patient with comprehensive care. PCPs are the patient's "first point of entry" into the healthcare system and coordinate health care services with specialists (AAFP, 2020b). By having a PCP as a "care manager," patients can better navigate the complex healthcare system (Schultz, 1995, p. 58; Wright & Mainous III, 2018). Data has revealed that "positive, trusting relationships with clinicians" that are developed over time aid patient recovery from mental illness (Green et al., 2008). When patients who were battling serious mental health conditions had long-term relational continuity of care with clinicians, "close, collaborative" relationships could develop, treatment and illness management was effective, and patient-directed decisions were supported (Green et al., 2008). Through a relationship of trust with a PCP, compassionate and ongoing healthcare can be provided to patients, and patients will be more receptive to the physician's recommendations. Healthcare professionals who are considered PCPs include family medicine physicians, internists, pediatricians, geriatricians, obstetricians/gynecologists (OB/GYNs), nurse practitioners (NPs), and physician assistants (PAs) (U.S. National Library of Medicine, 2019).

Though college students often view themselves as being relatively healthy, severe medical conditions may arise during this time, including appendicitis, toxic shock syndrome, mononucleosis, meningococcal meningitis, sexually-transmitted diseases (STDs), and the emergence of chronic medical problems and mental health issues (Grace, 1997). Furthermore,

the risky behaviors that undergraduate college students often engage in can detrimentally impact their health, and research shows that "college students risk some of the highest person years of life lost from illnesses and injuries that are largely preventable through alterations in their risky health behaviors (Grace, 1997). Traino et al. (2019) found that 6.1% of college students reported having a chronic medical condition, such as cancer, diabetes, or an autoimmune condition. With this in mind, college serves as an opportune time for preventative and screening measures. Significant positive associations between relational continuity of care and utilization of preventative services have been identified (Kristjansson et al., 2013). Thus, both college students with and without chronic medical conditions benefit from having a relationship with a PCP.

Benefits of relational continuity of care for patients have been found to include reduced mortality from all causes, lower rates of admittance to emergency departments, increased patient satisfaction, increased delivery of preventative services such as vaccinations, more effective chronic disease management, and lower healthcare costs (Hofer & McDonald, 2019; Haggerty et al. 2003; Wright & Mainous III, 2018; Goodell et al., 2009; Waibel et al., 2018). Despite these benefits, not only has the percentage of Americans with "an identified source of primary care" not increased in recent years, but it has actually decreased slightly, from 77% in 2002 to 75% in 2015 (Levine et al., 2020). This trend was especially evident amongst Americans who were "younger, less medically complex, of minority background, or living in the South." Notably, 71% of Americans in their 30s had a source of primary care in 2002, and this number declined to 64% in 2015. Individuals in their 20s were also less likely to have a source of primary care in 2015. It has been hypothesized that amongst younger patients, this trend may be attributed to the prioritization of the "convenience revolution" and nonlongitudinal interactions over relational continuity (Mehrotra, 2013, as cited in Levine et al., 2020, p. 466). Levine and colleagues (2020)

furthermore emphasize the importance of increasing the number of Americans with a source of primary care in order to improve overall health "in an efficient and cost-effective manner."

II. Population: Undergraduate College Students

There is every reason to believe that college students, like the rest of the population, would benefit from relational continuity of care. Lambert and Donovan identify young university students as being at a "critical stage of life" in regard to decision making (2016, p. 1979). It has been recognized that the typical college student is at a "transitional stage of development that lies somewhere between childhood and adulthood" (McIntosh, Compton, & Druss, 2012, p. 596). Many traditional college students may be tasked with assuming more "adult-like responsibilities" while still developing "the skills and cognitive maturity of adulthood" (Pedrelli et al., 2015). Grace (1997) suggests that "no other age group is so thoroughly misunderstood and overlooked when it comes to planning and financing their medical care." Many chronic medical conditions and mental health concerns arise during the college years, and some scholars have described young adults as "surprisingly unhealthy" despite common perception (Grace, 1997; Greenlee et al, 2017, p. 299). The college-age population experiences certain medical conditions more frequently, and younger individuals may be more prone to engaging in risky health behaviors that could negatively impact their long-term health (Grace, 1997). Unintended pregnancy, sexually transmitted diseases, substance abuse, injuries, and mental health concerns are common in this population (Callahan & Cooper, 2005; Cohen & Bloom, 2010; Garcia et al., 2014). Additionally, 6.1% of college students reported having a chronic medical condition in 2018 (American College Health Association, 2018; Traino et al., 2019).

As a new stage of life is entered, the undergraduate college student must assume greater responsibility for his or her own health care, needs to gain access to services suited for the

patient's evolving needs, and needs to establish a relationship with a non-pediatric PCP. As college students gain independence and live away from home, parental management of college students' healthcare is lessened (Lambert & Donovan, 2016). In general, individuals in the 18 to 24-year-old age group have the greatest likelihood of being uninsured, and those students who have insurance coverage may be significantly underinsured. This continues to be an issue even following the passage of the Affordable Care Act (ACA) (Conway, 2020). Data from the 2008 National Health Interview Survey reveals that 30% of young adults aged 20-29 lacked health insurance coverage (Cohen & Bloom, 2010). Through the (ACA), college students may now remain as dependents on their parents' health insurance plans up to age 26; however, these healthcare plans may not offer coverage outside of local service areas: a fact that is particularly relevant to college students living away from home (Grace, 1997; Kirzinger, Cohen, & Gindi, 2012).

Campus health resources serve to help provide care for students away at college; however, their effectiveness may be in question. It has been acknowledged that students are seldom engaged with campus health resources despite their accessibility (Lambert, 2012; Lambert & Donovan, 2016). In a survey conducted by the American College Health Association on college student utilization of student health resources, 49% (public institutions) and 43% (private institutions) of eligible students utilized student health services in the reporting period (McBride et al., 2010). Literature has identified the hesitancy of college students to seek care at college campus health centers due to concerns regarding the providers' competence and the quality of care provided (Davies et al., 2000; Delene & Brogowicz, 1990; Garcia et al., 2014; Perrault, 2018). College students are at a critical transitional stage, and healthcare resources for this group may not be meeting its needs appropriately.

PCPs are the providers most likely to manage and coordinate a student's medical treatment in a college setting (Davenport, 2017, p. 271). Given what we know about the benefits of relational continuity of care, it is imperative that college students understand the importance of establishing a relationship with new local providers or maintaining relationships with current providers to better manage health issues and conditions. Even college students without chronic medical conditions can benefit from establishing a relationship with a PCP, for college presents a period of unique challenges (Traino et al., 2019). Lambert and Donovan recognize relationship management as a critical component of patient care, and for college students, providers must "earn student trust in a very brief timeline to be effective caregivers" (2016, p. 1992).

Scholars discuss the difficulty in maintaining a therapeutic patient-provider relationship in an increasingly complex healthcare landscape, which includes greater sub specialization of health care providers and an increasing prevalence of chronic disease (Nolte & McKee, 2003; Australian Institute of Health and Welfare, 2016; Wright & Mainous III, 2018). This is likely a challenge for undergraduate college students in particular, since they are typically in the midst of multiple life changes, including new places of residence, social networks, and family relations.

At present, little is known about levels of relational continuity of care amongst college students (Marshall, 2011; Garcia et al., 2014). The prevalence of PCPs among undergraduate college students has not been identified, and it is not known if undergraduate college students are informed of the importance of having a PCP. Yet, it seems that providing continuity of care to the college student population is crucial not only for the maintenance of any chronic conditions but also for the adoption of healthy practices that are associated with positive health outcomes in the future. Given the distinctive nature of the college student population, this population may face a distinct set of barriers to the receipt of relational continuity of care.

III. How This Thesis Will Proceed

In Chapter 2, I will: review the existing literature on recognized barriers to relational continuity of care, provide an overview of the resources offered by University of South Dakota (USD) Student Health Services, and discuss the gaps in literature. Chapter 3 will describe the methods used to better understand the prevalence of relational continuity of care amongst college students and the barriers that stand in the way of receipt of such care. Chapter 4 describes the results of these data collection efforts, highlighting the identified barriers to relational continuity of care amongst this college student population. Chapter 5 summarizes the research findings and discusses the limitations of this study, its practical implications, and suggestions for future research.

I. Chapter Two: Literature Review Recognized

Barriers to Relational Continuity of Care

The scholarly literature has identified multiple barriers to relational continuity of care, some of which are particularly relevant to the college student population. Studies report that many college students have unmet health care needs (Marshall, 2011; Garcia et al., 2014) that can be attributed to barriers encountered when accessing health care. These barriers are thought to include a lack of knowledge about establishing with an appropriate new health care provider after outgrowing pediatric care and/or moving to another location to attend college, concerns involving health care coverage (such as a lack of coverage or dependent care coverage entailing a lack of privacy when parents receive explanation of benefits (EOBs) about their college student's health care services) (Frerich et al., 2012; Allen et al., 1998, as cited in Garcia et al., 2014, p. 388), logistics (including location/time of services and schedule conflicts), and a lack of awareness on the need to seek health care and the benefits of receiving such care (Garcia et al., 2014, p. 388).

College students may be reluctant to seek care due to under-developed independence skills and perceptions of the low quality of care that may be received from available health care providers, particularly in new areas or through student health services (Garcia et al., 2014). College may be the first time that undergraduate college students schedule medical appointments, fill prescriptions, and make independent health care decisions. Many are not adequately prepared to do these tasks (Malani, 2017). Unfamiliarity with new providers, particularly when transitioning from pediatric to adult care and beginning college (two events that often occur concurrently), is a motiving factor fueling this lack of comfort in seeing a new

provider. Two key challenges in this transfer are the need for continuity when moving from pediatric care to adult care and the establishment of relational continuity with the new adult provider (Rachas et al., 2016). Young people with long-term care needs and young adults who attend college experience a more difficult transition from pediatric to adult care due to both changes in their care needs and access to services (While et al., 2004; Traino et al., 2019). Recognized barriers to relational continuity of care during the transition from pediatric care to adult care include the intricacies of the disease itself (for those with chronic medical conditions), possible parental overprotection and safeguarding, and a lack of patient experience in personal care management (Hald et al., 2019). Rachas et al. (2016) have identified additional barriers, including low frequency of medical visits, lack of compliance with treatment regimens, and a higher risk of unplanned health care use.

College students who are leaving pediatric care and are entering the realm of adult care are learning to assume greater responsibility for their own health care, something that has a reciprocal relationship with parental involvement. As the role of parents diminishes and college students begin to schedule organize their own health care appointments during this transition, parents must also adjust to this new arrangement. The relationship of care becomes centered around the college student patient and the health care provider, and the focus of attention no longer encompasses the parent (Hald et al., 2019). Excessive parental oversight may serve as a barrier to college students assuming responsibility for their own health care, and it is important for this relationship to find a new balance as both parties recognize their changing roles. This transition can be further complicated by the college student's move to college when a new element of unfamiliarity is introduced. The challenge of discontinuity in health care during this transition is "associated with poor outcomes among young adults" (Institute of Medicine and

National Research Council, 2015, p. 275). Additionally, young adults may "struggle as they assume primary responsibility for their health care for the first time" (p. 277), and discontinuities of care for individuals with a chronic condition most often occur at 20 years of age (Gurvitz et al., 2013; Institute of Medicine and National Research Council, 2015). While lack of preparedness seems to stand as a barrier to relational continuity of care for college students, this has not been adequately addressed by empirical research. Adolescents must acquire skills in independence and self-reliance to successfully transfer into the adult realm of health care (Hald et al., 2019), especially since "systemic coordination" for the transition to adult care for those without chronic conditions is lacking (Institute of Medicine and National Research Council, 2015). A structured, coordinated health care transition plan from the child to the adult health care model will optimize the care of college students. (Cooley et al., 2011; Unwin et al., 2013).

Insurance is another barrier to relational continuity of care for undergraduate college students. According to the 2010 National College Health Assessment II conducted by the American College Health Association (ACHA), 64% of college students are dependents under their parents' health insurance plan, 13% are covered by college or university sponsored plans, and approximately 9% are uninsured (ACHA, 2010, as cited in Unwin et al., 2013, p. 597). It is important to note that the Patient Protection and Affordable Care Act (ACA) has enabled 1-3 million previously uninsured young adults to gain health insurance coverage since this measure was enacted (Blumenthal and Collins, 2014; Institute of Medicine and National Research Council, 2015). Individuals in the 18 to 24-year-old age group have the greatest likelihood of being uninsured, and students who are covered may be significantly underinsured, a trend that has persisted even following the implementation of the Affordable Care Act (ACA) (Cohen & Bloom, 2010; Institute of Medicine and National Research Council, 2015; Conway, 2020). While

colleges often require students to have some form of health insurance coverage, there still may be problems with this coverage. College students may remain as dependents on their parents' health insurance plans up to age 26; however, these health care plans may not offer coverage outside of local service areas (Grace, 1997; Kirzinger et al., 2012). Additionally, health insurance may be limited in the providers, networks, and types of services that they cover. The Centers for Disease Control National Center for Health Statistics note that "disruption of health insurance coverage can introduce barriers to health care" (Cohen & Bloom, 2010). Empirical research through this agency has identified rates of medical visits amongst young adults; however, this was not specific to college students (Kirzinger et al. 2012). Uninsured emerging adults aged 20-29 were less likely to have a regular source of medical care (44%) than were those with private insurance (80%) or Medicaid (84%) (Cohen & Bloom, 2008). Additionally, this same population was four times as likely (21%) as individuals with private insurance (5%) and two times as likely as those with Medicaid (9%) to have unmet medical needs (Cohen & Bloom, 2008). Racial discrepancies have also been identified (Cohen & Bloom, 2008) In general, people of color are more likely to be uninsured than White people (Tolbert et al., 2020). Annual preventative visits amongst emerging adults following the implementation of the ACA increased from 44% in 2009 to 48% in 2011, suggesting a link between having health insurance and routine health care acquisition (Lau et al., 2014b, as cited in Institute of Medicine and National Research Council, 2015, p. 298).

Insurance and other managed care organizations stand as one of the "countervailing powers" to the field of medicine, and their influence reflects "one of the most extensive changes in health care delivery" (Cockerham, 2017, p. 281). Cockerham (2017) views managed care organizations in two contrasting lights. From a positive perspective, they "organize and improve

health care in a stable, reliable, and less costly manner and combine prevention with patient education" (p. 281). On the other hand, managed care organizations "disrupt doctor-patient relationships" (p. 281). For the college student population, insurance coverage and policies may impede the reception of quality health care. Healthy college students may not see the need for health insurance and thus will not obtain it due to its cost (Cockerham, 2017, p. 175). The Kaiser Family Foundation (KFF) recognized the role of insurance in health care for some emerging adults. They published an article describing the risk of becoming uninsured after a young individual loses Medicaid eligibility and ages out of the Children's Health Insurance Program (CHIP) at age 19. Their research revealed that after age 19, approximately 42% of individuals who were previously covered by Medicaid or CHIP are uninsured (Schwartz & Damico, 2010). Other emerging adults are able to remain covered by their parents' private health insurance until age 26. Once an emerging adult reaches age 26, they may once again be in a state of limbo in regard to coverage. Additionally, insurance companies often dictate which services and providers are covered based on a patient's coverage plan (Cockerham, 2017, p. 381). This can make it challenging for PCPs to refer a patient to specialized care (Cockerham, 2017, p. 282).

Some college campuses have implemented Student Health Insurance Plans (SHIPs) to help students access primary care and mental health resources. SHIPs may serve as a possible solution to help provide students with "more comprehensive and affordable coverage" (ACHA, 2016, p. 1). The U.S. Government Accountability Office reports that there are an estimated 1,500 to 2,000 university-based health insurance plans at colleges and universities in the U.S. (United States Government Accountability Office, 2008, as cited in McIntosh et al., 2012, p. 597). All students who are currently enrolled at the University of South Dakota (USD) and who pay the general activity fee can utilize USD Student Health Services. Usually, this includes full-time and

part-time students, and students can choose to receive health care from an array of the clinic's providers, including M.D.s, D.O.s, P.A.s, and N.P.s. USD Student Health Services are located off-campus at the Sanford Vermillion Medical Center, just over a half-mile away. Students may receive free office visits through the Sanford Vermillion Medical Center, as well as reduced rates for allergy injections, immunizations, STD testing, labs, and physicals. Notably, Sanford Vermillion can coordinate students' health care with their parents and hometown PCPs. This helps facilitate relational continuity of care for USD college students who have a PCP in their hometowns. USD Student Health Services states that they participate with most health insurance plans (University of South Dakota, 2020). The South Dakota Board of Regents (SDBOR), the governing body for public higher education in South Dakota, offers a couple of SHIPs, Avera MyHealth and GeoBlue through Blue Cross Blue Shield. Other accepted coverage options include Avera Health plans, Sanford Health plans, and DakotaCare (SDBOR, 2015). Any service not covered under USD Student Health will be billed to the student's health insurance on file. Importantly, the SDBOR highly recommends that students purchase health insurance; however, it does not require health insurance for non-international students who are not in athletics (SDBOR, 2015).

Haggerty et al. (2003) acknowledges that patients are seen by an array of providers in a variety of organizations and places in order to manage long-term conditions, which raises concerns about fragmentation of care. In addition to having a PCP to coordinate care among specialist, the transfer of information fluently via electronic medical records (EMR) could help alleviate the risk of fragmentation. The efficiency and functionality of EMRs successfully promote collaboration and information distribution between health care providers (Fins, 2008, p. 38). This relatively new interface of information processing has its limitations though, for

various health care organizations utilize different EMR exchange formats. Schulte and Fry (2019) acknowledge that the thousands of EHRs in the U.S. "largely remain a sprawling, disconnected patchwork." Merging patient information, such as laboratory results, from multiple formats into the patient's overall electronic health record "still pose a daily threat" (Shukis, 2018, p. 34). For undergraduate college students, this concern is especially pertinent as the move to college is made. Students may be hesitant to establish with a PCP while in college due to concerns over how to inform a new provider about their medical histories. Additionally, concerns have developed regarding the impact of EMRs on the patient-provider relationship. EMRs may depersonalize the patient-provider interaction and fail to grasp the patient's complete story (Fins, 2008, p. 37). While EMRs may promote informational continuity in the health care setting, they may inhibit aspects of relational continuity through their effect on the patient-provider relationship.

A patient's sexual orientation may also impede health care acquisition and therefore relational continuity of care. It is believed that LGBT individuals experience health disparities related to "social stigma, discrimination, and denial of their civil and human rights" (Healthy People 2020). Other literature has suggested that "lesbian women do not receive quality health care or regular physical examinations for fear of discrimination and harassment by health care providers" (Hitchcock & Wilson, 1992; Ponticelli, 1998; Rankow, 1995; Scherzer, 2000; Stevens, 1994a, 1994b, 1995, 1996, 1998; Tiemann et al., 1998; White & Dull, 1998, as cited in Williams-Barnard et al., 2001, p. 129). Fears of rejection, coupled with potential homophobic fears of health care providers, discourages LGBTQ+ individuals from seeking health care.

Undergraduate college students may not recognize the importance of establishing a relationship with a PCP during their emerging adult years. This is another possible barrier that

has not been addressed by empirical studies. If college students are not informed of the benefits of relational continuity of care, acquiring a PCP will not be a priority, and routine health care will suffer. Logistical concerns, such as busy provider and patient schedules and geographical considerations, may also impede health care reception of undergraduate college students. Students may delay treatment until their class schedule allows for an appointment, and immediate care is then sought (Grace, 1997).

II. Gaps in Knowledge

Research on the prevalence of PCPs amongst the undergraduate college student population is lacking. Empirical studies have failed to address exactly what impedes college students from establishing a relationship with a PCP and seeking preventative and routine health care services. Additionally, the role of student health services in promoting and facilitating relational continuity of care is not emphasized. At present, we do not know: 1) the percentage of college students with PCPs; 2) how frequently college students see their PCPs; 3) what factors discourage college students from prioritizing relational continuity of care; and 4) which of the above-discussed barriers to relational continuity of care are the most salient to college students. Due to the numerous health benefits reaped from establishing with a PCP and maintaining a longitudinal relationship, as well as the transient nature of the traditional undergraduate college-age population, this area demands increased attention. By using the University of South Dakota as a case study, I seek to advance our knowledge of barriers to relational continuity of care that are faced by undergraduate college students in general. I also intend to improve our understanding of the barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota, specifically. I hope that this study will contribute to

efforts to both reduce these barriers and provide quality health care for college students at the University of South Dakota and elsewhere.

Chapter Three: Methods

To better understand barriers to relational continuity of care for undergraduate college students in southeastern South Dakota, I conducted preliminary interviews with area health experts, main interviews with junior and senior undergraduate college students and separate interviews with the mother of each student, and a survey of the undergraduate student population at a four-year university in southeastern South Dakota, the University of South Dakota in Vermillion. The purpose of the preliminary interviews was to identify what area health experts viewed as barriers from their years of experience in their respective fields. This mixed-methods approach was taken to: 1) obtain in-depth personal experiences from interviewed college students and their mothers, and 2) identify the prevalence of these barriers, as well as additional barriers, within the USD undergraduate student population.

I. Preliminary Interviews with Area Health Experts in Southeastern South Dakota

Preliminary semi-structured interviews were conducted with eight health experts in the southeastern South Dakota region in the fall of 2019. This group of eight health experts was comprised of a former administrator of diversity and inclusiveness for medicine at a university in the region, a former pediatrician at an area clinic, a family medicine physician practicing at an area clinic, a pharmacist from the region, the CEO of a hospital within southeastern South Dakota, the director of clinic services at an area health care facility, the assistant athletic director of sports medicine for the athletic department at a university in the region, and a mental health counselor at a student counseling center at a university in the region. Participants were asked a general set of open-ended questions pertaining to barriers to continuity of care for emerging

adults in southeastern South Dakota (Appendix A). These questions were derived from the literature review of identified barriers and gauged the prevalence of certain barriers in southeastern South Dakota. The area health experts were asked 29 questions in total; however, not every participant was asked every question. Questions were structured to reflect the interviewee's area of expertise. The interviews either occurred over the phone or in person and lasted approximately 30 minutes. The interviews were recorded and then transcribed using the secure transcription software Trint (Trint, 2021). The semi-structured format allowed each interviewee to contribute his or her own unique perspective derived from personal experience in his or her respective field. A ninth, more focused interview was conducted with the director of clinic services at an area health care facility. The director is also head of Student Health Services at the University of South Dakota, and 12 questions pertaining to the utilization of USD Student Health Services and the health care of college students were discussed.

II. Interviews with Junior and Senior Undergraduate College Students and Their Mothers

Following the preliminary interviews, seven undergraduate junior and senior college students at the University of South Dakota were interviewed, as well as separate interviews with the mother of each student (Appendix B, Appendix C). Upperclassmen were chosen because they have been away from home for several years, and thus they are more likely to have made the transition from pediatric to adult health care and to have established a relationship with a new PCP. Mothers were interviewed since they have been found to play a strong role in young peoples' health-related decision making. Thus, they may in some cases be better able to speak to the influence of some relevant factors (Gross & Howard, 2001). The seven interviewed upperclassmen were individuals with whom I had close relationships. While these students

represent a convenience sample, our previously established relationships helped encourage more detailed and personal responses. The interviews were conducted in the fall and winter of 2020, completed over the phone, and lasted approximately 15-30 minutes. Participants agreed to an IRB-approved consent form (Appendix D) and were given the option to not answer any questions that they did not feel comfortable answering. The interviews were transcribed and analyzed using the secure transcription software Trint (Trint, 2021).

Looking at a particular population in the emerging adult cohort, undergraduate college students, can provide key insight into relational continuity of care for this special group. This methodology allowed participants to provide in-depth details about their own experiences as patients. Demographics of the interviewed students are as follows. All seven participants identified as white or Caucasian, spoke English as a primary language, lived off-campus, had a personal income of less than $15,000 per year, and had health insurance through their parents' employment. Ages ranged from 20-22 years of age (mean = 21.3, standard deviation = 0.95), and four females and three males were interviewed. No participants identified as a member of the LGTBQ+ community. The undergraduate students consisted of five seniors and two juniors. Three students' parents had household incomes of $50,000-100,000, while the other four household incomes were greater than $100,000. Three students' hometowns are less than 100 miles from Vermillion, SD, where USD is located. Four students' hometowns are within 101-300 miles of Vermillion, SD. Home states included South Dakota, Nebraska, Iowa, and Minnesota. Two students stated that they had chronic health conditions.

Table 1
Demographic of undergraduate college student interview participants

Age (years)	Year	Race	Gender	Yearly income (student)	Yearly household income (parents)	Hometown Distance from Vermillion (miles)	Home State	Chronic Health Condition
20	Junior	White	Female	< $15,000	$50,001-100,000	< 100	SD	No
22	Senior	White	Male	< $15,000	$100,001 +	101-300	MN	No
21	Senior	White	Male	< $15,000	$50,001-100,000	< 100	IA	No
20	Junior	White	Male	< $15,000	$100,001 +	101-300	IA	No
22	Senior	White	Female	< $15,000	$100,001 +	101-300	NE	No
22	Senior	White	Female	< $15,000	$50,001-$100,000	101-300	IA	Yes
22	Senior	White	Female	< $15,000	$100,001 +	< 100	SD	Yes

Note. $N = 7$.

III. Survey of the University of South Dakota Undergraduate College Student Population

In February 2021, the undergraduate student population at the University of South Dakota in Vermillion was surveyed to better understand the prevalence of PCPs and what barriers to relational continuity of care these college students face. The 31-question survey was made available from Thursday, February 4th – Friday, February 12th and was distributed to all students at the University of South Dakota via email through USD Involved (Appendix E). This relatively short timeframe was given to encourage prompt responses. Only undergraduate college students were invited to participate, and an IRB-approved consent form was provided (Appendix F). The survey was prepared and initially analyzed in Google Forms and exported into an Excel

spreadsheet. The number of responses that were received totaled 230; however, only 229 were acceptable due to the requirement of being an undergraduate student. Participants were given the option to not answer any questions that they did not feel comfortable answering; therefore, the total number of respondents for a question may be below 229. A logistic regression analysis was then conducted on the survey data to examine the variation in the composition of the USD undergraduate student population. Two types of variation were examined: 1) having a chronic health condition; and 2) household income of students' parents, and their effect on one facet of relational continuity of care, having a PCP. Survey respondents are described demographically in the following paragraph and in Table 2.

Respondents consisted of 78 seniors (34.7%), 53 juniors (23.6%), 49 sophomores (21.8%), and 45 freshmen (20%). The ages of respondents ranged from 17-62 years of age (mean = 20.9, standard deviation = 3.9), with most respondents identifying within the range of 18-22 years of age (93%). Ninety-four (40.9%) undergraduate student participants were from hometowns within 100 miles of Vermillion, SD, 67 (29.1%) hometowns were 101-300 miles from Vermillion, 54 (23.5%) hometowns 301+ miles from Vermillion, and 15 (6.5%) undergraduate college students identified as international students. Yearly income was less than $15,000 for 91.7% of students. Yearly household incomes of students' parents or guardians were varied. Nearly half (45.7%) of household incomes were $100,000 or more per year, 26.5% were between $50,001-$100,000, 11.7% were $25,001-$50,000, 4.8% were less than $25,000 per year, and 26 respondents were not sure of the yearly household incomes of their parents or guardians. Most respondents (91.7%) identified as white, 3.9% identified as Asian, 2.2% identified as Black or African American, and 1.3% identified as American Indian or Alaska Native. 98.2% were not Hispanic or Latino. The majority of participants (82.5%) identified as

female, 16.6% as male, and 0.9% as gender nonconforming (trans, nonbinary, etc.). Meanwhile, 90.8% did not identify as a member of the LGTBQ+ community, and 7.9% did. The USD student population is comprised of 83.27% Caucasian/White students and 69.44% females, as represented in the university's 2017 student satisfaction survey (University of South Dakota, 2017). English served as the primary language of 95.7% of respondents, but it was not the primary language of 4.3% of survey participants. 58.7% are in a health-related major or minor, and 40% are not. Undergraduate student respondents residing in off-campus housing arrangements (58.5%) exceeded those living on-campus (41.5%). Chronic health conditions were present in 13.2% of respondents, while 86.3% did not report having one. Some of the chronic health conditions experienced by survey respondents included asthma, type I diabetes, muscular dystrophy, scoliosis, osteoarthritis, ulcerative colitis, hypertension, irritable bowel syndrome (IBS), Schmitt's Syndrome (type I diabetes, hypothyroidism, and Addison's disease), Samter's Triad Syndrome, Attention-Deficit/Hyperactivity Disorder (ADHD), depression, and anxiety.

Table 2

Demographic of undergraduate college student survey respondents

Age range	**Percentage (%)**
17-62	100
18-22	93
Year in School	
Freshman	20.0
Sophomore	21.8
Junior	23.6
Senior	34.7
Hometown distance from Vermillion	
< 100 miles	40.9
101-300 miles	29.1
301 + miles	23.5
International	6.5
Yearly household income (parents/guardians)	
< $25,000	4.8
$25,001-$50,000	11.7
$50,001-$100,000	26.5
$100,001 +	45.7
Not sure	11.3
Race	
White	91.7
Asian	3.9
Black or African American	2.2
American Indian or Alaska Native	1.3
Other	0.9
Gender	
Female	82.5
Male	16.6
Gender Nonconforming (Trans, nonbinary, etc.)	0.9
Member of LGTBQ+ community	
Yes	7.9
No	90.8
English as primary language	
Yes	95.7
No	4.3
Residence	
Off-campus	58.5
On-campus	41.5
Chronic health condition	
Yes	13.2
No	86.3

Note. $N = 229$.

I. Chapter Four: Results Preliminary Interviews with Area Health Experts in Southeastern South Dakota

Semi-structured interviews with eight health experts in the southeastern South Dakota region helped provide insight into what barriers to continuity of care may be impacting emerging adult individuals in this region. The goal of these interviews was to gain a deeper understanding of what barriers may be impacting continuity of care for emerging adult individuals in southeastern South Dakota, including students attending the University of South Dakota. These preliminary interviews served to supplement the literature review by providing information specific to this population in the region of study. The experts reported a lack of PCPs, suggesting that there may be low relational continuity of care amongst this population. Additionally, the most salient barriers to continuity of care for emerging adults in southeastern South Dakota were: 1) the lack of patient readiness in the transfer from pediatric care to adult care; 2) college students' lack of familiarity with and knowledge of USD Student Health Services; 3) the extent of insurance coverage; and 4) the transfer of electronic medical records (EMRs) between health care organizations. Following the discussion of the salient barriers to continuity of care, I will proceed to discuss the ninth, more focused interview with the director of USD Student Health Services.

PCPs. Without a PCP, relational continuity of care ceases to exist. PCPs play an integral role in the health care for emerging adults. The interviewed family medicine physician emphasized the importance of patients having a PCP, even for patients without chronic conditions. Relational continuity that is maintained over time reduces fragmentation of care, allows visits to be more efficient, and minimizes the likelihood of missing key details of a patient's condition. She

provided an example of a college student in her mid-twenties who had been seeing four to five providers. Potentially from a lack of information and communication, her meningitis was overlooked, and the patient passed away. Having a PCP to coordinate care from multiple providers and "look at the big picture" can improve quality of care and help ensure successful health outcomes. Awareness and education are crucial, for as noted earlier, emerging adults may view themselves as relatively healthy and not see the importance of establishing with a PCP during this life stage. Changes in residence, responsibilities, and roles during emerging adulthood can provide additional resistance to relational continuity of care. Additionally, relational continuity of care can be encouraged amongst undergraduate college students in multiple ways, including emphasizing the importance of establishing a relationship with a PCP, increasing awareness on the resources offered by student health services (such as their ability to coordinate care with hometown PCPs), and by establishing a relationship with a new PCP in an accessible location (such as in the college town). The director of clinic services, who works with student health at an area university, encourages patient establishment with a PCP in an area if the patient plans to reside there for four to five years. This should be encouraged and emphasized to college students.

1. Patient readiness in the transition from pediatric to adult care. In the transfer to adult care, the emerging adult patient must assume a much greater responsibility for his or her own health care. Interviewees mentioned patient readiness as one of the barriers to continuity of care for emerging adults in southeastern South Dakota. The pharmacist interviewee viewed the "lack of knowledge and experience with that age group" as a "self-created barrier" to continuity of care, for the "vast majority of young adults lack the knowledge necessary" to even "conduct continuity." With these considerations, he said that continuity of care for this age group may be

"less of an issue from a provider standpoint if the patient understands what is expected." Relatedly, the assistant athletic director of sports medicine perceived that the greatest challenge in the transfer to college is that emerging adults are now responsible for themselves. He said that college student responsibility can be encouraged by adequate education throughout the patient's adolescent years in order to successfully transfer the patient from pediatrics to adult medicine.

2. College students' lack of familiarity with and knowledge of USD Student Health Services. The director of clinic services at an area health care facility discussed how USD students are often unaware of the resources available to them. For example, students may not know that USD Student Health Services are covered by a general activity fee in the students' tuition. Additionally, parents may discourage the emerging adult from seeking health care services while away from home and suggest using familiar health care services at home. This may impede the emerging adult patient's readiness to assume responsibility for his or her own health care. As the hospital CEO mentioned, it is also not enough to simply tell emerging adults, "You'll figure it out." Having a strong support system that still encourages the individual's independence allows the emerging adult to acquire skills to navigate his or her own health care and establish relationships with area providers.

3. Insurance coverage. The extent of insurance coverage is a barrier to continuity of care for emerging adults. According to the former administrator of diversity and inclusiveness for medicine at a university in southeastern South Dakota, patients whose coverage ends upon reaching a designated age may have limited provider options. Medical care is expensive without insurance coverage, and plans may only cover certain services. Since many emerging adults consider themselves to be healthy, these individuals may not seek coverage or establish a relationship with a health care provider following dismissal from childhood coverage unless it is

necessary. Additionally, some insurance companies only cover certain providers, which can pose as an issue when only particular health care organizations are present within the region. At the University of South Dakota, the Sanford Vermillion Medical Center houses USD Student Health Services. If a student receives certain services that are not covered under USD Student Health and does not have insurance that covers health care services provided by Sanford, the student may have to pay a considerable fee. The hospital CEO mentioned how provider-owned insurance companies attempt to coordinate coverage within set provider networks, which do not extend beyond the organizations themselves. Additionally, when patients cannot see providers of their choice, continuity of care may be disrupted if a previously established relationship can no longer be continued. This is especially pertinent to college students who are attending college out-of-state or in a town with a health care system not covered by their insurance. The director of clinic services and student health at an area health care organization noted how insurance "dictates where patients can go," while the interviewed pharmacist perceived the "bureaucratic" nature of insurance companies as the "single largest barrier in health care." Insurance companies may "inhibit a continuous course of therapy for individuals," and two examples demonstrate the impact of this oversight. The first example was provided by the director of clinic services at an area health care facility. A student from out-of-state sought an HPV vaccination from student health at an area university but was deterred by her insurance provider. The company wanted preventative care to be conducted within her home state, thus discouraging the formation of a new patient-provider relationship. This can be detrimental for continuity of care, and insurance companies should implement different policies that are accommodating to college students. The second example provided by the area pharmacist displays the challenge of refilling prescriptions upon a change in insurance providers. One customer turned age 26 and was dropped from her

parents' private insurance. Without this coverage, her special-order prescriptions were not affordable and thus could not be picked up. A switch in insurance would require new prior authorization and a long wait time for the patient. Insurance coverage enables care to be allocated to patients, yet it can also impede reception of care.

4. Electronic Medical Records. Interviewees noted that much progress remains necessary in order for electronic medical records (EMR) to reach their full potential. The utilization of electronic methods for the transfer of information within the clinical setting has helped enable primary care providers and specialists to communicate effectively and efficiently. Communication between providers serves as a crucial element in continuity of care, and EMRs promote informational continuity. However, different health care organizations often implement various EMR interfaces that are not readily transferrable between providers. The family medicine physician stated that obtaining records from other health care facilities may be difficult, thus impeding care. This can be especially prominent in college students who leave home to attend school. The family medicine physician provided an example of a student attending a local college. The family medicine physician needed to call the providers from the student's home residence in order to receive access to the patient's health information. The family medicine physician could not administer infusions to the student to manage his chronic condition without orders from his providers. The records were sent to the wrong location, which delayed the patient's reception of care. Both the area pharmacist and the director of clinic services at an area health care facility acknowledged that some students away at college may not want providers at home to be informed of care received at another facility. This reluctance to share personal health information may be observed when students receive the results of a STD test. The use of EMRs

within the health care realm can provide unprecedented improvements in communication, yet it requires continued development in order to optimize their potential.

Through the ninth, more focused preliminary interview with the director of USD Student Health Services, information was obtained on student utilization and other aspects of USD Student Health Services. About 25 percent of the clinic's total volume is student utilization. Most of the students visit USD Student Health for acute needs, and most individuals with chronic health conditions remain with their current PCP depending on the PCP's location. The director of USD Student Health Services noted that most students have PCPs, particularly if they received annual well-child checks with a provider up to age 18. If a student does not have a PCP and has seen a certain provider at the clinic repeatedly, USD Student Health "attributes" one of their providers to the student if the student is planning to be in Vermillion for several years. Having an "attributed care provider" is not the same as having a PCP, but the designation is used for insurance purposes. From experience, the director stated that having a PCP in Vermillion likely varies with age. The older a student is, the more likely they have established a relationship with a PCP at the Sanford Vermillion Clinic. Females tend to seek out preventative health care more than males, and students with chronic illnesses may be more likely to seek out a PCP (or maintain a relationship with one) while in college. Ethnicity and military status also play a role in having a PCP, such as if a student receives routine health care from Indian Health Services (IHS) or from the Veterans Health Administration (VA). USD Student Health Services can also coordinate care with students' hometown PCPs, especially for students receiving allergy medicine and injections. If a student does not have a usual source of care and visits USD Student Health for an acute issue, an RN case manager can help facilitate routine health care services for the student. The director acknowledged that students may not seek care until they need health

care services. Sanford does provide financial assistance to college students to help ease the burden of health care costs, especially for uninsured students. The director of USD Student Health Services recognized the challenge of providing college students with preventative health care services due to the students' perceived state of overall health and lack of emphasis on preventative medicine.

Through these preliminary interviews with area health experts, foundational knowledge was garnered concerning barriers to continuity of care for emerging adults in southeastern South Dakota. The most emphasized barriers to continuity of care for emerging adults in southeastern South Dakota were the lack of a primary care provider (PCP), the lack of patient readiness in the transfer from pediatric care to adult care, the extent of insurance coverage, and the transfer of electronic medical records (EMRs) between health care organizations. Additional barriers that were expressed included socioeconomic status (SES), physical ailments and disabilities, rural geography, whether the patient was an immigrant or refugee, language and communication, biases, and identification as an LGBTQ+ individual. Additionally, parents may discourage emerging adults from seeking health care services while away from home and suggest using familiar health care services at home. This may impede the emerging adult patient's readiness to assume responsibility for his or her own health care. These preliminary interviews informed the rest of this study, with relational continuity of care being chosen as the focus. After the ninth, more focused interview with the director of USD Student Health, fourteen interviews were conducted with junior and senior undergraduate students at USD and the mother of each student, and a survey of the USD undergraduate population was completed. The interviews and survey will be examined and analyzed in the remainder of this chapter.

II. Interviews with Junior and Senior Undergraduate College Students and Their Mothers

Fourteen interviews were conducted with seven junior and senior undergraduate college students at the University of South Dakota and seven of their mothers. Through these interviews, barriers to relational continuity of care were identified, and perceptions of the importance of relational continuity of care were gauged. The main barriers to relational continuity of care as evidenced from the interview responses are as follows: 1) An overall lack of emphasis and awareness on the importance of receiving routine medical care, as demonstrated by a) college students' perception of having good health, and b) college students' schedules, which limited their amount of time available to receive routine health care; 2) the absence of a facilitated transition from a pediatric PCP to an adult PCP, characterized by a) the college students' lack of comfort in the transition process; and 3) college students' lack of familiarity with USD Student Health Services.

1. Lack of emphasis and awareness on the importance of receiving routine medical care. A prevalent theme amongst the interviewed college students was the lack of emphasis on obtaining routine medical care and the lack of awareness on its importance. Only two respondents reported that they receive health care checkups or preventative care services when not sick. While five of the seven students stated that they had a PCP, only three saw their PCP at least annually. It is important to note that all seven interviewed students stated that they had a consistent relationship with a medical provider throughout their childhood, and all also received annual well-child checks with a provider up to age 18. Upon starting college, health care acquisition largely became need-based, where students obtained health care only when necessary.

a) College students' perception of having good health. The interviewed college students largely prioritized health care only when necessary. The two students without PCPs did not view having a consistent relationship with a PCP to be a priority at this point in their lives, and the reasoning for this was their perception of having good health. According to one of these students:

> "Right now I'm healthy, so I wouldn't say [having a PCP is] really a priority of mine. But I'm sure my opinion will change. If I get sick, I'll say, 'Well, yes, I would definitely need someone I can go talk to who knows my history and knows about me… Just for right now, I think I would say it's something that I wouldn't consider a priority."

Interestingly, some mothers did not view annual exams as necessary for their college students either, largely due to the perception of their good health. One mother stated how her college student is "kind of passed that age now for routine checkups," and another mother shared how her entire family only goes to the doctor when needed. While other mothers wished that their college students would take advantage of annual visits with a provider, they felt like this decision was now the responsibility of their college student.

b) College students' schedules, which limited their amount of time available to receive routine health care. With all five of the students' PCPs being located in their hometowns, finding time to schedule appointments with providers proved to be challenging. Interviewed students noted how annual appointments had been neglected due to their busy schedules, even during breaks. When asked about what served as barriers to health care acquisition, one student said, "A busy schedule, I guess, especially during the school year. You know how it is, you don't want to make time to go do something when you could be doing something else." One student even recognized the benefits to relational continuity of care and having a PCP; however, due to

time commitments, he has not been seeing his PCP annually. Even for those with PCPs, without routine appointments, continuity suffers.

2. The absence of a facilitated transition from a pediatric PCP to an adult PCP. Some of the interviewees considered the transition from pediatric to adult care, including the lack of comfort with a new provider and the increased responsibility and independence, to be challenging. When students had PCPs who retired, they reported feelings of sadness and not feeling comfortable seeing a new provider. One student said:

> "It was pretty sad. And so when he left, it was a tough time. Felt like you were losing a friend. So it was definitely disappointing. [He was] probably the physician that I probably had the highest level of comfort with."

Another student's PCP retired right before he started college. He described how the lack of a facilitated transition to a new, adult PCP discouraged him from seeking out a new provider:

> "When my primary care physician did retire, I didn't really have anyone say 'You know, you should go see this doctor instead,' or no one told me what office I should go see next. I feel like if there would have been someone who said, 'Well, you should go see Doctor So-and-so now,' maybe I would have established a routine, you know, going to see that physician. But no one did that. And so I kind of just feel like I don't really have anyone that I could go to. I'd have to go find someone."

As a result, this student does not currently have a PCP and no longer obtains annual exams.

a) The college students' lack of comfort in the transition process. Interviewees described the close relationships that they had with their childhood PCPs, and transitioning to a new PCP was a daunting task. As one interviewee explained,

> "[It was hard] just trying to put myself on that level of comfort again with transitioning to a new doctor. I think with any doctor at first, I think it takes patients, you know, a while to really be comfortable. So I would say the greatest challenge wasn't so much, you know, trying to get them to pay attention to me, but just trying to make myself comfortable with them."

Being away from home, college students also struggle with seeing an unfamiliar provider at USD Student Health. One mother described how her daughter would not feel as comfortable going to an unfamiliar provider and would prefer her hometown PCP. She stated:

> "By going to her [hometown PCP], that relationship is established, and they both feel comfortable with each other. [She] wouldn't have felt as comfortable going to student health. She'd much rather go back to her regular provider than to go through student health, [to] somebody that she doesn't know…"

Students also shared concerns over their level of confidence in assuming responsibility for their own health care. They were asked to rate their level of preparedness for assuming responsibility for their health care upon starting college and presently, with one being not prepared and ten being very prepared. The results are depicted in Table 3 below. If a student stated two numbers (i.e. 8 or 9), the lower of these two numbers is used.

Table 3

Level of preparedness for assuming responsibility for one's own health care

Starting college		**Present**	
8		9	
4		8	
10		10	
x*		3	
7		8	
8		10	
7		8	
Mean	7.30	*Mean*	8.00
Standard Deviation	1.97	*Standard Deviation*	2.38

Note. $N = 7$.
Rating scale of 1 (not prepared) to 10 (very prepared).
*denotes no number chosen.

The mean level of preparedness upon starting college was 7.30, and the mean level of preparedness at present was 8.00. One student did not provide an explicit numerical rating for his level of preparedness upon starting college, perhaps due to confusion with the question that was asked. Mothers were also asked to rate their college students on their level of preparedness for assuming responsibility for their own health care. Almost all of the mothers' evaluations corresponded with the college students' self-ratings; however, one mother thought her son was much more prepared (8) than the rating he gave himself (3). Additionally, one mother's comment particularly stood out for a student that gave himself a 10, "I think it's a 10 because he is mature enough, but I think it's probably a 5 because he's a guy." Her comment raises questions about differences in willingness to seek health care between different genders.

3. College students' lack of familiarity with USD Student Health Services. The students were asked about their familiarity with the services offered by USD Student Health. Responses varied drastically and included "pretty familiar", "fairly familiar", and "not familiar." The lack of knowledge was primarily centered around what services were offered through USD Student Health. Mothers were also highly unfamiliar with the services offered by USD Student Health.

With the large array of resources that USD Student Health offers students, it is imperative that USD college students are informed of the health care services that they can obtain for free or at a reduced rate. Additionally, USD Student Health is able to facilitate continuity of care with students' hometown PCPs or help students establish a relationship with a new PCP at the Sanford Vermillion Medical Center; however, student knowledge of these capabilities would appear to be limited.

Additional Barriers. Students also discussed how insurance posed a barrier to obtaining health care services while at college. One student's insurance does not "connect well with the South Dakota companies, like Avera or Sanford." Out-of-state students seemed to have the most issues with insurance, including one having to move an MRI and surgery closer to home for coverage purposes and another needing to inform the insurance company when he was going back to college, thus making him out-of-network. Another barrier pertains to the providers and not to the college students. One mother, who had worked as a nurse in a local clinic, provided great insight into the perspective some providers have of the college student population.

> "…so many providers look at that particular age group as, 'Ah, they're just college students. They're not going to be around here for long.' And they don't really give them the time nor the attention that they really should…"

Interestingly, two mothers stated that their college students had PCPs, but in the students' interviews, neither considered themselves to have a PCP. This may shed light on another potential barrier to continuity of care. Parents may believe that their college student has a PCP; however, the student may not routinely see this provider once starting college or consider the provider his or her PCP.

Additional Results. Many of the interviewed college students stated that they considered having a consistent PCP to be a priority. Reasons included the PCP "having [the patient's] whole picture and history available to them," the patient's increased comfort with a familiar provider, and consistency. When asked if they were aware of some of the identified benefits to relational continuity of care, about half of the college students and mothers were not aware. Even though many of the interviewed college students claimed that having a consistent PCP was important, the intentional efforts of college students to pursue relational continuity of care were lacking.

In sum, salient barriers to relational continuity of care, as evidenced by the interviews, were: 1) an overall lack of emphasis and awareness on the importance of receiving routine medical care, as demonstrated by college students' perception of good health and lack of time for medical care; 2) the absence of a facilitated transition from a pediatric PCP to an adult PCP, characterized by students' lack of comfort in the transition process; and 3) college students' lack of familiarity with USD Student Health Services.

The interviews provided in-depth personal experiences from participants. To supplement these results and reach a broader swath of participants, survey questions were then composed and distributed to the USD undergraduate student population.

III. Survey of the University of South Dakota Undergraduate College Student Population

Through a survey of the University of South Dakota undergraduate college student population, salient barriers to relational continuity of care were identified. These echoed the results of the interviews. Barriers identified through the survey include: 1) the absence of routine visits with a PCP; 2) the absence of a facilitated transition from a pediatric PCP to an adult PCP; 3) college students' lack of familiarity with USD Student Health Services; 4) geography; 5) college students' perception of having good health and subsequent lack of emphasis on routine preventative care; and 6) the lack of knowledge on the benefits of relational continuity of care.

1. The absence of routine visits with a PCP. While having a PCP is vital to relational continuity of care, it is not enough on its own. The survey indicates that while most students have a PCP (73.2%), most students do not see that provider regularly, which is a necessary component of relational continuity of care. Of the survey respondents, 88.6% see their PCP in or near their hometown, and only 8.5% see their PCP in or near Vermillion. Importantly, 48.9% of respondents see their PCPs "only when I need to." This depicts that how routine medical care is not prioritized and is thus neglected by the college student population. While 61.2% responded that they consider having a consistent (long-term) relationship with a PCP who they see on a regular basis to be a priority, this statement is not accurately reflected by the student's actions.

2. The absence of a facilitated transition from a pediatric PCP to an adult PCP. The transition from pediatric to adult care upon starting college is another a barrier to relational continuity of care. Of the survey respondents, 26% still see the same medical provider that they saw as a child. Thus, the vast majority of respondents have left pediatric care and transitioned to adult care in some capacity, whether their visits are routine or intermittent. While the transition

from pediatric to adult care was emphasized as being difficult in only a small percentage of respondents (8.2%), it nonetheless has contributed to low levels of relational continuity of care amongst undergraduate college students. The transition may not necessarily be difficult if it is merely nonexistent. One respondent's comment highlights this important point. He describes how the transition was not difficult, but it was "just not prioritized. I do not make efforts to see my new doctor unless I am sick." Another said that she "just transitioned from [her] childhood medical provider because [her provider] retired." She has yet to find a new PCP. The retirement of pediatric PCPs can pose as a challenge to college students, especially without a facilitated transition to adult care. This issue was also described by one of the interviewed students, as depicted in the previous section. Another student had a difficult transition from pediatric to adult care following the passing of her pediatrician, and one student's response mentioned that she has not seen her pediatric PCP for a few years and would likely need to find a new PCP due to her age. One student's experience has consisted of seeing multiple PAs and NPs, which has admittedly inhibited the formation of a patient-provider relationship. Clearly, the transition from pediatric to adult care is absent, not facilitated, or difficult, which impedes relational continuity of care for college students.

3. College students' lack of familiarity with USD Student Health Services. Students were also asked about their knowledge of USD Student Health Services, and their lack of knowledge about USD Student Health Services serves as a barrier to relational continuity of care. As previously mentioned, USD Student Health Services is able to facilitate relational continuity of care by working with students' hometown PCPs or by helping students establish a relationship with a PCP in Vermillion. However, over two-thirds (68%) of students stated that they were "not familiar" or "somewhat familiar" with the services offered by USD Student Health. It is

imperative to recognize that students are uninformed of the resources available to them. Of the 65.2% of students that have received care from USD Student Health Services, most students visited for acute illness (49%), laboratory testing (35.8%), vaccinations (35.1%), and athletic physicals (32.5%). Only 19.9% of respondents utilized USD Student Health Services for routine well-check visits. Awareness on the importance of routine preventative care visits need to be emphasized to the college student population to ensure that healthy practices are adopted by this population, screenings are conducted, chronic diseases are detected, and preventative medicine can be obtained. It is also important that students are informed of how USD Student Health Services can help them establish and maintain relational continuity of care and provide them with these health care services.

4. Geography. Students were given a list of potential barriers to relational continuity of care and were asked to select all that applied to them. Of the respondents, 69.3% agreed with the statement "my primary care provider does not practice in the town I attend college," and an additional 23.9% acknowledged geography as impeding relational continuity of care. Having to travel long distances to see a PCP deters college students from taking the time to schedule and attend routine appointments, and thus geography is a barrier to relational continuity of care.

5. College students' perception of having good health and subsequent lack of emphasis on routine preventative care. Other respondents (37.2%) stated "I am in good health and do not need health care." College students' perception of having good health serves as a barrier to relational continuity of care, for they will not seek out health care services if they do not deem them as necessary. One student stated, "I do not get sick often and don't feel the need to go in for a yearly checkup besides my women's wellness appointment." Similarly, another student said, "I don't see a PCP unless I have something wrong or if I am injured." Additionally, 27.5% felt that

at one point or another, they did not feel comfortable assuming responsibility for their healthcare (scheduling appointments, finding a provider, calling in and picking up prescriptions, etc.). Without feeling confident, prepared, and equipped to take responsibility for their own health care, college students will not prioritize relational continuity of care. In regard to assuming responsibility for their own health care, some students commented that they were never taught "how to do it" or "that it was important." Finally, 21.6% said that they do not have time to see a provider routinely. College students' busy schedules are emphasized as a barrier in both the student interviews and in the survey. The survey responses to the question asking about potential barriers to relational continuity of care are depicted in Table 4.

Table 4
Barriers to having a single primary care provider during college

Barrier	Percentage (%)
My PCP does not practice in the town I attend college	69.3
I am in good health and do not need health care	37.2
At one point or another, I did not feel comfortable assuming responsibility for my health care (scheduling appointments, finding a provider, calling in and picking up prescriptions, etc.)	27.5
I must travel many miles to see my PCP	23.9
I do not have time to see a provider routinely	21.6
My health insurance does not cover my preferred health care providers or the providers available in the area I attend college	7.8
I cannot afford the cost of health care	6.4
I do not have health insurance	2.3
It is challenging to find a provider who understands my sexual orientation or gender identity	1.8
It is challenging to find a provider who can speak my preferred language	0.5

Note. N = 229.

6. The lack of knowledge on the benefits of relational continuity of care. The lack of awareness of the benefits of relational continuity of care serves as a barrier to relational continuity of care for undergraduate college students. As in the student and mother interviews, all survey participants were asked if they were aware of the numerous benefits to relational continuity of care, including reduced mortality from all causes, lower rates of admittance to emergency departments, increased patient satisfaction, increased delivery of preventative services such as vaccinations, more effective chronic disease management, and lower healthcare

costs (Hofer & McDonald, 2019; Haggerty et al. 2003; Wright & Mainous III, 2018; Goodell et al., 2009; Waibel et al., 2018). Of the respondents, 53.5% responded "no," and 41.7% said "yes." A similar trend was observed in the student interviews. While a couple of the participants were aware of these benefits, the others were unaware or only partially aware of the benefits. This emphasizes the need to increase college students' knowledge of the importance of having relational continuity of care with a PCP.

Additional barriers. Students were then given the opportunity to share any other barriers that have prevented them from obtaining health care services while attending college. This question was asked since barriers to health care acquisition in general can also be applicable to relational continuity of care. Judgement, whether from health care providers, peers, or family members, was also mentioned by students. One student responded with "the USD medical staff don't know my previous health issues," revealing the lack of comfort that college students have with unfamiliar providers. The time, money, and cost required for health care services and the gender of the healthcare provider also causes some issues for college students. One student stated that the transition to a new primary care provider from their pediatrician has been a barrier. Transportation to the clinic serves as a barrier for one respondent, and another stated, "I haven't been in one place long enough to feel comfortable to find a primary care physician." Insurance poses as an issue for some students, and some were concerned with the quality of care provided by USD Student Health Services. Additionally, anxiety deters some from seeking health care, and some students felt confused by the process and where to find USD Student Health Services.

R studio was utilized to conduct a logistic regression analysis on the survey data to examine the variation in the composition of the USD undergraduate student population. I examined two types of variation in the college student population: 1) having a chronic health

condition; and 2) household income of students' parents, and their effect on one facet of relational continuity of care, having a PCP. This analysis required that student answers of "not sure" and non-responses were filtered out of the data. Dummy variables were also created. Due to the nature of conducting a logistic regression analysis, the $100,000 + income bracket served as the base group. The results of this logistic regression analysis can be found in Table 5.

Individuals who have a chronic health condition are more likely to have a PCP holding the effect of income constant ($p = 0.013$). Having a chronic health condition has a non-zero positive effect on whether or not one has a PCP. Regarding income, all effects are negative. Estimates indicate that individuals in lower income brackets (estimate = -0.062, $p = 0.665$) are less likely to have a PCP, when holding constant the effect of having a chronic health condition. Only one income bracket is statistically significant, the $25,000-$50,000 range. The effect size is larger in this income bracket, and individuals in this income bracket are more likely to have a PCP ($p = 0.010$). Few respondents in other brackets may have influenced this observation. Both having a chronic health condition and income have predicted an effect on having a PCP.

Table 5
Logistic regression analysis of having a chronic health condition and household income on having a PCP

Independent Variable	Estimate	Pr (>| t |)
Chronic health condition	0.212	0.013*
Household income (<$25,000)	-0.062	0.665
Household income ($25,001-$50,000)	-0.248	0.010*
Household income ($50,001-$100,000)	-0.038	0.573

Note. $N = 186$.
* $p < .05$

The salient barriers to relational continuity of care as depicted in the survey responses were: 1) even with having a PCP, the lack of continuity; 2) the transition from pediatric to adult care being difficult or nonexistent; 3) college students' lack of knowledge about USD Student Health Services; 4) geography; 5) college students' perception of having good health and subsequent lack of emphasis on routine preventative care; and 6) college students' lack of knowledge on the benefits of relational continuity of care Additional barriers include judgement, whether from health care providers, peers, or family members; lack of comfort with unfamiliar providers; the cost of health care services; transportation to and from health services; insurance; concerns about the quality of health care from student health services; and anxiety.

Chapter Five: Discussion and Conclusions

This study identifies barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota. This thesis examined the magnitude of the relational continuity of care deficit and examined what barriers prevent students from experiencing relational continuity of care. Regarding the magnitude of the relational continuity of care deficit, this study found that while 73.2% of surveyed college students stated that they have a PCP, 88.6% see their PCP in or near their hometown. Because of geographical distance and time constraints, routine clinical visits and relational continuity of care suffer. Through interviews with and a survey of undergraduate students attending the University of South Dakota, it was found that main barriers to relational continuity of care in this population were: 1) PCP location and a long distance to travel to see PCPs; 2) college students' perception of having good health and the related lack of emphasis that they place on routine preventative care; 3) college students' lack of preparedness and comfort in assuming responsibility for their own health care; 4) college students' lack of familiarity with and knowledge of USD Student Health Services; 5) the absence of a facilitated transition from a pediatric PCP to an adult PCP; and 6) college students' schedules, which limit their amount of time available to receive routine health care.

The findings from this case study advance our knowledge and are applicable for college students across the United States. The aforementioned gaps in the empirical literature: 1) the percentage of college students with PCPs; 2) how frequently college students see their PCPs; 3) what factors discourage college students from prioritizing relational continuity of care; and 4) which of the barriers to relational continuity of care are the most salient to college students, have been addressed by this study. First, it has been recognized that simply having a PCP it not

sufficient for relational continuity of care. While college students may have a PCP (73.2%), routine visits are not prioritized. Of the surveyed college students, 48.9% see their PCPs "only when I need to." College students are discouraged from prioritizing relational continuity of care by their perception of having good health and the related lack of emphasis that they place on routine preventative care, the lack of involvement of student health services in facilitating relational continuity of care for college students, students' lack of awareness on the resources offered by student health services, and college students' schedules. This study sheds light on the important role that student health resources can play in facilitating relational continuity of care for college students, something that colleges across the United States can benefit from knowing.

This study's results point to the need to not only encourage students to establish a relationship with a PCP, but also for students to have a PCP in an accessible location to accommodate students' busy schedules. Additionally, 30.7% of respondents were "not familiar" and 37.3% of respondents were "somewhat familiar" with the services offered by USD Student Health. These data suggest the need to increase awareness on the resources offered by USD Student Health Services to help facilitate relational continuity of care. This study encourages action from students, student health resources, institutes of higher education, and health care personnel to address these issues and improve health care acquisition amongst this population.

The limitations of this study must be acknowledged. Due to the nature of conversations, the specific phrasing of certain questions throughout the interviews may have slightly varied. The demographics of interview and survey participants were also limited in diversity. Most students came from middle to upper-middle class backgrounds, and the large majority identified as white or Caucasian and were female. This means that the results shed less light on relational continuity of care amongst students from poorer backgrounds, students of color, and male

students. However, the USD student population is comprised of 83.27% Caucasian/White students and 69.44% females, as represented in the university's 2017 student satisfaction survey (University of South Dakota, 2017). Since a small percentage of the total undergraduate student population at USD responded to the survey, participants may not be entirely representative of the broader USD student population. Additionally, possible bias may be associated with survey respondents. More conscientious students may have been more inclined to participate. Since females have been recognized to seek health care services more frequently than males, this study may disproportionately represent the number of college students with PCPs since the survey sample was 82.5% female. Finally, while the survey was distributed to all students and faculty at the University of South Dakota via email, the message may have been blocked or moved to junk, depending on the user's settings.

Given the medical utility of relational continuity of care, there is a need to increase relational continuity of care amongst undergraduate college students. This study sheds light on what steps might be taken to increase those levels. Students (and possibly their parents) must be educated on the importance of establishing a long-term relationship with a PCP and seeing this same medical provider routinely. Education on the importance of relational continuity of care is crucial because routine health care visits encourage healthy lifestyle habits, screenings to be completed, and preventative medicine to be obtained. For this to occur, students must be equipped with the skills and knowledge to properly navigate the health care system, particularly during the transition to college.

Of particular importance for the University of South Dakota, this research reveals a lack of awareness of the resources and services offered by USD Student Health. This lack of awareness suggests a need for more education and outreach to students. I encourage USD

Student Health Services to promote relational continuity of care and to encourage students to establish a relationship with a PCP at their clinic, especially if they do not already have one. This action will make the provider more accessible, and relational continuity of care throughout the undergraduate college years will increase. Resources and programs for college students, their families, and health care providers can help facilitate the transition to college and bolster independence, comfort, and confidence within the college student population. A potential problem to this recommendation would be a provider shortage. USD could consider allocating more resources to its Student Health Services to address this issue should it occur.

Further research could be conducted to expand upon this study's findings. This study focused on only one university in one region of the country. A similar methodology could be implemented at other types of universities at other regions of the country, to gauge whether the barriers to relational continuity of care are constant or if they vary depending on factors such as the nature of the student population and university policies related to student health. Subsequent studies could also, for example, investigate the effect of different university health policies in promoting relational continuity of care. Researchers could also further examine if college students with chronic health conditions are more likely to have PCPs and to have experienced a facilitated transition from a pediatric PCP to an adult PCP. More logistic regressions could be run to identify which factors contribute to relational continuity of care and the relative significance of such factors, further examining students from low SES backgrounds.

In sum, this study has identified key barriers to relational continuity of care amongst undergraduate college students at USD. While college students' limited time to receive routine health care will persist as a barrier, increased emphasis from the health care community, student health services, families, and students alike can help make relational continuity of care a priority.

It is hoped that, through our improved understanding of the barriers to relational continuity of care amongst undergraduate college students in southeastern South Dakota, this study will contribute to efforts to both reduce these barriers and provide quality health care for this population.

References

Allen, L. B., Glicken, A. D., Beach, R. K., & Naylor, K. E. (1998). Adolescent health care experience of gay, lesbian, and bisexual young adults. *Journal of Adolescent Health*, *23*(4), 212–220. https://doi.org/10.1016/S1054-139X(98)00022-6

American Academy of Family Physicians (AAFP). (2020a). *Continuity of care, definition of.* https://www.aafp.org/about/policies/all/continuity-of-care-definition.html

American Academy of Family Physicians (AAFP). (2020b). *Primary Care*. https://www.aafp.org/about/policies/all/primary-care.html

American College Health Association (ACHA). (2018). American College Health Association national college health assessment II: Spring 2018 reference group executive summary. *American College Health Association,* Hanover, MD. https://www.acha.org/documents/ncha/NCHA-II_Spring_2018_Reference_Group_Executive_Summary.pdf

American College Health Association (ACHA). (2016). *Do you know why student health insurance matters?* [Fact sheet]. https://www.acha.org/documents/Networks/Coalitions/Why_SHIPs_Matter.pdf

Arain, M., Haque, M., Johal, L., Mathur, P., Nel, W., Rais, A., Sandhu, R, & Sharma, S. (2013). Maturation of the adolescent brain. *Neuropsychiatric disease and treatment*, *9*, 449–461. https://doi.org/10.2147/NDT.S39776

Arnett, J. J. (2016) *Human development: A cultural approach* (2nd ed.). Boston: Pearson Education, Inc.

Australian Institute of Health and Welfare (AIHW). (2016). Australia's Health 2016. Canberra: AIHW, 2016.

Blumenthal, D., & Collins, S. R. (2014). Health care coverage under the Affordable Care Act—a progress report. *New England Journal of Medicine, 371*(3),275-281. https://doi.org/10.1056/NEJMhpr1405667

Callahan S.T. & Cooper, W.O. (2005). Uninsured and health care access among young adults in the United States. *Pediatrics, 116*(1), 88–95. https://doi-org.usd.idm.oclc.org/10.1542/peds.2004-1449

Cockerham, W. (2017). *Medical Sociology* (14th ed.). New York: Routledge.

Cohen, R.A. & Bloom, B. (2010). Access to and utilization of medical care for young adults aged 20–29 years: United States, 2008. NCHS data brief, no 29. Hyattsville, MD: National Center for Health Statistics. Retrieved from https://www.cdc.gov/nchs/data/databriefs/db29.pdf

Cooley, W.C., Sagerman, P.J.; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*(1), 182-200. https://doi-org.usd.idm.oclc.org/10.1542/peds.2011-0969

Conway, D. (2020, October 26). *Adults age 26 had the highest uninsured rate among all ages, followed by 27-year-olds*. United States Census Bureau. https://www.census.gov/library/stories/2020/10/uninsured-rates-highest-for-young-adults-aged-19-to-34.html

Davenport, R. G. (2017). The integration of health and counseling services on college campuses: Is there a risk in maintaining student patients' privacy? *Journal of College Student Psychotherapy, 31*(4), 268-280. https://doi.org/10.1080/87568225.2017.1364147

Delene, L.M. & Brogowicz, A.A. (1990). Student healthcare needs, attitudes, and behavior: marketing implications for college health centers. *J Am Coll Health, 38*(4), 157–164. https://doi.org/10.1080/07448481.1990.9938436

Fins, J. (2008). Web of care: How will the electronic medical record change medicine? *The Hastings Center Report, 38*(5), 36-38. Retrieved from www.jstor.org/stable/25165368

Frerich, E. A., Garcia, C. M., Long, S. K., Lechner, K. E., Lust, K., & Eisenberg, M. E. (2012). Health care reform and young adults' access to sexual health care: an exploration of potential confidentiality implications of the Affordable Care Act. *American Journal of Public Health, 102*(10), 1818–1821. https://doi.org/10.2105/AJPH.2012.300857

Garcia, C. M., Lechner, K. E., Frerich, E. A., Lust, K. A., & Eisenberg, M. E. (2014). College students' preferences for health care providers when accessing sexual health resources. *Public health nursing (Boston, Mass.), 31*(5), 387–394. https://doi.org/10.1111/phn.12121

Goodell, L., Smith, S., Maestas, R. R., & James, J. (2009). First-year medical students' perspectives on continuity of care. *Family medicine, 41*(3), 175–181. https://fammedarchives.blob.core.windows.net/imagesandpdfs/fmhub/fm2009/March/Laura175.pdf

Grace, T. W. (1997). Health problems of college students. Journal of American College Health, 45(6), 243. https://doi-org.usd.idm.oclc.org/10.1080/07448481.1997.9936894

Green, C. A., Polen, M. R., Janoff, S. L., Castleton, D. K., Wisdom, J. P., Vuckovic, N., Perrin, N. A., Paulson, R. I., & Oken, S. L. (2008). Understanding how clinician-patient relationships and relational continuity of care affect recovery from serious mental illness:

STARS study results. *Psychiatric rehabilitation journal*, *32*(1), 9–22. https://doi.org/10.2975/32.1.2008.9.22

Greenlee, M. C., D'Angelo, L., Harms, S. R., Kuo, A. A., Landry, M., McManus, M., Talente, G. M., & White, P. (2017). Enhancing the role of internists in the transition from pediatric to adult health care. *Annals of Internal Medicine, 166*(4), 299-300. https://doi.org/ 10.7326/M16-0514.

Gross, G.J. & Howard, M. (2001). Mothers' decision-making processes regarding health care for their children. *Public Health Nursing, 18*(3):157-168. doi:10.1046/j.1525-1446.2001.00157.x

Gulliford, M., Naithani, S., & Myfanwy, M. (2006). What is 'continuity of care'? *Journal of Health Services Research & Policy*, *11*(4), 248-250. https://doi.org/ 10.1258/135581906778476490

Gurvitz, M., A. M. Valente, C. Broberg, S. Cook, K. Stout, J. Kay, J. Ting, K. Kuehl, M. Earing, and G. Webb. (2013). Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *Journal of the American College of Cardiology, 61*(21):2180-2184. https://doi.org/10.1016/j.jacc.2013.02.048.

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: a multidisciplinary review. *BMJ (Clinical research ed.)*, *327*(7425), 1219–1221. https://doi.org/10.1136/bmj.327.7425.1219

Hald, M., Carlsen, K., Nordgaard-Lassen, I., & Wewer, V. (2019). Challenges and obstacles in the transition process through the eyes of the gastroenterologist. *European Journal of*

Gastroenterology & Hepatology, 31(4), 486-493. https://doi.org/10.1097/MEG.0000000000001359

Healthy People 2020. (n.d.). *Lesbian, Gay, Bisexual, and Transgender Health.* Office of Disease Prevention and Health Promotion. https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health

Hofer, A. & McDonald, M. (2019). Continuity of care: Why it matters and what we can do. *Australian Journal of Primary Health, 25*(3). Retrieved from https://usd.illiad.oclc.org/illiad/pdf/577201.pdf

Institute of Medicine and National Research Council (2015). *Investing in the Health and Well-Being of Young Adults.* Washington, DC: The National Academies Press. https://doi.org/10.17226/18869

Kirzinger, W.K, Cohen, R.A., Gindi, R.M. (2012). Health care access and utilization among young adults aged 19–25: Early release of estimates from the National Health Interview Survey, January–September 2011. *National Center for Health Statistics*. Retrieved from: https://www.cdc.gov/nchs/data/nhis/earlyrelease/Young_Adults_Health_Access_052012.pdf.

Kristjansson, E., Hogg, W., Dahrouge, S., Tuna, M., Mayo-Bruinsma, L., & Gebremichael, G. (2013). Predictors of relational continuity in primary care: Patient, provider and practice factors. *BMC Family Practice, 14*(72). https://doi.org/10.1186/1471-2296-14-72

Lambert, C. A. (2012). Memorable health messages embrace student perspectives. *Public Relations Journal, 6*(5). Retrieved from: http://www.prsa.org/Intelligence/PRJournal.

Lambert, C., & Donovan, J. (2016). College health care providers' student-centered care. *The Qualitative Report, 21*(10), 1979-1998. Retrieved from https://nsuworks.nova.edu/tqr/vol21/iss10/14

Levine, D. M., Linder, J. A., Landon, B. E. (2020). Characteristics of Americans With Primary Care and Changes Over Time, 2002-2015. *JAMA Intern Med., 180*(3), 463–466. https://doi.org/10.1001/jamainternmed.2019.6282

Malani, P. (2017, October 7). *Off to college? Don't forget to pack a plan for your health.* National Public Radio (NPR). https://www.npr.org/sections/health-shots/2017/10/07/555901858/off-to-college-don-t-forget-to-pack-a-plan-for-your-health-care.

Marshall E. G. (2011). Do young adults have unmet healthcare needs?. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*, *49*(5), 490–497. https://doi.org/10.1016/j.jadohealth.2011.03.005

McBride, D. R., Van Orman, S., Wera, C, & Leino, V. (2010). 2010 survey on the utilization of student health services. *ACHA Benchmarking Committee*, 1-13. https://www.acha.org/documents/resources/survey_data/benchmarking/ACHA_Benchmarking_Report_2010_Utilization_Survey.pdf

McIntosh, B. J., Compton, M. T., & Druss, B. G. (2012). Students left behind: The limitations of university-based health insurance for students with mental illnesses. *Journal of American College Health, 60*(8), 596-598. https://doi.org/ 10.1080/07448481.2012.726301

Nolte, E. & McKee, M. (2003). Measuring the health of nations: Analysis of mortality amenable to health care. *BMJ (Clinical research ed.), 327*(7424), 1129. https://doi.org/10.1136/bmj.327.7424.1129

Pedrelli, P., Nyer, M., Yeung, A., Zulauf, C., & Wilens, T. (2015). College Students: Mental Health Problems and Treatment Considerations. *Academic Psychiatry: The Journal of the American Association of Directors of Psychiatric Residency Training and the Association for Academic Psychiatry*, *39*(5), 503–511. https://doi.org/10.1007/s40596-014-0205-9

Perrault, E. K. (2018). Improving student knowledge and perceptions of primary care providers at campus health centers. *Journal of American College Health*, *66*(8), 813–816. https://doi.org/10.1080/07448481.2018.1434781

Rachas, A., Lefeuvre, D., Meyer, L., Faye, A., Mahlaoui, N., de La Rochebrochard, E., Warszawski, J., & Durieux, P. (2016). Evaluating continuity during transfer to adult care: A systematic review. *Pediatrics*, *138*(1), 1–12. https://doi-org.usd.idm.oclc.org/10.1542/peds.2016-0256

Shukis, D. (2018). The constant evolution and challenges of electronic medical records. *MLO: Medical Laboratory Observer*, *50*(10), 34–35.

Schulte, F. & Fry, E. (2019, March 23). *Death by 1,000 clicks: Where electronic health records went wrong.* Kaiser Health News. https://khn.org/news/death-by-a-thousand-clicks/

Schultz, D. V. (1995). The importance of primary care providers in integrated systems. *Healthcare Financial Management, 49*(1), 58-63. Retrieved from https://search.proquest.com/docview/196367728?accountid=14750

Schwartz, K. & Damico, A. (2010). Aging out of Medicaid: What is the risk of becoming uninsured? *Kaiser Family Foundation*, 1-5. Retrieved from https://www.kff.org/wp-content/uploads/2013/01/8057.pdf

South Dakotas Board of Regents (SDBOR). *Policy manual: Student insurance* § 3:14 *et seq*. (2015).

Tolbert, J., Orgera, K., & Damico, A. (2020, November 6). *Key facts about the uninsured population.* Kaiser Family Foundation. https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/

Traino, K., Bakula, D., Sharkey, C., Roberts, C., Ruppe, N., Chaney, J., & Mullins, L. (2019). The role of grit in health care management skills and health-related quality of life in college students with chronic medical conditions. *Journal of Pediatric Nursing, 46,* 72-77. https://doi.org/10.1016/j.pedn.2019.02.035

Trint. (2021). https://trint.com/

Unwin, B. K., COL , MC, USA, Goodie, J., CDR, USPHS, Reamy, B. V., COL , USAF, MC, & Quinlan, J., CAPT, MC, USN. (2013). Care of the College Student. *American Family Physician, 88*(9), 596-604C. https://pubmed.ncbi.nlm.nih.gov/24364636/

University of South Dakota. (2017). *Student Satisfaction Inventory.* Noel-Levitz, LLC. https://www.usd.edu/-/media/files/institutional-research-planning-and-assessment/ssidatasets/ssi17report.ashx

University of South Dakota. (2020). *Student Health Services.* USD. https://www.usd.edu/student-life/student-health

U.S. National Library of Medicine. (2019). *Choosing a primary care provider.* MedlinePlus. https://medlineplus.gov/ency/article/001939.htm

Waibel, S., Vargas, I., Coderch, J., & Vázquez, M. L. (2018). Relational continuity with primary and secondary care doctors: a qualitative study of perceptions of users of the Catalan national health system. *BMC Health Services Research, 18*(1), N.PAG. https://doi-org.usd.idm.oclc.org/10.1186/s12913-018-3042-9

While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health & Development*, *30*(5), 439–452. https://doi.org/10.1111/j.1365-2214.2004.00440.x

Williams-Barnard, C. L., Mendoza, D. C., & Shippee-Rice, R. V. (2001). The lived experience of college student lesbians' encounters with health care providers: A preliminary investigation. *Journal of Holistic Nursing : Official Journal of the American Holistic Nurses' Association*, *19*(2), 127–142. https://doi.org/10.1177/089801010101900204

Wright, M., & Mainous, A. G., 3rd (2018). Can continuity of care in primary care be sustained in the modern health system?. *Australian journal of general practice*, *47*(10), 667–669. https://doi.org/10.31128/AJGP-06-18-4618

Appendix A: Semi-structured interview questions for area health experts

1. Reflecting on your expertise within the realm of medicine, what do you perceive as barriers to continuity of care for emerging adults within our region?
2. How has continuity of care evolved over the years?
3. How do insurance providers play a role in continuity of care for emerging adults, such after age 26 when insurance is no longer provided by individuals' parents or when the Children's Health Insurance Program (CHIP) expires at age 19?
4. How does the transfer to college impact continuity of care for emerging adults? Of the three types of continuity of care (longitudinal, management, and relational), which do you perceive as most affected by this transition?
5. What is your perspective on the impact of telemedicine services on continuity of care? Do you see these services playing a role in USD athletics?
6. How are the emerging adult patients responding to these services?
7. What is the importance of continuity of care in treating infectious diseases? What is its importance in chronic disease management?
8. What are some notable differences between pediatric and adult care? Are there mechanisms in place to help bridge this gap during the transfer process?
9. It has been noted that individuals with chronic health conditions typically interact with multiple health care providers. How is information relayed between primary care providers and specialists, particularly when separated by geographical distance? Is there a disconnect between primary care providers and specialists?
10. How are medical records shared with necessary providers, especially with the different interfaces used for electronic medical records?

11. What role does the pharmacist play in continuity of care for emerging adults? Are any of these roles unique to the southeast region of South Dakota?
12. What are some unique ways that Student Health at USD contributes to patient needs and promotes continuity of care within its system?
13. What is the importance of mental health during the emerging adult years?
14. How readily are mental health services utilized by students? Are there some biases/stigmas that inhibit the reception of care?
15. How does the transfer to college impact continuity of care for emerging adults, particularly in regards to mental health?
16. What is the importance of continuity of care in treating mental health conditions? Is continuity maintained for students and counselors following graduation?
17. Are there differences between pediatric and adult mental health care? Are there mechanisms in place to help bridge this gap during the transfer process?
18. Is information relayed between primary care providers and mental health specialists?
19. Are electronic medical records kept for mental health services?
20. What are some possible ways to expand mental health services? Do you see telemedicine playing a role?
21. What are some unique ways [a particular health care institute] contributes to patient needs and promotes continuity of care within its system?
22. What is the impact of having a team physician on continuity of care for emerging adult athletes at USD? Is communication maintained with the athlete's PCP?
23. What role do the athletic trainers play in encouraging continuity of care for emerging adult athletes?

24. What are some challenges for the athletic department in regards to referrals? How is continuity maintained throughout this process?
25. How do insurance policies play a role in continuity of care for emerging adults, especially after age 26 when insurance is no longer provided by individuals' parents??
26. Does the importance of continuity of care differ between treatment of an infectious disease, chronic disease management, and an injury?
27. What are some expectations of the athlete in regards to care (rehabilitation, maintenance, prevention)?
28. Does the training staff at USD address all aspects of health (physical, mental, spiritual)?
29. How do the organizational aspects of [a particular health care institute] help promote collaboration between providers? Are you aware of other clinics with this arrangement of services?

Semi-structured questions for Director of USD Student Health Services (in 9th interview):

1. Are statistics on student utilization of USD Student Health Services available?
2. How common it is for a USD college student to have a primary care provider (PCP)? Does this vary by age or other factors?
3. Please describe the coordination of care between USD Student Health and students' hometown doctors and parents. Is this often requested by students?
4. Is health care transition planning for college students encouraged/facilitated by the USD Student Health Center?
5. How is student health promoted on the USD campus? Are USD Student Health Services a resource for part-time students as well (do they pay the general activity fee)?
6. Some university health centers implement student health insurance plans (SHIPs). How is health insurance addressed at USD student health? Is GeoBlue a type of SHIP? Is there no charge for office visits with providers? What about immunization coverage?
7. Which Sanford Vermillion providers (MDs, NPs, PAs, etc.) provide care for USD students through USD Student Health Services? Can students maintain continuity with a specific provider at USD Student Health?
8. What are the benefits/drawbacks of having USD Student Health Services off-campus? Has USD Student Health Services always been off-campus? Have has utilization been impacted by its off-campus location?
9. Are there benefits/drawbacks to integrating USD Student Health Services and the counseling center? Have the USD Student Health Services and the student counseling

center always been separate? How has utilization been impacted by the separation of these two services?

10. For women students, how common is it for OB/GYNs to also serve as their PCPs?
11. Can you describe the relationship between parents, students, and insurance companies regarding how health information is shared?
12. I am also planning to conduct a survey of the USD student population. Do you have any recommendations as to what questions would be advantageous to include?

Appendix B: Interview questions for junior and senior undergraduate USD students

Students

Part 1: General

- Name
- Age
- Year in school (Junior or Senior)
- Major/Minor
- Race/Ethnicity
- Gender & sexual orientation
- Primary language, other languages spoken
- Yearly income (student) (SES)
    - Student ranges: < $15,000; $15,000-$30,000; $30,000-$60,000; $60,000+
    - Parent ranges: < $50,000, $50,000-$100,000, $100,000+
- Education level of parents/guardians (SES)
- Hometown (rural/urban)
- Residence while at school (on-campus, off-campus)
- How much attention do you pay to getting good health care?
- Do you obtain health care “check-ups” or preventative care services when not sick?
- Do you have any chronic medical conditions that require ongoing treatment? If so, please describe how and where you receive care for these conditions while at college.
- For females: Have you ever obtained gynecological health? (PAP smear, birth control pills, etc.)

- Have you ever experienced difficulty in obtaining health care? If so, please describe.
- Did you receive annual well-child checks with a provider up to age 18?
- As a child, how difficult was it for you to obtain health care services?

Part II: Experience with Identified Barriers

1. Lack of preparation in the transition from pediatric to adult care

- On a scale of 1 to 10, how prepared did you feel about assuming responsibility for your health care (including setting up appointments and that sort of thing) upon starting college? On a scale of 1 to 10, how prepared do you feel now about assuming responsibility for your health care?
- When you were a child, did you have a consistent relationship with a medical provider? If so, what was their classification (pediatrician, family practice, nurse practitioner, physician's assistant, clinical nurse specialist, etc.)? Have you continued to see that provider after the age of 18?
- Have you established with (routinely seen) a provider other than your childhood provider (an "adult" provider)? If so, at what age?
- Do you schedule your own medical appointments?
- Do you attend your medical appointments alone? If so, at what age did your parent/guardian no longer accompany you?
- Please describe your transition from pediatric to adult care. (if applicable)
- Have you ever ordered/picked up your own prescriptions?
- What do you see as your greatest challenges during the transition from pediatric to adult care (if any)? How have these challenges impacted the health care you receive?

2. Lack of a Primary Care Provider

- How familiar are you with the term Primary Care Provider (PCP)?
- Do you have a Primary Care Provider? If so, what is their classification (pediatrician, family practice, internal medicine, nurse practitioner, physician's assistant, OB/GYN, clinical nurse specialist, etc.)? Where do you see your PCP (Vermillion, hometown)? How often do you see your PCP? Do you see your PCP during the school year? Do you see your PCP over the summer?
- Is having a consistent Primary Care Provider something that you would consider a priority? Why or why not?
- If you see other providers (i.e. student health, specialists), have you ever requested to share information about your visit or information from your health record with your PCP (and if so under what circumstances)?
- Do you prefer to see a single provider for your health care needs? In what circumstances are you comfortable utilizing whatever provider is on-call? In what circumstances are you not comfortable utilizing the on-call provider?
- Would you consider the emergency department as a regular source of medical care for your health care needs?

3. Insurance

- Are you covered by health insurance?
- If so, how is this coverage obtained?
- Do you know what providers are covered/in-network with your health insurance? Is Sanford Health included in this coverage?
- Have you ever not seen a certain provider because he or she was not covered by your health insurance?

- Do you share your health information with your parents/guardians? If so, are they granted access to your personal health information, or do you communicate desired information to them?
- Have you ever tried to avoid going to the doctor because of the cost? If so, under what circumstances would you go to the doctor, and under what circumstances not?
- Is there anything else that would keep you from going to the doctor?

4. Electronic Health Record Transfer

- If you have seen multiple providers, do you know if they have access to your Electronic Health Record (EHR)?
- Have you ever needed to re-share any aspect of your medical history with multiple providers?

Part III: USD Student Health Services

- Have you ever received care from USD Student Health Services?
- If so, how many times have you received care from USD Student Health Services?
- If so, why did you visit USD Student Health Services?
- If so, what are your perceptions on the quality of care obtained from USD Student Health Services?
- How familiar are you with the services offered by the USD Student Health Services?
- Do you see USD Student Health Services promoted around campus? Can you recall where and how this promotion was accomplished?

Part IV: For USD Student-Athletes

- Do you utilize the Sanford Coyote Sports Center (SCSC) athletic training room?

- How often (number of times per week) do you visit the training room?
- Do you receive care from the Sanford medical providers who provide care for USD student-athletes? If so, do you consider one of these providers your PCP?
- Do you know if your insurance covers health care services received by Sanford Health? (if applicable)
- Did you know that seeing the same provider over time for multiple health events is associated with positive health outcomes including reduced mortality from all causes, lower rates of admittance to emergency departments, increased patient satisfaction, increased delivery of preventative services such as vaccinations, more effective chronic disease management, and lower healthcare costs (Hofer & McDonald, 2019; Haggerty et al. 2003; Wright & Mainous III, 2018; Goodell et al., 2009; Waibel et al., 2018).

Conclusion

- To your knowledge, are there any other barriers that have prevented you from obtaining health care services while attending college?

Appendix C: Interview questions for the mother of each interviewed junior and senior undergraduate USD student

Parents/Guardians

Part 1: General

- Name
- Age
- Race/Ethnicity
- Gender & sexual orientation
- Primary language, other languages spoken
- Yearly income (parents/household) (SES)
    - Student ranges: < $15,000; $15,000-$30,000; $30,000-$60,000; $60,000+
    - Parent ranges: < $50,000, $50,000-$100,000, $100,000+
- Education level of parents/guardians (SES)
- Residence (rural/urban)
- How much attention do you pay to your child's health care?
- Are you involved in arranging for your child to receive health care? If so, to what extent?
- Do you communicate with your child regularly about your child's health care?
- Have you ever experienced difficulty in obtaining health care for your child? If so, please describe.
- Does your child have any chronic medical conditions that require ongoing treatment? If so, please describe how and where your child receives care for these conditions while at college.

- Did your child receive annual well-child check-ups up to age 18?
- When your child was growing up, did your child have a consistent medical provider? If so, what was their classification (pediatrician, family practice, nurse practitioner, physician's assistant, clinical nurse specialist, etc.)?
- When your child was younger, how difficult was it for you to obtain health care services for your child?

Part II: Experience with Identified Barriers

1. Lack of preparation in the transition from pediatric to adult care

- On a scale of 1 to 10, how prepared do you feel your child is about assuming responsibility for your child's health care?
- Please describe your child's transition from pediatric to adult care (if applicable). How was your involvement impacted by this transition?
- What have been the greatest challenges during this transition? How have these challenges impacted the health care received by your child?

2. Lack of a Primary Care Provider

- How familiar are you with the term Primary Care Provider (PCP)?
- Does your child have a Primary Care Provider? (provide definition) If so, what is their classification (pediatrician, family practice, internal medicine, nurse practitioner, physician's assistant, OB/GYN, clinical nurse specialist, etc.)? Where does your child see your child's PCP (Vermillion, hometown)? How often does your child see your child's PCP?

3. Insurance

- Is your child covered by health insurance?

- If so, how is this coverage obtained?
- What providers are covered/in-network with your child's health insurance?
- Have you ever not had your child see a provider due to the provider not being covered by your insurance?
- How does your child's health insurance cover your child's health care expenses? How does your child being away at college impact this coverage?
- The University of South Dakota Student Health Services are associated with Sanford Vermillion. Does your child's insurance cover services provided by Sanford Health? If not, have any problems arisen due to this lack of coverage?
- Does your child share your child's health information with you? If so, are you granted access to your child's personal health information, or does your child communicate desired information to you?
- If your child's health insurance is provided under your health insurance plan, do you receive explanation of benefits (EOB) of your child's health care services?
- For parents/guardians of student-athletes: Does your child receive services from the Sanford medical providers who provide health care for the Coyote student-athletes? Does your child's insurance cover these services?

Part III: USD Student Health Services

- Has your child ever received care from USD Student Health Services?
- If so, do you have an opinion on the quality of care obtained from USD Student Health Services?
- How familiar are you with the services offered by the USD Student Health Services?

- Did you know that seeing the same provider over time for multiple health events is associated with positive health outcomes including reduced mortality from all causes, lower rates of admittance to emergency departments, increased patient satisfaction, increased delivery of preventative services such as vaccinations, more effective chronic disease management, and lower healthcare costs (Hofer & McDonald, 2019; Haggerty et al. 2003; Wright & Mainous III, 2018; Goodell et al., 2009; Waibel et al., 2018).

Conclusion

To your knowledge, are there any other barriers that have prevented your child from obtaining health care services while attending college?

Appendix D: IRB consent form for interviewed undergraduate USD college students and their mothers

UNIVERSITY OF SOUTH DAKOTA
Institutional Review Board
Informed Consent Statement

Title of Project:	Barriers to Relational Continuity of Care for Undergraduate College Students in Southeastern South Dakota
Principal Investigator:	Louisa Roberts, East Hall 308, University of South Dakota, Vermillion, SD 57069 (605) 667-5402 Louisa.Roberts@usd.edu
Other Investigators:	Laura Nelson, University of South Dakota, Vermillion, SD 57069 (605) 760-1716 Laura.Nelson@coyotes.usd.edu

Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be enrolled as a junior or senior undergraduate student at the University of South Dakota, or be a parent. Taking part in this research project is voluntary. Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the study about and why are we doing it?

The purpose of the study is to identify barriers to relational continuity of care with a primary care provider (PCP) for undergraduate college students in southeastern South Dakota. This study will explore what factors impede healthcare acquisition and creating a long-term relationship with a primary care provider for undergraduate college students in southeastern South Dakota. About 14 people will take part in this portion of the research. It is our intention to provide the health care field with useful information through this research project. By identifying barriers to continuity of care for undergraduate college students in southeastern South Dakota, efforts can be made to reduce these barriers and to provide quality health care for this population.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to answer questions in a one-on-one phone interview at a scheduled date and time.

For students, questions will ask about your health care experiences, the types of health care services you have received, where you have obtained health care services, and who provides you with health care services. Some questions may ask about Protected Health Information (PHI) and may be sensitive in nature. Questions about healthcare insurance coverage, your health history, and female gynecological health may fall under this category.

For parents/guardians, questions will be similar in nature but will be about your child's health care, not your own.

The interview will last approximately 30 to 60 minutes, and the interview will only occur once. The interviews will be audio recorded, and interviews with students will be separate from the interviews with the student's parent/guardian.

What risks might result from being in this study?

Some questions may be of a sensitive nature, and therefore you may become uncomfortable as a result.

However, these risks are not viewed as being in excess of your experiences in everyday life. Nonetheless, if you become upset by questions, you may stop at any time or choose not to answer a question.

If you are a student and would like to talk to someone about your feelings regarding this, please contact The University of South Dakota's Student Counseling Center at 605-677-5777 which provides counseling services to USD students at no charge.

How could you benefit from this study?

There is no direct benefit from participating, but you might learn more about yourself and acquire a better understanding of the importance of a long-term relationship with a health care provider.

By identifying barriers to relational continuity of care for undergraduate college students in southeastern South Dakota, efforts can be made to reduce these barriers and provide quality health care for this population. Depending on what type of barriers I find, my project may draw attention to the need for a public education campaign to emphasize the importance of a longitudinal patient-provider relationship, demonstrate need for insurance reform for this age cohort, or improve student health services available at the University of South Dakota.

How will we protect your information?

We will protect the confidentiality of your research records by making the data anonymous, removing your name, and deleting audio recordings upon transcription of the interviews. Interviews will be conducted in private, and HIPAA guidelines will be followed. You have the right to review/edit the audio recordings of your interview, if desired. Only the student and principal investigators will have access to these recordings. The audio recordings will be used in order to transcribe the interview and then will be erased.

The records of this study will be kept confidential to the extent permitted by law. Any report published with the results of this study will remain confidential and will be disclosed only with your permission or as required by law. To protect your privacy we will not include any information that could identify you. We will protect the confidentiality of the research data by storing identifiers with collected data and deleting your name upon transcription of the interview.

It is possible that other people may need to see the information we collect about you. These people work for the University of South Dakota and other agencies as required by law or allowed by federal regulations.

Your Participation in this Study is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer.

Contact Information for the Study Team and Questions about the Research

The researcher conducting this study is Laura Nelson. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Laura Nelson at (605) 760-1716 or Dr. Louisa Roberts at (605) 677-5402 during the day.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 658-3743. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

Your Consent

Before agreeing to be part of the research, please be sure that you understand what the study is about. Keep this copy of this document for your records. If you have any questions about the study later, you can contact the study team using the information provided above.

Appendix E: Survey questions for USD undergraduate college students

1. **Year in school (undergraduate)**

   Freshman

   Sophomore

   Junior

   Senior

2. **Age**

3. **From Vermillion, my hometown is located**

   <100 miles

   101-300 miles

   301+ miles

   I am from another country

4. **Your yearly income**

   < $15,000

   $15,000-$30,000

   $30,000-$60,000

   $60,000+

5. **Household income of your parent(s) / guardian(s) (you may make your best approximation)**

   <$25,000

   $25,000-$50,000

   $50,000-$100,000

   $100,000+

6. **Race**

   American Indian or Alaska Native

   Asian

   Black or African American

   Native Hawaiian or Other Pacific Islander

   White

   Other

7. **Ethnicity**

   Hispanic or Latino

   Not Hispanic or Latino

8. **Gender**

   Male

   Female

   Gender Nonconforming (Trans, Nonbinary, etc.)

   Prefer not to say

   Other

9. **Do you identify as a member of the LGTBQ+ community?**

   Yes

   No

   Not sure

10. **Is English your primary language?**

    Yes

    No

11. Other languages spoken fluently?

12. Are you in a health-related major or minor?

Yes

No

Not sure

13. Residence while at school

On-campus

Off-campus

14. Do you have a chronic health condition(s)?

Yes

No

Not sure

15. If you do have a chronic health condition(s), please list:

16. A primary care provider (PCP) is a medical provider who provides continuing health care for a patient and has a sustained (long-term) relationship with the patient. Do you have a primary care provider?

Yes

No

Not sure

17. If yes, how long have you seen your primary care provider?

< 1 year

1-2 years

3-4 years

5+ years

18. If yes, where do you see your primary care provider?

Vermillion or near Vermillion

Hometown or near hometown

Other

19. If yes, how often do you see your primary care provider?

Yearly/routinely

Only when I need to

Yearly/routinely and when I need to

20. Is having a consistent (long-term) relationship with a primary care provider who you see on a regular basis something that you would consider a priority?

Yes

No

Not sure

21. Do you still see the same medical provider that you saw as a child?

Yes

No

Not sure

I did not see one provider consistently as a child

22. If you are NOT still seeing your childhood medical provider, did you experience a difficult transition from pediatric to adult care?

Yes

No

Not sure

Other

23. Have you ever received care from USD Student Health Services?

Yes

No

Not sure

24. If so, why did you visit USD Student Health Services?

Acute illness

Vaccination

STD testing

Laboratory tests

Medical Imaging (X-ray, MRI, CT scan, Ultrasound, etc.)

Well-check (routine check-up)

Athletic physical

Gynecological health (PAP smear, birth control, etc.)

Other

25. How familiar are you with the services offered by the USD Student Health Services?

Very familiar

Familiar

Somewhat familiar

Not familiar

26. Are you a student-athlete at USD?

Yes

No

27. If you are a student-athlete at USD, have you received care from the Sanford medical providers that routinely visit the athletic training room?

Yes

No

Not sure

28. If you are a student-athlete and have received care from the Sanford medical providers that routinely visit the athletic training room, do you consider one of these providers to be your primary care provider (PCP)?

Yes

No

Not sure

29. Which of these barriers to having a single primary care provider you see regularly have you experienced since transitioning to college? Select all that apply.

- It is challenging to find a provider who understands my sexual orientation or gender identity
- My primary care provider does not practice in the town I attend college
- At one point or another, I did not feel comfortable assuming responsibility for my healthcare (scheduling appointments, finding a provider, calling in and picking up prescriptions, etc.)
- My health insurance does not cover my preferred healthcare providers or the providers available in the area I attend college
- It is challenging to find a provider who can speak my preferred language

- I do not have health insurance
- I cannot afford the cost of health care
- I do not have time to see a provider routinely
- I must travel many miles to see my primary care provider.
- I am in good health and do not need health care.

30. **To your knowledge, are there any other barriers that have prevented you from obtaining health care services while attending college?**
31. **Did you know that seeing the same provider over time for multiple health events is associated with positive health outcomes including reduced mortality from all causes, lower rates of admittance to emergency departments, increased patient satisfaction, increased delivery of preventative services such as vaccinations, more effective chronic disease management, and lower healthcare costs?**

    Yes

    No

    Not sure

Appendix F: IRB consent form for undergraduate college student survey participants

UNIVERSITY OF SOUTH DAKOTA
Institutional Review Board
Informed Consent Statement

Title of Project: Barriers to Relational Continuity of Care for Undergraduate College Students in Southeastern South Dakota

Principal Investigator: Louisa Roberts, East Hall 308, University of South Dakota, Vermillion, SD 57069 (605) 667-5402 Louisa.Roberts@usd.edu

Other Investigators: Laura Nelson, University of South Dakota, Vermillion, SD 57069 (605) 760-1716 Laura.Nelson@coyotes.usd.edu

Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be an undergraduate college student at the University of South Dakota. Taking part in this research project is voluntary. Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the study about and why are we doing it?

The purpose of the study is to identify barriers to relational continuity of care with a primary care provider (PCP) for undergraduate college students in southeastern South Dakota. This study will explore what factors impede healthcare acquisition and creating a long-term relationship with a primary care provider for undergraduate college students in southeastern South Dakota. Undergraduate college students at the University of South Dakota are invited to take part in this portion of the research. It is our intention to provide the health care field with useful information through this research project. By identifying barriers to continuity of care for undergraduate college students in southeastern South Dakota, efforts can be made to reduce these barriers and to provide quality health care for this population.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to complete a survey about your health care

experiences, including the types of health care services you have received, where you have obtained health care services, and who provides you with health care services. Some questions may ask about Protected Health Information (PHI) and may be sensitive in nature. Questions about healthcare insurance coverage, your health history, and female

gynecological health may fall under this category. The survey will take approximately 10 to 15 minutes.

What risks might result from being in this study?

You may experience frustration that is often experienced when completing surveys. Some questions may be of a sensitive nature, and therefore you may become uncomfortable as a result. However, these risks are not viewed as being in excess of your experiences in everyday life. Nonetheless, if you become upset by questions, you may stop at any time or choose not to answer a question. If you would like to talk to someone about your feelings regarding this, students are encouraged to contact The University of South Dakota's Student Counseling Center at 605-677-5777 which provides counseling services to USD students at no charge.

How could you benefit from this study?

There is no direct benefit from participating, but you might learn more about yourself and acquire a better understanding of the importance of a long-term relationship with a health care provider.

By identifying barriers to relational continuity of care for undergraduate college students in southeastern South Dakota, efforts can be made to reduce these barriers and provide quality health care for this population. Depending on what type of barriers I find, my project may draw attention to the need for a public education campaign to emphasize the importance of a longitudinal patient-provider relationship, demonstrate need for insurance reform for this age cohort, or improve student health services available at the University of South Dakota.

How will we protect your information?

We will protect the confidentiality of your research records by making the data anonymous and not collecting your name. The records of this study will be kept confidential to the extent permitted by law. Any report published with the results of this study will remain confidential and will be disclosed only with your permission or as required by law. To protect your privacy we will not include any information that could identify you. We will protect the confidentiality of the research data by keeping the data anonymous.

However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant in our study, we want you to be aware that certain "key logging" software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

It is possible that other people may need to see the information we collect about you. These people work for the University of South Dakota and other agencies as required by law or allowed by federal regulations.

Your Participation in this Study is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer.

Contact Information for the Study Team and Questions about the Research

The researcher conducting this study is Laura Nelson. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Laura Nelson at (605) 760-1716 or Dr. Louisa Roberts at (605) 677-5402 during the day.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 658-3743. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

Your Consent

Before agreeing to be part of the research, please be sure that you understand what the study is about. Keep this copy of this document for your records. If you have any questions about the study later, you can contact the study team using the information provided above.