Integrated Healthcare in the U.S. Safety-Net System: Meeting the Needs of Patients through Comprehensive Medical and Social Care

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INTEGRATED HEALTHCARE IN THE U.S. SAFETY-NET SYSTEM: MEETING THE NEEDS OF PATIENTS THROUGH COMPREHENSIVE MEDICAL AND SOCIAL CARE

by

JACQUELINE M. DEVANEY
B.A. University of Central Florida, 2016

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts in the Department of Anthropology in the College of Sciences at the University of Central Florida Orlando, Florida

Summer Term, 2023
ABSTRACT

This thesis examines how a Patient-Centered Medical Home addresses, implements, and provides medical and social resources and services within the Florida U.S. safety-net system, and how patients and providers perceive health care interactions between each other. The safety-net clinics seek to fill the care gap for millions of uninsured low-income U.S. residents who cannot afford private insurance, are unemployed, self-employed, undocumented, or their low income exceeds the qualification threshold, and they face barriers in accessing expensive medical care in the U.S.

I have conducted ethnographic research at Grace Medical Home, a safety-net clinic in Central Florida, which included five months of primary data collection via participant observation, informal interviews, and 22 semi-structured interviews with healthcare providers, volunteers, and patients. My secondary data analysis focused on health policies and guidelines.

Based on the study findings, I argue that safety-net clinics are vital in addressing health care gaps for the uninsured, and are in the position to provide comprehensive services by integrating social care (e.g., transportation, housing, food) together with medical services, including mental healthcare. The generative labor approaches evident at my research site are valuable in mitigating structural vulnerabilities and remaining barriers in the delivery of social care. An example of generative labor of healthcare providers is assisting a patient that is applying for the prescription application program (PAP) which provides free medications to patients for a year. This can be a complicated process but the assistance from a healthcare provider mitigates these complexities by utilizing the provider’s expertise of the PAP process. However, the safety-net clinics must navigate complicated and challenging state and government policies. The interview narratives also show that care is conceptualized beyond medical and social needs, with
the goal of restoring dignity in care, fostering relationships, and offering Christ-centered, non-judgmental care. In my discussion, I apply critical medical anthropology approaches through an analysis of the health care structures, health inequalities, and the political economy of health care for vulnerable people.

This study is significant to anthropology and public health because it demonstrates the implementation of integrative, comprehensive medical and social care in addressing social determinants of health within the Florida safety-net system. It also advances our understanding of the way care is conceptualized at a faith-based safety-net clinic. As patient-centered care is becoming the gold standard in recent decades, this study also contributes an ethnographic analysis of how a safety net clinic achieves the goal of providing this form of care.
ACKNOWLEDGMENTS

I would like to thank Dr. Joanna Mishtal, my mentor, thesis chair, and friend, for her exemplary guidance and support throughout my educational career and her words of encouragement “Bird by Bird.” I thank my thesis committee, Dr. Shana Harris and Dr. Lindsay A. Taliaferro, for their encouragement and guidance during my research process. To my mother, Kathleen, thank you for always believing in what I can accomplish. And lastly, this research would not have been possible without the Grace Medical Home leadership board who approved my study, and the participants enthusiastic participation and commitment to sharing their stories, thank you.
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CHAPTER 1: INTRODUCTION

The Centers for Disease Control and Prevention (CDC) on August 18th, 2020 launched the fifth iteration of the Healthy People 2030 Campaign. The goal of this government campaign is to create a society in which all people can achieve their full potential for health and well-being while promoting, strengthening, and elevating the nation’s people through improving these five categories: health conditions, health behaviors, populations, settings and systems, and social determinants of health. This program has been running for over four decades to improve overall quality of life among the U.S. population. How do these programs access vulnerable populations and how do individuals living with chronic illnesses find resources through this kind of national program? Chronic disease management has significant health and economic cost in the U.S with the CDC reporting that 90% of the annual healthcare budget is spent on people with chronic and mental health conditions, therefore preventing or managing chronic symptoms can help reduce these costs.¹

The State of Florida data identify obvious health disparities among populations with high economic hardship within several zip codes that include higher rates of hospitalization and deaths from chronic conditions such as diabetes, cardio-vascular disease, and cancer compared to higher income populations in higher income zip codes.² Individuals within Orange County experiencing economic hardship, making less than $25,000 a year, are more likely to be uninsured (Florida Health: Orange County 2019). The U.S. market-based healthcare system generates gaps in health insurance coverage, leaving the most vulnerable populations who fall

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¹ Data obtained from CDC website: https://www.cdc.gov/chronicdisease/about/costs/index.htm#ref1
² Floridahealthcarts.gov is an interactive map that shows several health and income disparities in all FL counties. Specific data can be obtained from a zip code and indicating what health risk factors you want to research: https://www.arcgis.com/apps/webappviewer/index.html?id=94e5d8f155934192ac999a3a9fd7960d&extent=-10885565.6504%2C2548005.9719%2C-7754704.9718%2C3863945.8509%2C102100
within these gaps of inequitable health services and resources uninsured. Within Florida, 16.3% of nonelderly individuals were uninsured in 2018.³

As I will argue, this creates a need for researchers to address ideologies of healthcare as a right versus a privilege vis-a-vis healthcare access and how local and federal infrastructure can impose unintended structural violence (Rylko-Bauer and Farmer 2016) among vulnerable populations, such as the health disparities of the uninsured based on income and zip code. Anthropologists can research efficient health policy implementation methods within structurally vulnerable populations through collaborations with government institutions like the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and local state agencies. A way this can be achieved is by examining multiple safety-net field sites and the impact of healthcare structural vulnerabilities within the U.S., with the goal of finding solutions to reduce health inequities by examining illness narratives of individuals within marginalized communities. Central Florida Maps 1 and 2⁴ below represent selected economic hardships and health disparities within Orange County, Florida.

Figure 1 below shows that the highest rate of asthma hospitalizations over a period of 5 years, from 2013 to 2017, has been in two zip codes: 32808 and 32805. These zip codes are also areas with high economic vulnerability. Figure 2 below shows the prevalence of another relevant chronic disease, namely diabetic hospitalizations, in a 5-year period from 2013 to 2017, within the same two zip codes. These figures highlight how socioeconomic status and chronic disease prevalence overlap with continuous health disparities within Central Florida.

³ Data obtained from Kaiser Family Foundation (KFF) website: https://www.kff.org/statedata/election-state-fact-sheets/florida/
⁴ Data obtained from Florida Department of Health: https://www.arcgis.com/apps/webappviewer/index.html?id=94e5d8f155934192ac999a3a9fd7960d&extent=-10885565.6504%2C2548005.9719%2C-7754704.9718%2C3863945.8509%2C102100
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Figure 2: Tate of Diabetes Hospitalizations in Orange County Florida from 2013-2017 (Source: Florida Department of Health)
On the national level, Figure 3 highlights the states that adopted and did not adopt the expansion of Medicaid after the ACA implementation. In comparison, Figure 4 shows the areas of the U.S. with the highest rates of uninsured people, revealing again an overlap between the lack of Medicaid expansion and uninsured due to insurance status.

Figure 3: Medicaid Expansion by State from 2023 (Source: Kaiser Family Foundation [https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/](https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/))

According to Huguet and colleagues (2018) following the ACA implementation, community health centers reported fewer visits from uninsured patients and an increase in Medicaid paid visits from Medicaid expanded states, which improved access to government health insurance programs. Community health centers, federally qualified health centers, and non-government organizations, also known as safety-net clinics, are essential facilities where the uninsured and underinsured may be able to find care.

In my research conducted in 2022-2023, I examine, through a health systems analysis, how providers provide and address medical and social services and resources for low-income adults with inadequate healthcare coverage.

Limitations and Strengths

I experienced two limitations during this research project. The first limitation involved time constraints with data collection. I submitted my research proposal in June 2022 to the UCF
IRB and did not obtain approval until August 2022, with data collection beginning in September 2022. Since data collection at my field site, Grace Medical Home (GMH), began during the 2022 academic year, I had less time to dedicate to research hours. I anticipated having two to three days per week of participant observations and interviewing during the summer. However, this time was reduced to one day a week during the fall. This reduced fieldwork time impacted my ability to recruit patients, given this recruitment was slower than expected and would have required several more months to reach the target sample size. However, conducting most of the research in the fall strengthened my ability to collect data with staff and volunteers because more of them work at GMH in the fall than in the summer when people take vacations and breaks.

The second limitation to this research project is that I do not speak Spanish. When I started volunteering in the registration department, I realized that the majority of patients seen at GMH are Spanish speakers. This language barrier limited my ability to recruit Spanish-speaking patients to collect data about their chronic illness narratives in the safety-net system. Consequently, by October 2022, in consultation with my committee, I redirected my research focus on an institutional ethnography study to understand how GMH addresses social, mental, medical, and structural elements of health access for their patients, in particular for patients with chronic illnesses. The guiding research questions were:

1.) What are the lived experiences of individuals who fall into the health insurance coverage gap that requires them to utilize safety-net clinics for chronic illness treatments and services?

2.) How does GMH address social and structural elements of healthcare access and services for their chronically ill patients?
CHAPTER 2: INTEGRATIVE CARE: IMPLEMENTING COMPREHENSIVE MEDICAL AND SOCIAL CARE IN THE FLORIDA SAFETY-NET

The first section of the thesis is a manuscript titled “Integrative Care: Implementing Comprehensive Medical and Social Care in the Florida Safety-Net,” prepared for submission to the Human Organization journal, the peer-reviewed flagship journal of the Society for Applied Anthropology (https://meridian.allenpress.com/human-organization). This article examines the strategies that make the implementation of healthcare services within the safety-net system of Orange County, Florida, resourceful through a holistic and comprehensive approach to the delivery of medical and social services. This article is distinct from the second article of my thesis, “What does it Mean to Provide ‘Care’ in the U.S. Safety-Net System?,” which examines ideas of care, resources, services, and labor in the context of a commodified and marketed healthcare system. The first article relates to the thesis in its entirety by discussing the results of this research, which examines medical and social care in political and socioeconomic contexts.
Article:
Prepared for submission to journal: *Human Organization*

Abstract

The U.S. safety-net system is comprised of government and non-government medical clinics that provide needed medical services and resources to underserved or uninsured people. This article examines approaches underpinning the delivery of care provided in the management of chronic illness at a faith-based Patient-Centered Medical Home (PCMH) in the Florida’s safety-net system from the perspective of healthcare providers and patients. Ethnographic methods included primary data collection in the form of five months of participant observation, informal interviews, as well as 22 semi-structured interviews with healthcare providers, volunteers, and patients, as well as a secondary data analysis of health policies and guidelines. I argue that safety-net clinics are vital in addressing healthcare gaps experienced by the uninsured. My findings contribute to critical medical anthropology by offering an analysis of the healthcare structures, the analysis of health inequalities, and the political economy of health care for vulnerable people in the Florida safety-net. It is evident from the findings of this study that PCMH safety-net clinics are in the position to provide comprehensive medical and social care to their patients. However, safety-net healthcare providers must navigate complicated and challenging state and government policies associated with accessing healthcare services. This study is significant to anthropology because it demonstrates the implementation of integrative, comprehensive medical and social care in addressing social determinants of health within GMH and Orange Country for chronically ill patients.

**Keywords:** Social Care, U.S. Safety-Net, Integrative Healthcare, Patient-Centered Medical Home
Introduction

Since the late 1970s, the U.S. healthcare system transformed into a market-based healthcare model shaped by competition, commercialization, and corporatization of health services through managed care, pharmaceuticals, and biotechnology industries (Rylko-Bauer and Farmer 2002). Through this marketization, the healthcare field experienced higher health costs, growth of corporate structures, and quality of care became measured based on patient satisfaction surveys. This created a consumer model of care that placed patients as “consumers” and health services as the “product” through insurance exchange groups, which authorize or deny services based on cost of health procedures (Rylko-Bauer and Farmer 2002). Through various political and industry reforms, the U.S. healthcare system became separated into two distinct sectors: private and public healthcare markets. High-income patients most often utilized private health insurance, while publicly funded health insurance supported by state and federal programs, such as Medicaid and Medicare, are predominantly used by those of low socioeconomic status (SES) who either cannot afford insurance from their workplace, or are unemployed, disabled, or self-employed (Becker 2007).

In 2002, 43.6 million Americans were uninsured – one of the highest rates of uninsured and healthcare costs within industrialized nations (Becker 2004) – due to healthcare options being limited to only private and public insurance. A severe gap in insurance coverage resulted for people lacking employment or those who were under their state’s poverty level and, therefore, not eligible for public, government programs. Due to this stratification of access, the need for health services for the uninsured was addressed by the creation of “safety-net” charity care provided by loosely organized privately and publicly funded hospitals, health departments, and clinics (Becker 2004). These low to no cost clinics can include federally qualified health centers
(FQHC), community health centers (CHC), Non-Government Organizations (NGO), and Disproportionate Share Hospitals (DSH) funds. Due to the overwhelming number of the uninsured and underinsured people in the U.S., and pressure from other industrialized and developed countries with universal health coverage, the U.S. passed a comprehensive healthcare reform bill in 2010 under the Obama Administration to address some of these deficiencies.

This major healthcare reform in 2010, titled the Patient Protection and Affordable Care Act (ACA), attempted to close the gap in healthcare coverage for millions of Americans. This expansion expanded medical coverage of current government programs, such as Medicaid and Medicare; created health insurance marketplaces, which are private insurance plans purchasable through the government for citizens who have small business, have no plan provided by their employer or are above the state poverty level; extended insurable age of dependents to include individuals under the age of 25; the individual mandate; and eliminating preexisting condition limits, which benefited pregnant people (Horton et al. 2014; Joseph and Marrow 2017).

However, gaps in coverage persist for millions of Americans despite the passing of the ACA. Migration studies scholars, Joseph and Marrow, observe that the 19 states that did not expand Medicaid for nonelderly adults living under 138% of the poverty level were located primarily in the South and West in 2016 (2017, 1969). States refusal to expand Medicaid was an option made available through the Supreme Court’s 2012 ruling that was spearheaded by conservative U.S. legislators who favor privatization of care over the expansion of publicly funded services (Joseph and Marrow 2017). As of 2023, 41 states (including DC) opted into the Medicaid expansion program. Florida is one of the 10 states that has not expanded Medicaid (Kaiser Family Foundation 2023).
Sociologist Susan Sered (2018) conducted a multisite ethnographic fieldwork study spanning over a decade that examined individuals’ healthcare coverage before and after the ACA reform to determine how access to services changed for Americans following these policy decisions. Sered found that the overall number of uninsured Americans decreased significantly post-ACA, but the healthcare landscape still remained stratified by coverage gaps, interruptions in insurance due to job changes, and coverage linked to employment (Sered 2018). Joseph and Marrow (2017) scrutinized how the ACA heavily restructured the funding of the safety-net system though FQHCs by increasing funding to counties, which provide needed health services to income eligible residents, but reduced funding to DSH, which subsidizes care to Medicaid and indigent patients through the hospitals (2017). The populations most at risk for lack of services and access are ethnic/racial minoritized, low SES, and immigrant populations who still cannot afford or access adequate healthcare services.

Safety-Net Research

Scholars in several academic disciplines have conducted research on the safety-net system before the ACA was implemented, but only a dearth of studies exist post-ACA. Most public health and medical scholarship within the topic of “the safety-net” focus on the role and relevance of various public and private safety-net institutions within the U.S., showing that populations seeking these services are predominantly uninsured and vulnerable groups, i.e., low income, minorities, and migrants (Darnell 2011; Nguyen et al. 2016). Anthropology and sociology are two disciplines that have a fundamental and deep understanding of barriers, access to quality care, and patient engagement within safety-net institutions among vulnerable populations (Fleming et al. 2021; Huguet et al. 2018; Hurstuck et al. 2017; and Kamimura et. al. 2019).
Medical anthropologist Gay Becker (2007) conducted an extensive ethnographic study within safety-net institutions with 215 chronically ill uninsured ethnic minority patients that examined their continuity of care. This study focused on county hospitals, community clinics, and social service agencies. Researchers found that the primary barrier to continuous quality care was patients’ uninsured status. Many participants reported struggling to schedule specialists because of their lack of insurance, and were often not given the same physician, creating poor continuity of care (Becker 2007). Becker argues that “one critical, yet largely hidden, facet of this dilemma is how the management of the problem facilitates racialization. The numbers of uninsured are disproportionately composed of ethnic minorities who are poor and who receive their health care in the public-sector system, where they experience discrimination” (2007, 315). Even within community health clinics, volunteer medical staff may not provide consistent health services. Since participants manage their illnesses with costly medication, such as insulin for type 2 diabetes, these patients often reported difficulties choosing between health expenditures and daily living expenses. Building on Becker’s work, anthropologist and public health scholar Mark Fleming and colleagues’ (2021) study focused on how providers assist chronically ill patients within two safety-net urban hospitals. They found that the hospitals addressed care beyond clinic services, from conducting home checks to coordinating resources, such as transportation, to helping patients manage their illnesses within their daily living routines.

Sociologist Akiko Kamimura and colleagues (2016) conducted a study to understand the experiences of undocumented and uninsured individuals utilizing a free clinic and found an important additional barrier experienced by vulnerable populations involved lack of internet access and knowledge, which impeded their utilization of healthcare services. Participants in this study reported interest in learning more about healthy lifestyles and the ACA, but were unable to
obtain information about available resources (Kamimura et al. 2016, 19). With many health and government agencies utilizing the internet, and placing forms and documents on websites to access potential services, this reliance on the Internet creates a new modern barrier to healthcare access for populations that are structurally vulnerable. Thus, structural and social determinants of health (SDH) are key in understanding how sociocultural factors influence health outcomes. SDH is defined by the World Health Organization (WHO) as “the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development [economic] agendas, social norms, social policies and political systems” (WHO 2023).

The ACA was never designed to overhaul the U.S. health care landscape, as health care coverage is still linked to employment, reinforcing U.S work ideology to validate those that work and stigmatize those who cannot work (Castaneda and Mulligan 2018). Within the U.S. healthcare system, access is primarily linked to employment, which can leave individuals who have lost employment or are employed part-time with gaps in health insurance coverage while finding new employment opportunities.

Many public health and social science studies of healthcare access focus on aspects of the patient experience to improve care delivery or the provider experience of the delivery of care (Fleming et al. 2021; Huguet et al. 2018; Hurstack et al. 2017; and Kamimura et. al. 2019). There are very few studies focusing on how vulnerable populations embody their illness experiences and the ways healthcare providers implement strategies to mitigate SDH associated with barriers to accessing needed care in clinical settings. The purpose of this study involved examining how low-income adults with inadequate healthcare coverage manage their chronic illness experiences
within the safety-net system of Orange County, Florida. Within Florida, 16.3% of nonelderly individuals were uninsured in 2018 (Orgera, Tolbert, and Singer 2023). The research question that guided this study was: How does a safety-net clinic address social and structural elements of healthcare access and services for their chronically ill patients?

**Theoretical Frameworks**

**Political Economy of Health**

Within anthropology, the intersectional concept of political economy lies within the systematic, institutionalized structures that govern political and economic modes of production, power, and globalization (Roseberry 1988). Medical anthropologist Hans Baer describes these structures within healthcare contexts as “the impact that the capitalist mode of production has on the production, distribution, and consumption of health services and how these processes reflect the class relations of the larger societies within which medical institutions are embedded” (1982, 1). Philippe Bourgois (2003) furthers this framework by integrating social suffering experiences of the individuals that fall within these political and economically violent structures within the U.S. healthcare system.

**Structural Vulnerability**

The concept of structural vulnerability is particularly important for this study because, according to anthropologists Barbara Rylko-Bauer and Paul Farmer (2016), it allows the analysis of social dynamics between poverty and institutions of power. Specifically, it is the violence of injustice and inequity that is embedded in social structures, such as economic, political, legal, religious, or cultural, which are then normalized by those institutions and the public’s experiences. They argue that applying the structural violence framework in public health contexts shifts perceptions of risk and health inequalities through an analysis of power structures
to include the understanding of how those sociopolitical and economic structures shape those risks and community realities (Rylko-Bauer and Farmer 2016). Anthropologist James Quesada and colleagues (2011) further stress the importance of extending the structural violence analysis to the internalized physical and psychosocial embodiment of those sociopolitical and economic forces on the individuals. The utility of the framework in this research also helps to highlight how structural vulnerability of patients is recognized by a safety-net clinic and how it is accounted for in the care and resources the clinic provides.

**Methods**

*Study Setting*

This paper draws on 5 months of ethnographic data collected between 2022 and 2023 at Grace Medical Home (GMH), including participant-observation, informal interviews, semi-structured interviews, and a state/federal health program analysis, which includes researching websites from the Florida Department of Health, the Center for Disease Control and Prevention, and Primary Care Access Network for health conditions, health services, and healthcare statistics. GMH is a safety-net clinic in Central Florida that provides essential health services to medically underserved vulnerable populations. GMH is a private faith-based organization accredited by the National Committee for Quality Assurance as a patient-centered medical home (PCMH) for employed, but uninsured, patients who are below the 200% federal poverty level.

*Data Collection and Recruitment*

I conducted participant observation through volunteering in a non-clinical department, informal interviews with staff/volunteers, and shadowing non-clinical and clinical staff with patients to build rapport to develop a holistic and deep understanding of GMH’s work (DeWalt and DeWalt 2011, Fetterman 2019). Extensive fieldnotes became an essential source for
This study focuses on the primary sample of 20 in-depth semi-structured interviews I conducted with key informants representing all aspects of work at GMH: clinical staff, managers, and clinical and non-clinical volunteers. Key informants had to be with GMH for at least 3 months, at least 18 years old, and able to speak English. Key informants were defined as those with a significant role within the provision of safety-net care and important insights to share due to their seniority or specialist roles (Marshall 1996). From an anthropological perspective, “studying up” GMH’s staff was important for understanding the institutional setting and provided understanding about potential ways to improve care (Nader 1972). Interviews with key informants followed an 18-item interview guide with topical domains of: role and experience in the clinic; impacts of socioeconomic, transportation, social, and other factors on clinic’s patients; and approaches to the provision of care in each department. Purposive sampling allowed for the recruitment of key informants aimed to collect data from each aspect of GMH’s work, allowing saturation with this sample (Bernard 2006,145, 436).

Of the 20 interviews, 18 were conducted in-person within a private room at GMH, and 2 via Microsoft Teams. Nineteen participants permitted audio recording, while 3 did not. Interviews lasted 27 to 60 minutes. Key Informants were not remunerated. The names of participants are pseudonyms and specific locations are de-identified. Table 1 illustrates the demographic characteristics of the 20 key informants. Key Informants who were employed or volunteered at the clinic held a variety of positions, including manager, intern, physician, volunteer, counselor, social worker, clinical worker, and represented every department in the clinic. Their ages ranged from 20 to 74 years (35 – 54 years: n=8, 20 – 34 years: n=7, and
55 – 74 years: n=5). In terms of gender identity, 18 of 20 providers self-identified as female or feminine when asked their gender identity. Self-identified ethnicity/race was reported as Hispanic or white Hispanic (n=9), white (n=7), Asian or Korean Asian (n=2), and Black or African American (n=2). English was the primary language for most of the sample. Religious representation in the sample included Christian or Catholic, Islam, and no affiliation.
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Data Analysis

All audio files were transcribed verbatim, and the transcripts were coded both manually and using Dedoose software. The state/federal health program analysis of websites such as Florida Department of Health, the Center for Disease Control and Prevention, and Primary Care Access Network for health conditions, was analyzed for health services, and healthcare statistics were used to reference chronic health conditions, treatments, and available health care resources. I generated and refined codes and subcodes through an iterative process, wherein I used frequent comparisons between the interview text and the codes, and created a codebook to reference code and subcode meanings (Charmaz and Bryant 2016). The directed content approach was used in the initial coding process that allows for the use of existing theories to develop initial deductive codes prior to thematic data analysis, but also allows for additional revised and refined inductive codes to develop through the analysis if needed (Hsieh and Shannon 2005, 1286). From the refined codes, I mapped out larger themes of the coded data. The thematic analysis included coding for both predetermined a priori codes, as well as inductive, not previously considered factors and/or explanations (Strauss and Corbin 1998).

Results and Discussion

Overall, my data show that GMH addresses social and structural elements of healthcare access and services to patients with chronic illnesses by providing integrative and comprehensive healthcare. However, some barriers in the accessibility of care persist. The main themes that emerged from this research included: holistic approach to patient care, social care and generative labor approaches in mitigating structural vulnerabilities, and remaining barriers in the delivery of social care.
Theme 1: Holistic Approach to Patient Care

*Interdepartmental Collaboration*

GMH operates and administers care through clinical and non-clinical staff and volunteers within their six departments. These departments consist of Care Coordination, which coordinates specialty care with community partners who donate services or volunteer physicians with specialty clinics; Dental, which has an established dental staff with dental students; Primary Care-Adults and Pediatrics, which consists of volunteers, interns, and clinical staff; Spiritual Care, which provides spiritual guidance through the Pastor and volunteers; Behavioral Health and Social Services, which provides social and mental health resources and services through staff and volunteer clinical social workers, and Patient Registration, which is primarily volunteer based and registers patients. Each department has its own separate responsibilities to the patient, but works together with the other departments to provide integrative medical and social healthcare to uninsured patients. Arianna, a clinical technician with GMH for four years, describes the impact of GMH departmental integration working in the medication room, where medications are stored.

We need to have the integration of each department. Providers can't be with us, the patients need the providers. We [med room] are a good piece of the puzzle, but we would not be as impactful without the team, somehow we are all connected. In the med room specifically. The goal when a provider looks for meds or prescription application program, is to have the patient to stop here and not go to the pharmacy, not wait, not spend money at pharmacy, or transportation because there can be problems. There is one stop. They go to CC and then pick up meds, Pick-up food from nutrition.

PCMHs began as a way to address a variety of primary and specialty care through a patient-centered lens that focuses on the best health outcomes for a patient through quality and efficiency of healthcare delivery (Sugarman et. Al. 2014). Within PCMH structures, primary care
providers are no longer solely responsible for a patient’s health plan. Instead, they become part of a team collective that addresses dental, mental, medical, and social care needs (Howard, Malouin, and Callow-Rucker 2016). Orange County, Florida includes over 20 PCMH safety-net clinics, creating the Primary Care Access Network (PCAN), comprised of various community health centers. These various clinics operate differently but consist of resources and services available to residents in Orange County. GMH practices holistic medicine through Christ-centered care, which sees the mind, body, and spirit as intertwined with health, wellbeing, and illness. Christ-centered care is a foundation of many faith-based NGO clinics that provide Christian ministry and healthcare within clinic practice (Bresick and Porter 2017).

Medical Community Partnerships

Another reason GMH has comprehensive, integrative medical care and services due to their diverse medical community partnerships. Many faith-based safety-net clinics rely on “partnerships between local health departments and faith-based organizations… offering a collaborative means to provide for vulnerable populations using shared resources” (Levin 2016, 346). However, GMH has extensive support from community partnerships that enable GMH to treat patients with comprehensive medical care from the services and resources provided by these partnerships. Chandel, a department manager, describes these various partnerships.

It’s divided between community partners – in house and out of house. In house is voluntary specialists that will come to our facility. KNIGHTS Clinic run by UCF medical students, they bring specialists but depends on physician availability. Typically, two times a month. Then out of house, there is the two hospitals we have partnerships with. They donate services like MRI/CT screenings, cardiologists, etc. And then there is another specialty care center Orange County Medical Center (OCMC) that is similar to Grace but only does specialty care.
GMH meets the specialty care needs of patients primarily through their community hospital partnerships located throughout Orange County. GMH provides primary care and chronic illness management, as well as coordinates, tracks, and schedules specialty care with their community partners. Aisha, a volunteer, describes coordinating specialty care between GMH and a hospital for an ophthalmology patient.

So there's patients who have neurological issues and so that affects their eyes. So, we send them to an [ophthalmology] office in Orlando. So they need to get a follow up every six months with that provider at that office. What we [CC] have to do is on the patient chart, you have to kind of record when their last appointment is and kind of put an appointment reminder for the next six months. So when that date comes closer, I can coordinate with the patients and see what date works for them so that I can schedule that appointment in that office.

Intensive work is coordinated between GMH, a community partner, and a patient to comprehensively administer high quality care for vulnerable patients who would have difficulty navigating these administrative tasks. Anthropologist Heidi Castañeda (2017) notes that many safety-net clinics in rural counties that lack a major urban hospital or medical district represent the only source of healthcare for the uninsured. GMH can serve the uninsured community in comprehensive ways largely because of the clinic’s urban setting and partnerships with two hospital systems. However, the partnerships with organizations that donate services in the community have fluctuated over the years. For example, one such partnership involving the coordination of mammogram screenings for women fell apart when a hospital discontinued donating mammograms. The CC department pivoted to strengthen a partnership with a mobile bus NGO that would allow GMH to access their mammograms on GMH property, instead of meeting patients at another location. This coordination of care within the CC department highlights holistic healthcare delivery for their patients, as GMH is always looking for specific
grants or funders to keep GMH operating and meeting a wide range of their patients’ needs. Even with the community support they receive from churches, community centers, and hospitals, limitations exist in meeting the needs of some patients at GMH who are undocumented in the U.S. OCMC has strict eligibility requirements for specialty care treatment, allowing only U.S. citizens and residents below 135% of the federal poverty level to access the OCMC facility. Even within GMH’s comprehensive system, undocumented individuals and visa holders experience limitations in obtaining specialty care (discussed in the barriers section below).

**Theme 2: Implementing Social Determinants of Health Interventions**

*Social Care through Care Encounters*

My data show that the services delivered by GMH are a form of what I call social care, which is integrated, comprehensive, and aims to meet the needs of patients beyond biomedical interventions. The social needs of patients are addressed at GMH within a social determinants of health (SDH) framework, which includes health needs that are structural in nature such as transportation, housing, employment, food, etc. that influence health outcomes of people (Castañada et. al. 2015). Marisol, a department manager, provides an example of a patient’s experience with social needs within their complex structures of daily living from the patient’s perspective as follows:

‘If I don't have access to resources, meaning… To come to Grace, I need my car or I need to pay $80 for somebody to take me or $100 for somebody to take me and bring me back home. But that means that I miss a whole day of work. So now I miss a whole day of work. I have to pay $80. I need to go buy food for my kids. My kids are in school, so who's gonna take care of them?’ So all of that, it's very overwhelming.

Most staff/volunteer participants had a firm understanding of SDH and impact their care may have through addressing SDH needs of their patients. By understanding these complex
socioeconomic experiences of their patients, such as lack of income, transportation, and childcare, GMH aims to improve positive health outcomes for their patients through implementing programs at the clinic such as the prescription application program to access free prescriptions, a food pantry on premises to mitigate food scarcity, and partner with other community organizations to connect patients with needed resources.

Zarita, who is a clinical technician, describes her impact on patients with her care “Besides taking care of them [patient], let's say that they're here for blood work or X-rays. Somehow, they open up to you. And then their social life come in front of you, you know, it just goes in front of you. And it could be that's, in your family, be their way of living… their journey, coming to where they're at.” Being a volunteer or staff member at GMH does not just entail treating a patient for a medical condition but learning about a patient’s lived experience and journey that are embodied with how a patient understands and receives their medical and social care (Kleinman 1988).

I define social care within the healthcare system as services provided that go beyond biomedical care models in helping to meet patients’ needs related to education, food, housing, employment, transportation, etc., with a focus on building relationships with the patient through care encounters. The concept of social care is similarly viewed within the United Kingdom’s public healthcare system which “treats care as an activity and a set of relations lying at the intersection of state, market and family (and voluntary sector) relations” (Daly and Lewis 2000, 296). To administer social care adequately and comprehensively in medical clinics, a deep understanding of the sociopolitical experiences of the patient population is needed. Social care is treated as equal to medical care and an essential part of healthcare delivery within GMH. Resources come from community partnerships, volunteers and staff. Even though GMH cannot
address every need a patient may have there are processes in place to assess patients’ needs, such as the Social Service Questionnaire, which is given to patients at every registration appointment and anytime something is mentioned with their medical provider that would be a social resource need. The structural vulnerability of chronic illness within the safety-net encompasses many SDH factors. Heather, who has been working as an administrative manager at GMH for a few years, explains these vulnerabilities by describing a pediatric patient and the integrated care provided by GMH.

I think there was a kid who was either hard of hearing or deaf…. Was able to get him a spot at school that has specific programming for students with hearing impairments…he got caught up academically because he was being taught in a method that actually worked for him. But she [Hailey] walked along. She was with that mom and her patient, and I think would talk with one of the social workers at the school. Which, I know all of that is like, yes, those are things that like other like, non-Grace providers can do, but they’re not actually going to go to the meetings and Hailey is there at the meetings. The mom only spoke Spanish, so Marisol would translate them. And then I think they had transportation issues too that we helped them…….Just really taking the time to figure out what all of the pain points were for that family and coming together as a team…

There were many descriptions in my data of this exact team collaborating to address needs of patients outside of medical care related to structural systems access, such as adequate methods for education, transportation and food insecurity, and understanding a patient’s family dynamic, as part of the integrative healthcare process at GMH.

*Generative Labor*

Exceptional ways in which GMH staff and volunteers mitigate structural vulnerabilities for their patients in clinical practice is through advocacy efforts in the form of generative labor. Anthropologists Jessica M. Mulligan and Madeline Weil (2022) define generative labor as learning how to navigate the everyday social and biological processes within daily living that are
uncompensated labor within a neoliberal healthcare model. My data show that generative labor is evident in navigating a fragmented patchwork safety-net system and is experienced by healthcare providers and patients utilizing health services. I argue that this system is an issue of fragmented access to resources that is perpetuated through biopolitics of care, namely how safety-net systems and patients utilizing these systems, navigate through state and government policies in negotiating medical and social care within their community structures. However, the burden of generative labor for patients is significantly reduced by staff and volunteers at GMH through several social care programs that help patients navigate in accessing prescriptions, child educational resources, and food resources through a closed pantry, which is only available to GMH patients.

The two main programs that participants highlighted as fundamental resources to their patients are the Prescription Application Program (PAP) and student educational assistance. The PAP is a program that any U.S. resident can access and apply for, but this program is difficult to navigate and there are many pharmaceutical companies that offer this program with different and complicated requirements. Arianna, a clinical technician in the med room, describes how GMH takes on the generative labor of the patient in applying for PAP. She explains:

It runs like any regular pharmacy, just not a registered through American Pharmacy. We call pharmaceutical companies and advocate for the patient...... It means any step they [patients] can do on their own, we can do, that will take for the application for PAP. There is an application they would do on their own, the provider will sign what they need, but the patient would be responsible for applying, faxing, prescription refills, etc. All on their own. We do that for the patient. I follow up and make sure that all is followed through. That is why the pharmaceuticals send the meds to us.

This program is renewed every year and gives the patient access to free prescriptions, and GMH’s staff complete it for any patient in need of prescriptions. As Arianna says, “We do that
for the patient.” Patients that manage chronic illnesses such as type 2 diabetes, hypertension, asthma, depression, etc., primarily receive their medications from this program. Not only does GMH staff become their advocates, GMH also eliminates the cost of medications that many people state is a barrier to managing their illnesses (Becker 2004; Becker 2007). This prescription cost barrier to managing type 2 diabetes is especially problematic for immigrant Hispanic farmworkers where the patients were prescribed affordable oral medications over expensive insulin. As Tyson et. al. (2019) show in their study, even though the medical providers were cognizant of immigrant cost limitations and their socioeconomic context, they still operated within symbolically violent healthcare policies in providing prescriptions that are only available through donations and special rates. For example, research has documented that healthcare providers in the Eastern Shore of Maryland could not recommend the PAP for their undocumented patients since they did not qualify. However, there are PAP applications that do not require a social security number (Sangaramoorthy 2018). Lack of program knowledge within safety-net providers has severe health consequences for their undocumented patients’ ability to get access to needed medicines that should otherwise be available to them.

Another way in which GMH reduces the generative labor for patients is by their volunteers who assist parents and children in establishing Individualized Education Programs (IEP) within their schools. This labor varies from paperwork processing to attending IEP meetings with school officials in tandem with the parent. Morgan, a volunteer in CC department, describes her role in assisting patients through social care practices at GMH as follows:

Many a times, it is literally just asking for paperwork where the student is of special needs. In other words, if they have any, some physical needs that need to be addressed in the school or the occupational therapy, physical therapy, speech therapy. If they're in a wheelchair, elevator issues, or if they have any educational struggles and they need to be evaluated for learning disabilities….
So it's seeing what services the school provides and if we then need to supplement that.

Morgan's comment exemplifies the holistic, social care discourse of the GMH staff and volunteers who proactively address the burdensome and complicated struggles of medical and social services and resources through their own expertise of these systems. GMH link resources for the patient and their families, something that may be elusive for many patients in the U.S. healthcare and educational system, regardless of socioeconomic status.

How sustainable is social care within the larger political economy of health? According to Heather, a manager within administration, the cost of social care outside of GMH would be expensive “I think it would be significant…I mean how much can be saved on the other end in the inefficiencies in our system right now too…. everyone knows it's broken, but how to fix it? It would have been fixed by now if we knew how to do it.” Even in European countries such as the UK where there are established social care departments within the public healthcare system, there is difficulty in quantifying and compensating for social care services (Rummery and Coleman 2003).

Theme 3: Remaining Barriers
Limitations to Social Care

Despite the collaborative integration of health and social care services, barriers remain for patients in accessing this care. GMH is navigating through a difficult political landscape in some of the social care they deliver to their undocumented patients. Medical care is never withheld or rationed at GMH, but there are limits to how they can address social and structural needs of these patients outside of medical care. When I asked Marisol about how resources differ for undocumented patients, she explained how her team navigates policies of immigration.

And so, because many of them [patients] are from other countries and so… But the challenge there is we have a partnership with a
legal agency, and we have an in-house attorney that sits here and helps some of our patients, but her funding is federal. So, they [the attorney] cannot help somebody that doesn't have legal status and so, and that was something that was difficult.

Navigating through U.S. policy is not only difficult for an undocumented patient trying to receive care, but it is also difficult for healthcare workers. This political climate is emblematic of biopolitics which refers to how government entities inform how healthcare is distributed through policy to populations and through individuals adhering to that policy (Stevenson, 2014). Biopolitics is not only controlling medical resources in the context of GMH, but access to resources beyond medical care: legal aid, employment, and housing resources that in turn can affect long term health outcomes for undocumented people. Marisol describes some ways in which GMH works within this structurally violent framework of immigration policies is reaching out to community partners “And so we had to get partnerships with like Catholic charities, and we would direct them there. They're overwhelmed as well with a lot of people. So that's one of the biggest challenges, that… not to be able to help them….” Generating positive health outcomes for structurally vulnerable people within sociopolitical landscapes of care for the uninsured involves navigating systems of care between patients and safety-net institutions.

Navigating the safety-net system for patients can also highlight structural vulnerabilities patients may face seeking healthcare. I have observed and heard from two staff members that there is no clear process on how an undocumented individual with no insurance gets healthcare access. There is substantial generative labor on the patient’s part to sift through websites for information on affordable health insurance plans, resources for managing chronic health conditions, and healthcare facilities to access when uninsured. My research shows that public information about these safety-net clinics in Orange County is lacking. There is no public health
campaign through the Florida Department of Health (FDOH) that advertises their PCAN system for residents.

**Florida State Policy**

GMH addresses social and structural elements of healthcare access through a highly integrated healthcare organization that collaborates with many community partners to provide quality social and medical care within the Florida Safety-net system, however there are some limitations to their care implementation that involves several state policy decisions. One such policy is Florida’s continued refusal to expand Medicaid even after the detrimental impact that the COVID-19 pandemic has had on many Florida residents’ wellbeing and health (Palacio and Tamariz 2020). This failure to expand Medicaid to provide needed insurance access and stable healthcare access has left many patients at GMH frustrated.

One such patient, Claudia, recounts her displeasure with this non-expansion and her experiences with navigating being uninsured with her family. Claudia is a Black woman in her early 60s and has been a patient at GMH for about 4 years. Her husband and daughter are also patients at GMH. I built a rapport before meeting her in the PR department while performing an errand. While re-registering, Claudia expressed how GMH has been a life saver for her and her family and that she is hoping to start her own small business with antiques. She said her daughter would have died if she was not a patient at GMH. Her daughter was extremely ill and they were uninsured when she heard of GMH from a friend at church. Claudia’s family discovered through a series of specialty care visits that were coordinated by GMH to their community partners’ facilities that their daughter had Grave's disease, an autoimmune disorder where the thyroid overproduces thyroid hormones. Her daughter is now on medication and is managing her disease thanks to the medical care received and coordinated at GMH.
Through her daughter’s story, Claudia observed how “people need to understand this insurance problem and your research is important for that.” Claudia continues “Did you know that Florida did not expand Medicaid here?... I don’t understand why that is, it’s money given by the federal government, why not take it? It doesn’t make sense. I would have Medicaid if they [Florida] expanded.” Through her understanding of Medicaid access and non-expansion we see how state policy decisions play a key role in shaping healthcare access for U.S. residents. Actions of the state may cloak racialized policies that are aimed primarily at vulnerable populations and can be seen as forms of discrimination, such as the 2012 Supreme Court ruling with Medicaid Expansion that ultimately weakened the impact of the ACA in expanding coverage for government insurance programs in several states. Claudia and her family represent many Florida residents who fall in the gap of Medicaid expansion policy.

Through specific political ideology of neoliberalism, which creates a distance between the decisions of formal political institutions and other social actors, such as residents, the residents (and patients) are conceived as subjects of supposed self-responsibility, autonomy, and choice that are assumed to shape and utilize their freedom (Becker 2004). In reality however, this neoliberal ideology shifts government’s responsibility of healthcare to that of the individuals through structural violence of deficient health policies imposed and maintained by the U.S. government. How can an individual take responsibility for their health when structural and social barriers of care exist within their healthcare system? Over four decades of neoliberal politics toward healthcare in the US have shown that the current system is failing a significant portion of the population (Harvey 2007) with little hope for improvement within the current structures of care.
Discharge of Patients

Other ways that state polices negatively shape healthcare access is through Florida’s sovereign immunity program that GMH uses to access malpractice insurance for their voluntary physicians. In order to qualify for sovereign immunity GMH has to follow strict financial guidelines when registering patients. These guidelines include serving uninsured Orange County residents that are under the 200% federal poverty level (FPL), and residents under 65 years. If any of these parameters are unmet by patients seeking care, they will be discharged from GMH.

Being discharged at GMH can be a celebratory or stressful experience for patients and staff/volunteers. Many patients “graduate” when they obtain health insurance, or when they “age out” and start on Medicare at 65. Some limitations of this “age out” are for immigrants utilizing GMH. As one staff member at GMH explained, immigrant patients are of concern, “I worry what happens to our elderly patients that age out of Grace. I know that there is [acute clinic] but they don’t have chronic health management. What else is there for them?” Immigrants that do not have U.S. status are excluded from Medicare. She is especially concerned for the elderly immigrant patients in the safety-net because even though there are many FQHCs, CHCs and NGO-based clinics, they do not have the integrative comprehensive care, resources, and relationships that GMH provides. Dr. Song, a physician who has worked at GMH for 10 years, also expanded on this gap of integrative care by describing how FQHC sliding sale payment work for immigrant patients.

Yes, they can [go to FQHCs], but they pay. And for many of them, because they are paid under the table, they don't have legitimate pay stubs with taxes. And so, the clinics charge them the top fees because they don't believe the self-reported income... So, it's very expensive for these folks and all of the clinics. When you hit a $200 bill that you have not paid in, and that could be labs, it could be other things than just your visit and a specialist visit, if they
even have a specialist…. they won't see you anymore, so you're done.

As Dr. Song points out, patients might abandon their care if they cannot pay their bill. Cost and chronic illness management is a huge barrier for immigrants who are utilizing the safety-net system. In both qualitative and quantitative studies of uninsured adults utilizing the safety-net system, cost and medical care affordability had an impact on patient’s discontinuing medical care (Becker 2007, Choi, DiNitto, and Choi 2020).

Another limitation to federal and state policy with Medicare is the assumption that any U.S. citizen can obtain Medicare at the age of 65. Even in a theoretical paper examining the ethics of Medicare and coverage of certain procedures over others, this assumption still persists: “At its most basic, Medicare is an ethical program, in the sense that it provides state-sponsored health services for any older citizen. That part is obvious” [my emphasis] (Kaufman 2010, 412). Medicare is not available to all older citizens, only to those that have been paying the taxes for this federally sponsored health insurance program. There is a myriad of reasons that a U.S. citizen upon the age of 65 may not qualify. One such experience came up during fieldwork when I got to know Ella, a Black woman, who was “graduating” from GMH. Ella could not qualify for Medicare because she did not pay into this program due to caring for her legally disabled son of 37. When I met her for her last appointment she was distressed and crying. She has type 2 diabetes and has been obtaining care from Dr. Song for a few years in managing her chronic illness. Ella mentions that she appreciates all the care Grace has given her and emphasized how prayer is central to her wellbeing, “I never had a doc pray for me.” Before Ella is discharged Dr. Song with myself, a nurse and a scribe pray over her in guiding her to a good physician, possibly getting Medicare through a loophole, and her continued wellbeing.
There is no tax credit for parents or relatives that care for their disabled children. Ella did not have a job through which she could pay for Medicare tax credit. During an interview with Dr. Song, I followed up on this process. She explained:

So, you have to put into Medicare to get Medicare. So you have to work and pay taxes and have taken out of your taxes the Medicare tax and Social Security tax. If you never pay taxes because you've never worked anywhere, except taking care of your autistic son.... And some like her [Ella], legitimately, our country should have a way that if you're caring for a disabled loved one that you somehow earn credits but you don't....... if you didn't pay into it, you can't get anything out of it.

This is how neoliberal health policy is being enacted in the U.S. that places “productive” U.S. citizens in a precarious position of administering care for their loved ones over themselves. Women are disproportionately represented among those who provide uncompensated care work for relatives and therefore are at higher risk of missing employment, earning less income (Elson 2017), and ultimately not qualifying for Medicare, as Ella’s case exemplifies. Why is Ella punished by the U.S. healthcare system for the medical and social care that she gives to her son? Ideas of legitimacy are also reckoned within a political economy of health within provider discourses of insurance and productivity.

Individuals become structurally vulnerable when they are subject to the broader framework of health disparities that are perpetuated by structural violence within the U.S. healthcare system. This structural vulnerability can be understood institutionally through policies implemented at state and national governments, within medical institutions, healthcare provider education, and through provider healthcare services, as well as to the individuals themselves that are subjected to these policies.
Conclusions & Significance

The U.S. still ranks below most industrialized nations in healthcare with significant inequalities experienced by individuals through their socioeconomic status, ethnicity, and race (Hansen and Metzl 2016). U.S. residents are still lacking adequate and consistent health services despite the health reform through the ACA. My findings show that safety-net clinics are vital in addressing these gaps and contribute to critical medical anthropology by offering a critical analysis of the healthcare structures, the analysis of health inequalities, and the political economy of health care for vulnerable people in the Florida safety-net. It is evident from the findings of this study that PCMH safety-net clinics such as GMH are in the position to provide comprehensive medical and social care to their patients, however they must navigate state and government policies of healthcare access that are complicated and challenging. GMH’s highly integrative healthcare for vulnerable populations addresses both medical and social needs for better health outcomes through holistic PCMH initiatives within the safety-net system.

Through PCMHs in the safety-net, residents who are uninsured get access to medical and social care that is primarily centered in one building, reducing time off and transportation costs for patients with multiple primary, mental, and specialty care appointments being scheduled in a single day. My work also documents a shift from previous safety-net clinic research that showed multiple medical providers seeing one patient throughout their chronic illness treatments to one primary physician assigned at GMH to follow a patient, creating continuity of care for the patient involved, which improves overall health outcomes (Pereira Gray et.al. 2018). Without intentional structuring within primary care facilities to implement a social service department and social care integration in all aspects of medical care, there can be no true attempt to address SDH. I argue that there is a greater need for SDH frameworks to integrate social aspects of care at the
primary care level. Without understanding complex socioeconomic landscapes, health disparities, and potential structural vulnerability of patient experiences there can be no true way to “address” SDH in the current U.S. healthcare safety-net and broader healthcare system. An intentional policy reform is needed to incorporate social services and workers for a comprehensive integrated healthcare system.

Even though larger policy reform is necessary to structurally reconstruct social services into medical systems, private and public clinics can slowly implement these strategies to create better health outcomes for their patients. GMH staff also have extensive knowledge and understanding of patient vulnerabilities and chronic illness management within the context of uninsured status, living situations, and undocumented status. The generative labor does not need to fall solely on clinical providers, but on collaborative efforts of multiple departments.

There are still many ways in which Florida state biopolitics interact with social care given at GMH due to safety-net institutions working under the guidelines of sovereign immunity for healthcare workers. However, GMH navigates these policy restrictions through connecting with community outreach programs to address SDH concerns for their undocumented patients, demonstrating that there are various ways that safety-net clinics operate within Florida policy to treat and serve uninsured vulnerable populations.

Future scholarship should investigate and contextualize the experiences of residents seeking healthcare in the U.S. safety-net through ethnographic and other research. By examining a Florida safety-net system, PCAN, within a multi-ethnographic study of safety-net clinics in Orange County, studies could provide further insight into how residents navigate uninsured status and seeking health services within PCAN.

**Ethical approval**
This research was reviewed and approved by the University of Central Florida’s Institutional Review Board in August 2022, study #00004436.

Acknowledgements

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Disclosure

No conflict of interests was reported by the author.

Appendix
References


CHAPTER 3: WHAT DOES IT MEAN TO PROVIDE “CARE” IN THE U.S. SAFETY-NET SYSTEM?

The second section of the thesis, a manuscript titled “What does it Mean to Provide ‘Care’ in the U.S. Safety-Net System?” and is prepared for submission for publication in the journal of Anthropology and Medicine, a peer-reviewed medical anthropology journal (https://www.tandfonline.com/journals/canm20). This article manuscript is dedicated to the ideas of care, resources, services, and labor in the context of a commodified and marketed healthcare system. This article exists in contrast with – but not opposition to – the first article of my thesis, “Integrative Care: Implementing Comprehensive Medical and Social Care in the Florida Safety-Net System,” which examines healthcare services and recourses provided within the safety-net system of Orange County, Florida through holistic, comprehensive medical and social services. The second article relates to the thesis in its entirety by discussing the results of this research, which examines perceptions of care among providers and patients.
**Article:**
Prepared for submission to journal: *Anthropology & Medicine*

**Abstract:**
The United States healthcare system consists of employment-dependent private insurance and government-funded programs of Medicaid or Medicare. People who cannot afford private insurance, are unemployed, self-employed, undocumented, or their low income exceeds the government qualification threshold face barriers in accessing the expensive medical care in the U.S. The burden of providing care to millions of uninsured U.S. residents falls on the Safety-Net clinic system which attempts to fill the care gap for low-income patients. This article examines the nature of the care provided at a faith-based Patient-Centered Medical Home in the Florida’s Safety-Net system from the perspective of healthcare providers and patients. This article draws on primary data collected in 2022 and 2023 using ethnographic methods, including five months of participant observations, informal interviews, and semi-structured interviews with 22 healthcare providers, volunteers, and patients, as well as secondary data analysis of guidelines for patient-centered care. My findings show that health care is perceived beyond medical and social services. The clinic’s strategies to achieve high quality of patient-centered care include showing respect and dignity to patients, incorporating Christ-centered care practices, establishing provider-patient trust through multiple care encounters, building personal relationships, and spending substantial time and emotional labor to understand the complex medical and social needs of chronic illness experiences of patients. This study is significant because it advances our understanding of the way that care is conceptualized at a faith-based safety-net clinic. As patient-centered care is becoming the gold standard in recent decades, this study also contributes an ethnographic analysis of how a safety net clinic achieves the goal of providing this form of care.
**Keywords:** Patient-Centered Medical Home, Safety-Net Healthcare, Chronic Illness, Medical Trust, Doctor-Patient Relationships, Christ-Centered Care

**Introduction**

Patient-centered care, also known as people-centered health care is defined by the World Health Organization as healthcare systems promoting affordable, accessible, safe, ethical, effective, evidence-based and holistic health care that involve patient health literacy, decision-making, and choice in health care services (World Health Organization 2007). Patient-centered care also advocates for proactive preventative care measures in chronic disease management. There has been a major shift in the U.S. healthcare system in orienting patient-centered healthcare in the last few decades (Bromley 2012).

The growing need for primary care facilities to encompass holistic, integrative primary and specialty care led to the development of Patient-Centered Medical Homes (PCMH). PCMHs practice patient-centered care through combining the primary care services through “enhancing patient engagement and care coordination, achieving improved health outcomes, providing a better patient experience of care, improving efficiency and use of health information technology, and, ultimately, reducing costs” (Goldman et. al. 2015, 168). Scholars have also described PCMHs as places where “patients metaphorically share a home with a medical team responsible for coordinating patient care within the home and between the home and the larger service network. Medical teams provide patients with same-day access for emergent, acute needs and continuity of care for preventive and chronic disease services” (Solimeo et. al. 2017). Since the early 2010s PCMH have been implemented in both insurance-based and safety-net clinic settings.
The U.S. safety-net system comprises many different clinics ranging from Federally Qualified Health Centers (FQHC), Community Health Centers (CHC), and Non-Government Organizations (NGO) that provide a variety of primary and secondary care services on a sliding to no cost fee for uninsured or underinsured people (Nguyen, Anil, and Halm 2016). However, the U.S. safety-net system is not a homogenous system of access but consists of fragmented clinics dependent on various federal or private funding sources and services, from volunteer providers, to donated medications and equipment (Mulligan and Weil 2022). Kamimura and colleagues (2019) report that uninsured non-U.S. born minority, Spanish speaking patients’ perceptions of patient-centered care utilizing safety-net clinics was that they received lower levels of patient centeredness and patient involvement than U.S. born patients. These perceptions of care depend on how provider, patients, and the healthcare system conceptualize health care services and resources.

**Conceptualizing Care**

But in what ways is care conceptualized within medicine, healthcare, and the individuals providing that compensated or uncompensated care labor? Anthropologist Elena Buch shows how “care practices and moral economies of care highlight the formative potential of care to generate and sustain social persons…. Both care practices and political economies of care play crucial roles in the constitution of personhood” (Buch 2015, 281). Within this analysis care is conceptualized between the person providing care and the person receiving care. Care can also be perceived as “the way someone comes to matter and as the corresponding ethics of attending to that other who matters” (Stevenson 2014, 3). These corresponding ethics shift care from the value placed the medical gaze (Foucault 1973) and the perspective of the healthcare provider, to one that focuses on understanding the patient’s experience in how care is received.
The safety-net system has also been considered as a form of moral economy. Medical anthropologist Thurka Sangaramoorthy (2018) argues that the moral economy of care creates dynamic social relations between providers and their patients which are framed within informal economic and material care giving. She defines this care exchange as band-aid care that requires well intended safety-net providers to navigate impersonal, reciprocal, and relational exchanges of their patients’ care and the neoliberal, self-interest logic of traditional healthcare systems in negotiating care within this system (Sangaramoorthy 2018). Band-aid care within the safety-net system is the result of neoliberal healthcare policy shaping healthcare access and delivery that places both patients and providers within structurally violent systematic practices which forces them to negotiate inventive practices for health care exchanges.

**Theoretical Frameworks**

*Chronicity*

Chronicity shifts our perceptions of disease within the context of a bio-medical model to a person’s narrative of their own embodied illness experience with intersectional identities of socioeconomic roles, loss, and change of self that encompass illness (Estroff 1993). From a provider perspective chronicity identifies treating a patient’s illness experiences within their own sociocultural contexts that are framed within larger political/cultural structures (Kleinman 1988, 5). Chronicity therefore is an important concept for addressing several biocultural systems that influence people’s illness experiences within their broader defined living conditions and situations. How then does this illness identity, social and economic changes that come with embodying a chronic illness, fit within a neoliberal, political economy of health?

*Political Economy of Health*

The political economy of health framework is directly relevant for this study because it highlights the political and economic forces that shape everyday health experiences. Within
anthropology the intersectional concept of political economy refers to the systematic, institutionalized structures that govern political and economic modes of production, power, and globalization (Roseberry 1988). Medical anthropologist Hans Baer describes these structures within healthcare contexts as the outcome of “the impact that the capitalist mode of production has on the production, distribution, and consumption of health services and how these processes reflect the class relations of the larger societies within which medical institutions are embedded” (1982, 1). Philippe Bourgois (2003) furthers this framework by integrating social suffering experiences of the individuals that fall within these political and economically violent structures within the U.S. healthcare system.

Methods

Study Setting

This paper draws on 5 months of ethnographic data collected between 2022 and 2023 at Grace Medical Home (GMH), including participant-observation, informal interviews, semi-structured interviews, and a state/federal health program analysis, which includes researching websites from the Florida Department of Health, the Center for Disease Control and Prevention, and Primary Care Access Network for health conditions and healthcare statistics. GMH is a safety-net clinic in Central Florida that provides essential health services to medically underserved vulnerable populations. GMH is a private faith-based organization accredited by the National Committee for Quality Assurance as a patient-centered medical home (PCMH) for employed, but uninsured, patients who are below the 200% federal poverty level.

Data Collection and Recruitment

I conducted participant observation through volunteering in a non-clinical department, informal interviews with staff/volunteers, and shadowing non-clinical and clinical staff with patients to build rapport to develop a holistic and deep understanding of GMH’s work (DeWalt
and DeWalt 2011, Fetterman 2019). Extensive fieldnotes became an essential source for understanding clinic operations and interactions among patients and volunteers (DeWalt and DeWalt 2011, 159).

This study focuses on the primary sample of 20 in-depth semi-structured interviews I conducted with key informants representing all aspects of work at GMH: clinical staff, managers, and clinical and non-clinical volunteers. Key informants had to be with GMH for at least 3 months, at least 18 years old, and able to speak English. Key informants were defined as those with a significant role within the provision of safety-net care and important insights to share due to their seniority or specialist roles (Marshall 1996). From an anthropological perspective, “studying up” GMH’s staff was important for understanding the institutional setting and provided understanding about potential ways to improve care (Nader 1972). Interviews with key informants followed an 18-item interview guide with topical domains of; role and experience in the clinic; impacts of socioeconomic, transportation, social, and other factors on clinic’s patients; and approaches to the provision of care in each department. Purposive sampling allowed for the recruitment of key informants aimed to collect data from each aspect of GMH’s work, allowing saturation with this sample (Bernard 2006, 145, 436).

Of the 20 interviews, 18 were conducted in-person within a private room at GMH, and 2 via Microsoft Teams. Nineteen participants permitted audio recording, while 3 did not. Interviews lasted 27 to 60 minutes. Key Informants were not remunerated. The names of participants are pseudonyms and specific locations are de-identified.

Table 2 illustrates the demographic characteristics of the 20 key informants. Key Informants who were employed or volunteered at the clinic held a variety of positions, including manager, intern, physician, volunteer, counselor, social worker, clinical worker, and represented every
department in the clinic. Their ages ranged from 20 to 74 years (35 – 54 years: n=8, 20 – 34 years: n=7, and 55 – 74 years: n=5). In terms of gender identity, 18 of 20 providers self-identified as female or feminine when asked their gender identity. Self-identified ethnicity/race was reported as Hispanic or white Hispanic (n=9), white (n=7), Asian or Korean Asian (n=2), and Black or African American (n=2). English was the primary language for most of the sample. Religious representation in the sample included Christian or Catholic, Islam, and no affiliation.

Table 3 illustrates the demographic characteristics of two patients with chronic illnesses that participated in the study between 20 and 34 and 35-54 years old, one was Black/African American, one was Trinidadian, both identified as female, and had a high school education. English was the primary language for both patients. One patient had no religious affiliation, the other did not disclose religious affiliation.
Table 2: Key Informant Demographics

<table>
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<tr>
<th>Role</th>
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<th>Gender Identity</th>
<th>Ethnicity/Race</th>
<th>Primary Language</th>
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Data Analysis

All audio files were transcribed verbatim, and the transcripts were coded both manually and using Dedoose software. I generated and refined codes and subcodes through an iterative process, wherein I used frequent comparisons between the text and the codes and created a codebook to reference code and subcode meanings (Charmaz and Bryant 2016). The directed content approach was used in the initial coding process that allows for the use of existing theories to develop initial deductive codes prior to thematic data analysis, but also allows for additional revised and refined inductive codes to develop through the analysis if needed (Hsieh and Shannon 2005, 1286). From the refined codes, I mapped out larger themes of the coded data. The thematic analysis included coding for both predetermined a priori codes, as well as inductive, not previously considered factors and/or explanations (Strauss and Corbin 1998).

Results and Discussion

My data show that the overarching approach of the GMH medical and social care providers is to restore dignity in care and foster relationships. The themes that emerged which explain this model of healthcare were: Christ-centered care as the foundation of all services, establishing trust through relationship building for better health outcomes, and how care is rationalized through reducing the impact of chronic illness hospitalizations within the community and the partnerships of managing chronic illness between the patient and provider.

Restoring Dignity in Care

Pillars of Christ-Centered Care

Since GMH is a faith-based PCMH, this organization is rooted in a Christian mission for healthcare delivery. Every week GMH staff members meet to discuss the previous week’s highlights through themes of mission integration which describes ways to integrate Christ-
centered care with patient encounters, cultural shoutouts which signify building relationships with patients and fellow staff and volunteers, and prayer requests from patients, staff and volunteers. During this meeting a staff member leading mission integration asked the individuals in the room “what distinguishes us from other care organizations? Because other healthcare organizations incorporate excellence and compassion as the standard of healthcare settings.” The room went quiet. I proceeded to answer the question based on the last few months of being a volunteer and researcher “I think it has to do with how you build relationships with your patients and take the time to establish that relationship.” He says that is a component of care, but the primary pillar of Christ-centered care is restoring the dignity and respect of patients that walk through GMH’s doors.

This care concept of restoring dignity and respect is central to how care is provided, and it is what participants perceive as what distinguishes GMH health care from other forms of health care. Carol, one of the managers, describes the impact that GMH has for uninsured people in Central Florida: “I mean we want to get them to the next level where they have insurance on their own, but just treating them with respect and you know making them feel loved and just being there for them and following them on their journey, whatever it is, I mean we do at home visits, we pray with their patients.” The concept of social dignity has been described in the context of public health as treatment of marginalized people with civility, active listening, inscribing positive identity and autonomy to their unique lived experiences, destigmatizing their experiences, and being able to relate and participate in the patient’s life (Schmidt, Trappenburg, Tonkens 2021). This type of social dignity is practiced within GMH’s operationalized concept of Christ-centered care.
Fostering a Spiritual Environment

Another aspect of restoring dignity in care at GMH is through fostering a spiritual environment. Horatio, a spiritual counselor, explains the body and spirit being interconnected to a patient’s health outcome.

It also involves educating our patients and our staff members and volunteers, about how connected we are as a whole person. Which means, whatever happens to us in the spiritual aspect, it will result in an impact into our physical aspect and to our mental health. Because everything is interconnected…We are created with three natures which are spiritual and body.

Horatio’s explanation stands in contrast to what scholars have described as the fragmentation of the body in western medicine. Medical anthropologists Nancy Scheper-Hughes and Margaret Lock argue that western biomedicine understand the body and self as dichotomies, with illness residing in the mind or body, in contrast to many ethnomedical concepts where the mind, body, and self are indistinguishable, and illness can encompass all three simultaneously (1987). In GMH’s model of care, mind, body and spirit cannot be separated from the health and illness experiences of the patient and are seen as important aspects to treat within medical, mental, and social care domains. Part of this spiritual environment and its impact is described by Bert, one of the counselors.

[W]hen you work at Grace, and when you enter Grace, it does feel like a family. … I feel like while being here, it's soul… it makes your soul feel cuddled and you feel amazing just being here. Everyone has a smile for you, everyone has a compliment. Everyone wants you to do good. And whenever you're doing bad, you can just count on them.

This warm, inviting environment is also noticed by Helen, a Black woman in her early 30s, mother of two, and a patient at GMH for over eight years, when she was discussing her depression, “Everyone here was too jolly for me. Too happy, too happy. But, and I also didn't
know that it was, it was a Christian medical home. I didn't know that until maybe like two years after being with them. But they was always welcoming, they was always warming. They was always willing to help out no matter what the situation was.” My participant observation suggest that this Christ-centered approach to care starts the moment the patient walks into the welcome room of GMH, and continues to the interactions with volunteers in non-clinical departments, to the medical and mental health care a patient receives in times of crisis.

Heather, a manager at GMH describes Christ-centered care as a calling, “I think all of our providers feel a higher calling as well that this has been a path that they’ve been led down. And as Christians, it's our responsibility to care for those who have less than and who have been placed on our doorstep.” Curlin and colleagues (2013, 47) argue that providers perceptions of a higher calling within faith-based clinics allows providers to foster and influence spiritual environments and mission within a Christian friendly environment “in which their core values coincided with those of their colleagues and with the mission of the CHC. For such providers, faith-based CHCs appear to provide distinctive opportunities for the fulfilment of their religious aspirations.” This aspect of spiritual fulfillment when evoking care for patients is evident in many participants’ experiences providing care and receiving care.

Olivia, a volunteer intern in Care Coordination, also describes GMH’s holistic approach to health care in meeting spiritual, mental, and social needs during medical visits as follows: “OK, the provider needs the pastor or a spiritual care team [member], the patient has a spiritual need that needs to be addressed in that visit. If it’s an emotional need, we have on site mental health counseling. We have social service workers [for social needs].” As Olivia's comments imply, there is an opportunity for direct intervention, with the patient’s permission or request, in
addressing spiritual or social needs within medical appointments. These interventions create holistic care encounters for patients – an experience that is rare in contemporary biomedicine.

There are limitations to the spiritual care that is provided at GMH. Horatio expands on these limitations when probed on different religious beliefs and faiths. “So in that way we have limits, that means we cannot help a person. For example, if a Buddhist person asked me to find a Buddhist temple, I cannot. I can honestly and openly and recognize my limitations... I can respect your religion and I can provide spiritual care as much as much as you accept in the tools I can give you.” These limitations however do not diminish the respect and social dignity that is given to patients, but does limit any additional spiritual care and resources a patient may be struggling with. Patients who have no religious affiliation are not expected to take part in prayer. Utilizing an anthropological analysis of the nature of Christ-centered care and the overarching goal of restoring dignity in care, can be reasonably understood as a universally valuable approach to treating patients from across religious backgrounds.

**Fostering Relationships through Care**

*Care as Building Trust*

My findings show that care comes in many forms at GMH that address complex economic, historical, medical, and psychosocial concerns for their patients with chronic illnesses through interdisciplinary collaboration of its departments. Marisol, a manager, describes this integrative care between the behavioral health and social services and the primary care departments “We also respond to crisis. Situations upstairs, so a patient can be in a room for a medical appointment and then something happens, and they call us to go in and kind of assess for suicide or domestic violence and give them resources and things like that.” Here we see how
each department coordinates with each other for the benefit and care of the patient, especially patients with multiple chronic health conditions.

Within healthcare research this shift of patient-centered care that involves both the providers and the patients, to negotiate care and treatment plans together, and trust is at the core of these encounters. Fleming and colleagues (2021) researched similar patient-centered engagement through Complex Care Management (CCM) programs that assessed how patients and providers negotiated care for their patients through interdisciplinary teams. This program of CCM and how they manage different health and social conditions of their patients differs from how GMH addresses these care concerns. Care delivered at GMH encompasses primary, specialty, dental, spiritual, social, and mental all in one place with a focus on building a long-lasting relationship with their patients outside of their medical care. When asked about how GMH is different, Marisol observes, “You know, Dr. Shore reminds us all the time, that this is about relationships, this is about connection, like we need to know them. So I think that’s present all the time and that message is not there in many agencies.” Almost all of the staff and volunteers interviewed described building relationships with patients as an important component of care at GMH. For instance, Chandel, a manager, describes how developing relationships with patients begins with building trust.

Trust, that’s biggest impact. Just knowing that we are taking care of them. One family, husband had family, he had cancer. We got his treatment plan set up, then we took the family at Grace. They all got access. He died. But we still continued the family’s care. We made sure that the wife and kids became patients at Grace, counseling, medical needs. I remember going with doctor to hospital with the wife to give support. It was trust for the wife. The husband was being moved to hospice. Being there for them as a family.
During my participant observation in the adult primary care department, I witnessed the process of building trust between providers and their patients and how negotiation of care is developed for the wellbeing of the patient. Dr. Spade, an employee physician, handles what she describes as the “complex patients” at GMH. These patients have been identified as having several non-compliance of care issues at GMH. Types of non-compliance involve patients missing scheduled appointments, not following their care plan, or being confrontational to staff and volunteers. One such medical encounter I witnessed involved a phone consultation with Frankie, a Hispanic male in his early 20s, to follow up on his type 2 diabetic management plan. GMH follows the Centers for Disease Control and Prevention’s recommendations of managing type 2 diabetes with follow up care every three months for established standard care (CDC 2022). Dr Spade explains how Frankie was once discharged due to non-compliance as he was not following his care plan and was being confrontational with staff during his medical visits. After Frankie was discharged, he did not manage his diabetes and consequently experienced a diabetic coma and was unresponsive in his home. During this detrimental health crisis, his mother calls Dr. Spade distressed and seeking help. Dr. Spade called the police for an immediate health intervention. Frankie was initially mad at Dr. Spade, but after his recovery in a hospital he called GMH again to get back to managing his diabetes. When he was updating Dr. Spade on his progress of reducing his sugars, he informed her that he has not been keeping up with his daily diet intake log since he was grieving the death of a friend. But he noted how he is keeping up with his exercise plan and making some progress in his treatment plan. After this follow up for his primary care, Dr. Spade asks if he would like to start taking blood tests to gauge his A1C (blood sugar) levels, but he still was not willing to do labs yet. Dr. Spade then informs me that patients in standard primary care offices would be considered non-compliant and be discharged,
for refusing labs, since it is required type 2 diabetic management. Still, to Dr. Spade and GMH, there is a partnership in negotiating care between the patient and provider and this negotiation was attempted, as Dr. Spade summarized, “We are a partnership that meets the patients where they are.” This process of care is understood within anthropology and public health as cultural competency and humility (Reeves et. al. 2023) in which Frankie’s cultural knowledge, experiences, and comfort are understood and respected by physicians through their own continual validity of his illness narrative and health experiences. I do not know Frankie’s illness narrative or his reasons for resisting blood tests, but his return to seek care at GMH suggests that he finds GMH’s care essential to his chronic illness management. This negotiation of care is built on trust and understanding the psychosocial status of a patient’s wellbeing.

Fleming and colleagues (2021) study with safety-net providers in two hospital systems describe similar development of trust and engagement with marginalized patients with treatment as not an expectation but as a process in building trust and relationships. This particularly applies to patients that developed a mistrust of their healthcare systems due to problematic histories of exclusion and poor treatment. This concept of medical mistrust in the healthcare system due to racial discrimination and experimentation has lasting effects (Jaiswal and Halkitis 2019). As Fleming and colleagues and my own findings show, it is imperative that trust and care is a continued negotiated relationship between the patient and the providers of that care.

Non-Judgmental Care Rationalization

The narratives in my study demonstrate that non-judgmental care and trust are closely intertwined, in particular in chronic care. Rori, a clinical volunteer in the primary care department argued that trust is essential to providing care for patients with chronic illnesses.

I do feel like there has to be a lot of trust between the provider and the patient to kind of manage chronic illness... There are like
diabetics who are clearly not taking their medication as they should be and (laughs). I think it takes trust to be able to own up to that… Because if they don’t own up to that, then it’s like, OK, well, then we’re gonna up the dosage on your medication and then it’s like they start taking it at that dosage and then it’s way too much medication.

This form of trust is also rationalized as being non-judgmental care that coincides with the pillars of restoring patient dignity. Medical anthropologist and physician Carolyn Sufrin (2015) explores how the conventional ethics of both anthropology and medicine necessitate non-judgments with vulnerable and marginalized patient experiences. She argues that “it is the relational practice of cultural relativism. But in medicine, this professional ethic often runs counter to paternalistic tendencies which still pervade practice, that sometimes we think we know what is best for a person…. When patients do not “comply” with our advice, we are taught to non-judgmentally explore why, concealing our frustration with the patient.” For example, Sufrin recounts her ethical reckoning with being a physician that needs to medically advise her patients verses an anthropologist that listens and performs social care in attending to the patient outside of a medical encounter (Sufrin 2015). She raises questions, Is the doctor's obligation to enforce evidence based medical protocols for treatment? Or is it to allow the patient to depart from what clinical research evidence would suggest is the best course if the patient's priorities are other than longevity? This duality of care between professional discourses is similar to how GMH staff and volunteers conceptualize the medical care that they provide to their patients within Christ-centered care. The care provided to the patient involves medical negotiations, social care beyond medical interventions, and establishing trust through multiple care encounters that solidify a dynamic relationship, all encompassed through non-judgmental spaces of Christ-centered care provision.
Helen, a Black woman in her early 30s, a mother of two, and has been a patient at GMH for over eight years, describes how being loved and cared for is represented by not being judged in managing her chronic illness of depression and anxiety.

It's crazy because Grace actually helped out with the depression. Just being around people that’s love, you know? Being around people who is for you and not dealing with people who is judging just because of what you're going through or anything like that. Knowing Christ just as well as you know Christ as well. Which is also another great thing that I liked. The more I came, the more I wanted to be here and the more I wanted to be involved. I used to see people like, you know I want that for myself, and, like just you’re so happy, I want to be happy too.

Sofia, a manager, also conceptualizes care through love and walking with them on their health journey and the mission of Christ-centered care, “We want to walk the journey with them and that's loving on them, that's support. It's a lot of things and it's perhaps unconventional for a clinic to provide all of that…. And so that helps us keep our focus on providing that type of care rather than a very straightforward clinical based type of care, and building relationships is another way that we love on them.” My findings show through my participant-observation, informal interviews, and semi-structured interviews that developing relationships through trust, love, and empathy are viewed as an essential element of healthcare between patients and providers.

*Time as Essential Care Practice*

The temporal nature of care has also arisen as an important element in fostering relationships. But in what context is time impactful and creates meaningful care to patients receiving health services and resources at GMH? Providing the needed emotional labor, and commitment to addressing a myriad of complex health needs for marginalized, vulnerable
patients is addressed through time. Dr. Song, a primary care physician in the adult care department describes how longer lasting appointments, either initial or continuous care encounters, is central to understanding the lived experiences of her patients.

Well, I think number one, the appointment time [75 minutes for new patients] because you can finally listen, and they’re heard because in regular offices with a 15-minute appointment and you have 10 things wrong with you, only maybe two things are addressed. So the fact that we can hear their stories, you suddenly can make a diagnosis and figure things out.

Being there, providing social and emotional support to GMH patients can last beyond appointment times for medical, mental, or dental services. Care involves the dedicated time, resources, and emotional labor provided to address patient concerns and grief through fostering relationships as social support systems. Many participants told me about knowing the story and experiences of their patients. Nicolette, a pediatric nurse, describes how she spends time learning about the complex social and medical needs of her patients with a chronic illness.

In PEDs, [pediatrics] we do a lot of teaching on how to navigate the healthcare system, right… So we have to follow up on all of those [specialist] referrals. Teach the parents how to navigate that system. Teach them how to use a pharmacy….. So that whole education process is different with kids with chronic conditions. The more conditions they have and the higher acuity, the more complicated they are. The more teaching, the more time, the more appointments, the more follow up to make sure that things are getting done.

The question of time emerges in scholarship as an element that is determined by the “economics” of care, often defined based on the perceived complexity of care, primarily involving the resources, time, and services needed to address health care concerns for patients. Medical anthropologist Denise Spitzer (2004) argues the economy of care in the restructuring of
healthcare delivery in Canada encouraged unequal maternity care practices for racially/ethnically minoritized women in the time nurses spent with them, as compared to longer time spent with white women. At GMH, time is conceptualized as a quantifiable entity within patient-centered care practices that determines what level of care a patient perceives they are receiving from clinical staff. GMH is cognizant of how impactful care is within the framework of time and how time equals quality healthcare for their patients, especially in understanding the complex educational levels and sociopolitical positions of immigrant patients. Likewise, patients see how quality of time, resources, and services create positive impacts on patients’ chronic illness experiences (Braddock and Snyder 2005).

**Economic Impact of Care**

My findings demonstrate that holistic, respectful care, which involves building trusting relationships, is perceived by both patients and staff/volunteers as essential healthcare. But care is also conceptualized through reducing costs and hospitalizations for Orange County hospitals. Chandel, a manager within GMH, argues that the impact of managing patients with chronic illnesses at GMH has the effect of reducing costs to the community hospital systems.

Well, Grace started, you know, by avoiding having visits to the hospitals. That’s why we have the partnership with both hospitals. A lot of patients we have are patients that have been in the hospital, and they are referred to us, as partners. About the acute and the chronic depending on what we want to avoid, is for them to go to the hospital. So, if they have a condition, let’s put asthma, and if we are able to treat it and provide the tools that the patients needs, like the pump the different medications, then it will avoid having the patient go into the hospital.

Many participants responds in similar ways when asked about GMH’s impact in Orange County, especially participants in management. My findings show that participants perceive the impact of care within the wider framework of a safety-net clinic as reducing costs to the local
healthcare system by taking on uninsured patients who have been frequently hospitalized with unmanaged chronic illnesses, such as type two diabetes and asthma. This political economy of care within the structure of safety-net clinics is observed and reported by Fleming and Colleagues (2019) who show that such clinics reduce hospital costs of “super utilizers,” uninsured patients who are structurally vulnerable, housing insecure, people with problematic drug use, and those who have multiple chronic illnesses. Care for these patients warrants extensive medical and social resources and services that are deemed expensive for hospitals. These patients also require extensive medical, mental health, and social service resources and may require more time to develop appropriate care plans.

Here I present an emblematic example of how GMH and a community hospital worked together in providing medical and social resources, restoring dignity and respect for patient care, and the extended time to establish care. Javier, a Guatemalan construction worker, living in the U.S. for over 15 years, became unable to work due to his diminishing eyesight last year. Earlier in the year, through a community hospital free clinic evaluation, Javier became diagnosed with Chronic Kidney Disease (CKD) along with type 2 diabetes and hypertension. Javier attended his medical appointment with a nurse from the hospital to manage his case in establishing primary care to qualify for a dialysis assistance program. Even though Dr. Spade could have obtained all of Javier’s medical information from his case manager, she proceeded to ask open ended questions about his life in Guatemala, coming to the U.S. and his current relationships with his roommates. These questions complemented the medical information physicians typically collect during primary care visits such as family history and current health problems. This appointment lasted over 90 minutes. When he was describing his difficulty seeing, Dr. Spade mentioned finding him a diabetic blood reader that verbally spoke in Spanish, because he would have
difficulty reading a text version of the reader. At the end of the appointment Dr. Spade, myself, a
scribe, the nurse case manager, and the translator prayed for his successful admittance to the
dialysis program as well as his improved health and wellbeing.

Another example of what many participants considered a foundation in providing high
quality care that was different from other PCAN clinics and CHCs, involved time constraints to
care due to reimbursement and billing standards. Heather provides an emblematic example of
how GMH staff and volunteers provide different care through unrestricted time.

It really just depends on the type of care that you want to provide
like certainly not knocking FQHCs but because there’re receiving
that reimbursement it limits, and kind of sets the parameters on,
what the care you provide looks like, and how many patients you
have to see and all of that. So we just, our founders decided we
didn’t want to go that route because we want to provide spiritual
care. We want appointments that can be 90 minutes to two hours
long. Because the reality is when you’re talking to someone who’s
been uninsured for 10 years and potentially has immigrated here,
they may not, like they don’t have any vaccines and they have
never had a dental appointment. And so, it’s going to be that first
visit is, to establish care, it’s going to be really complex. And you
want to spend time with that patient. So why let someone else who
doesn’t know that patient face-to-face, set the parameters on how
long we can spend with them, and determine what we can and
can’t do with them.

Howard and colleagues (2016), who examined the successful implementation of PCMHs
in private, insurable markets, argue that their physician participants valued the care manager job
responsibilities (similar to care coordination staff and volunteers within GMH) who work with
patients with chronic illnesses in coordinating specialty appointments and diagnostic testing by
dividing the time that medical providers could spend on medical and health concerns. This
division of labor created a positive economic impact at the PCMHs by reducing physician hours
with patients, but still allowed patients to have assistance in coordinating specialty care.
However, PCMH providers were worried how the pilot funding for care managers would be allocated, they also cited how many PCMH lost their care managers once grant funding stopped (Howard et. al. 2016). This contrasts the safety-net system and PCMH structure of GMH in justifying costs by supplementing various department positions with volunteers, employing only key managers, physicians, and nurses to manage the volunteers of the various departments.

**Conclusions**

Through my findings, it is evident that unconventional “care” is perceived by both patients and staff and volunteers as an essential healthcare practice. This concept of care is specific to my study, but I would argue represents a growing shift in how healthcare providers and patients perceive health care delivery in the U.S. As my findings show, perceptions of time dedication, personal support in grief and economic need, conversations of disease and illness education, and a level of trust and relationships in medical care provision were key components in conceptualizing exceptional care received in a PCMH. These medical, social, and spiritual care distributions reflect effective implementation of a multi-team collaboration in creating optimal health outcomes for patients within the safety-net system in the U.S. This study contributes to the nuanced understanding of how patients and providers feel about the quality of care given, patients that are arguably, seen as a cost burden within the healthcare landscape due to their uninsured and documentation status. The current healthcare system in the U.S. is driven by commodified, market-based healthcare delivery which places responsibility of health and wellness on the patient (Rylko-Bauer and Farmer 2002). The intentional, integrative care practices at GMH may be challenging to advance in clinics that are driven by the economics and "efficiency" models. There have been many challenges in steering medicine away from a specialized, and therefore fragmented, conceptualization of the body and person toward the view
of the patient as imbedded in their sociopolitical and economic contexts. This is another challenge as new medical technologies and advances are only increasingly narrowly specialized, and interest of medical students in general practice has long been on the decline (Peterson et.al. 2015).

At GMH, the concept of care, through medical, spiritual, and social encounters is not considered within a cost ideology as stated by many participants’ interviews. Rather, it is viewed within their mission and responsibility as Christians upholding Christ-Centered care practices in the U.S. safety-net system. This study contributes to medical anthropology and public health by demonstrating through patient and medical and social care providers narratives, the various ways in which a safety-net clinic providers and patients conceptualize care through the relationships built between patients and care providers, rather than medical resources and services provided. This study also contributes to anthropological inquiry into the perceptions and experiences of providers and patients with Christ-centered care practices. Even though many faith-based NGO clinics are Christian or Catholic based (Haakenstad et.al. 2015), there is a dearth of studies on the implementation of such care practices in the context of safety-net clinic healthcare provision.

**Ethical approval**

This research was reviewed and approved by the University of Central Florida’s Institutional Review Board in August 2022, study #00004436.

**Acknowledgements**

I am grateful to research participants who generously shared their perspectives and experiences with me. I thank the Grace Medical Home management for their support and providing permission for this study.
Disclosure

No conflict of interests was reported by the author.

Appendix

References


CHAPTER 4: CONCLUSIONS

My influences for designing and conducting research on the safety-net system stem from my own experiences navigating this system. I personally utilized a safety-net clinic in Orange County in 2019 while I was uninsured. My experience at this clinic was negative due to the intake process. I waited four hours to be seen by a physician to be told that they could not help me with the problem I was experiencing. This negative experience discouraged me from trying another safety-net clinic.

I have also been uninsured for most of my teen and young adult life due to my father, who was the only employed adult in my family, being diagnosed with brain cancer. This diagnosis led to his inability to work and a series of changes in my family’s socioeconomic status. He obtained Medicare due to his cancer diagnosis, but the rest of my family did not qualify for any federal health insurance programs. We were in that liminal gap of health access that was prevalent in pre-ACA healthcare era.

This positionality of having experienced inadequate healthcare access through most of my young adult life has helped me understand patients I have met at GMH that have similar narratives. However, some of these narratives contrast my own experiences because I am a U.S. citizen, whereas many GMH patients are not. There are several ways in which immigrant patients at GMH are structurally vulnerable that relate to documentation status, socioeconomic status, and communication barriers with indigenous speakers of Latin America. There are also a myriad of other socio-economic situations that influence health access and decision-making in the U.S. My own structurally vulnerable positionality has been a resource in developing my thesis and in gaining rapport with patients and staff/volunteer members as I understand some of these complexities though my own lived experiences. At the same time, I was aware of the
potential bias that may stem from my past experiences with a safety-net clinic, and to counter any such biases I focused on retaining a scholarly distance during fieldwork.

This thesis builds on and contributes to literature in medical anthropology, public health, and medicine by demonstrating how healthcare providers address social and structural elements of healthcare access and services to chronic illness patients through the integration of comprehensive, holistic healthcare delivery in the U.S. safety-net system within a PCMH. As evident with the growing shift in how patients and providers view patient-centered health care services and resources, my thesis shows that ways to provide exceptional health care through integrated social care encounters during medical appointments, understanding the vulnerable, complexed experiences of marginalized and immigrant patients in context to their chronic illness(es), and that care is conceptualized through trust, social relationships, and establishing time in understanding a patient’s health and wellness journey. I argue that this integrated, comprehensive medical and social care, that expands beyond immediate medical treatments is a model that demonstrates resourceful and innovative practices in addressing SDH through continuity of care for chronic illness patients, which may be questioned in present day neoliberal U.S. health care system as impossible to achieve. I argue that the limitations of this thinking are rooted in hegemonic constructions of capitalist, profit based rationales for the healthcare delivery prevalent in the US. I suggest that thinking outside of this box may open new possibilities of conceptualizing the need for both comprehensive and holistic healthcare both within the safety-net and in general healthcare primary practice. This new conceptualization need not be limited by the dominant discourse, which argue that this model is impossible from an economic perspective.

Future Research
Future directions for ethnographic and mixed methods field work should focus on patients suffering from chronic illnesses who rely on safety net clinics and the embodiment of their illness(s) within daily life. I also suggest that comparative data from safety net clinics between states that expanded Medicaid and those that have not, may be useful for understanding how such policies that are vital for the uninsured are impacting patients with chronic illnesses. Additionally, anthropological studies should direct an applied scholarly focus toward the analysis of experiences of patients who “age out” of safety net clinics without transitioning to Medicare, as these are highly vulnerable people and for the most part invisible in the discussions of health care reform at the national level.
APPENDIX A: IRB APPROVAL LETTER
EXEMPTION DETERMINATION

August 12, 2022

Dear Jacqueline Devaney:

On 8/11/2022, the IRB determined the following submission to be human subjects research that is exempt from regulation:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study, Initial Study</th>
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<tbody>
<tr>
<td>Title:</td>
<td>Patients’ Chronic Illness Experiences within a Safety-Net Institution</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Jacqueline Devaney</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>STUDY00004436</td>
</tr>
<tr>
<td>Funding:</td>
<td>None</td>
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<td>Grant ID:</td>
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</tr>
<tr>
<td>Documents Reviewed:</td>
<td>- HRP-251- FORM - Faculty Advisor Scientific-Scholarly Review fillable form.pdf, Category: Faculty Research Approval; - Email From GMH with Permission to Conduct My Research Project.pdf, Category: Other; - GMH Patient Interview Guide.docx, Category: Interview / Focus Questions; - GMH Staff Volunteer Interview Guide.docx, Category: Interview / Focus Questions; - Patient Recruitment Flyer.pdf, Category: Recruitment Materials; - Study 4436, ConsentPATIENT, TrkChg3_JMD.pdf, Category: Consent Form; - Study 4436, ConsentSTAFF, TrkChg3_JMD.pdf, Category: Consent Form; - Study 4436, GMH Research Announcement, TrkChg1_JMD.docx, Category: Other; - Study 4436, Protocol, TrkChg4_JMD.docx, Category: IRB Protocol; - Updated GMH Field Notes.png, Category: Other;</td>
</tr>
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This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made,
there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Gillian Bernal
Designated Reviewer
Thank you for agreeing to talk with me today. My name is Jacqueline Devaney, and I’m an anthropology master’s student at the University of Central Florida. In this interview I’m interested your role at GMH and how you assist patients with chronic illnesses within GMH. All the information you give me will be confidential – I will not ask you for your name or any information that could identify you. The interview is voluntary, and it will take 30-60 minutes. You can stop the interview at any time and refuse to answer any question if you are uncomfortable answering. May I audio record our interview? Would you like to start now?

Interview Site: ____________  Participant ID: ____________
Date: ____________  Time: ____________  Length: ____________

1. What is your role at GMH?
   a. What responsibilities do you have?
   b. How long have your worked/volunteered for GMH?
   c. Can you give any specific examples of your interactions with patients in your role?
2. What do you feel makes the biggest impact on patients who are treated at GMH?
3. Can you describe any experiences with patients with chronic illnesses?
   i. What services and/or resources have you provided?
4. How does GMH address social determinants of health for their patients?
5. How do the needs of patients with chronic illnesses differ from patients with acute illnesses?
6. What are some positive services and/or resources at GMH that are helping assist patients with chronic illness?
7. How does GMH make an impact in Central Florida for uninsured people?
   a. Do you have any specific examples that stood out to you?
8. Based on your experience working/volunteering at GMH, what do you see as a primary barrier for people with chronic illness/es?
9. What state/county/federal programs do you know that help uninsured people?
10. What additional resources and/or services do you think is needed by healthcare workers to assist patients with chronic illness in their treatments and within their daily life?

Demographic Questions:
1. What is your age?
2. What is your gender identity?
3. What is your ethnicity?
4. What is your race (if they do not specify ethnic identity)?
5. Language
   a. What is your primary language?
b. Do you speak any other languages?

6. Education
   a. What is your education level?

7. Religious Affiliation?

8. What is your annual income?
   a. Does this include income from family members?
   b. Are you the only one working in your immediate family?
Preliminary Interview Guide Patients

Project Title: Patients’ Chronic Illness Experiences Within a Safety-Net Institution
(After informed verbal consent and explanation of research project)

Thank you for agreeing to talk with me today. My name is Jacqueline Devaney, and I’m an anthropology master’s student at the University of Central Florida. In this interview I’m interested in your chronic illness experiences as a patient within GMH. All the information you give me will be confidential – I will not ask you for your name or any information that could identify you. The interview is voluntary, and it will take 30-60 minutes. You can stop the interview at any time and refuse to answer any question if you are uncomfortable answering. May I audio record our interview? Would you like to start now?

Interview Site: _____________ Participant ID: _____________

Date: __________ Time: __________

First, I am going to ask you some questions about your illness experiences and perspectives

1. What chronic health issue(s) are you dealing with?
   a. When did you experience your chronic health issue(s) for the first time?
   b. Has your initial experience with your chronic health issue(s) changed over time?
      i. How would you describe this change?
   c. How do you view your body and your health condition(s)?

2. Support System(s)
   a. How would you define your family life?
   b. How would you describe the support you receive from your family in dealing with your illness?
   c. How do you manage your illness while at home?
   d. How would you describe your relationships outside of your home with friends, coworkers, community members and/or online support groups?
      i. How do these systems provide support for you?

3. Employment
   a. What do you do for work?
   b. How would you describe your employment status?
   c. How accommodating or understanding are your coworkers or superiors towards your chronic illness?
   d. How do you manage your chronic illness while you are at work?
   e. If you do not work, why?
      i. How has your chronic illness affected your work capabilities?
4. How do you manage your chronic illness while doing daily activities?

5. Has your illness changed your life in any significant ways?
   a. Do you feel there has been any impact on your interpersonal relationships because of your illness?
   b. Do you feel you have to change how you interact with certain people? Do you have any examples?
   c. How has your illness changed the way others see you?
   d. How do you feel about yourself in relation to your illness?
6. What is the most difficult part about dealing with your illness? And, why?

These next set of questions are related to your experiences within the healthcare system

7. How would you describe your experience within the healthcare system?
   a. How would you describe your experience setting up appointments, finding physicians, attending appointments, etc.?
   b. Can you describe how your chronic health issue(s) were managed prior to GMH?
      i. How would you describe the quality of care you received?
8. How did you hear about GMH?
   a. How has your illness been managed while at GMH?
      i. Do you see the same physician and nursing staff each visit?
      ii. How does this have an impact on how you feel about your quality of care?
   b. What impact have the people or services provided at GMH had on you?
   c. Have you utilized any other GMH services outside of your illness management?
      i. (ie. This can be social services, food pantry, counseling services, or spiritual services)
9. Can you describe your experience applying to GMH?
   a. What were your feelings through this process?

Next are a few questions on health program understanding

10. Have you used any state or federal programs such as the Healthy People 2030 campaign or Self-Management Education programs from the CDC that help address chronic illness conditions?
    a. How helpful was this program in managing your chronic illness?
11. What do you need to help you with your illness?

Some of the last set of questions I will ask are about your general information

12. What is your age?
13. What is your gender identity?
14. What is your ethnicity?
15. What is your race (if they do not specify ethnic identity)?
16. Language
a. What is your primary language?
b. Do you speak any other languages?

17. Education
   a. What is your education level?

18. What is your monthly income?
   a. Does this include income from family members?
   b. Are you the only one working in your immediate family?

19. Living Situation
   a. Do you live with others?
      i. If yes, who do you live with?
   b. In what area of Orange County do you live?
   c. Do you have reliable access to the internet?
      i. Does this have an impact on your healthcare decision making and access to information?
   d. Do you have reliable housing?
      i. How does this impact your daily life and illness experiences?

20. Transportation
   a. What type of transportation do you use?
   b. Does this have a significant impact on your daily life?
      i. If yes, how so? Can you explain or give examples?
   c. Does it impact how you get to your health appointments?
      i. Do you have an example?

Thank you so much for your time! Do you have any questions that I did not ask during the interview?
APPENDIX D: RECRUITMENT MATERIALS
VOLUNTEERS NEEDED FOR RESEARCH ABOUT CHRONIC ILLNESS:

Patients’ Chronic Illness Experiences within a Safety-Net Institution

This research aims to understand the experiences of uninsured individuals with chronic illnesses who use safety-net clinics.

WHO IS ELIGIBLE?

Participants must be 18 years or older, be a patient at Grace Medical Home for at least 6 months, speak English, and have at least one chronic illness. Examples of chronic conditions include diabetes, chronic obstructive pulmonary disease (COPD), asthma, and kidney disease.

CONFIDENTIAL INTERVIEW:

Participants will be asked to participate in a CONFIDENTIAL interview lasting no more than 1 hour in-person or through Zoom, depending on your preference. Participation is voluntary.

CONTACT INFORMATION:

To learn more about this research, eligibility criteria, or to participate please contact Jacqueline Devaney, Principle Investigator, MA Student, UCF. Email: jdevaney@knights.ucf.edu Phone: (407) 766-0098

University of Central Florida, Department of Anthropology, 4000 Central Florida Blvd, HPH 309, Orlando, FL 32816
RESEARCH PROJECT ABOUT CHRONIC ILLNESS:

Patients’ Chronic Illness Experiences within a Safety-Net Institution

This research study at Grace Medical Home aims to understand the experiences of uninsured individuals with chronic illnesses who use safety-net clinics. This research project involves voluntary interviews of patients conducted by the researcher, Jacqueline Devaney, and participant-observations of general clinic operations.

CONFIDENTIALITY:

Participants who meet eligibility criteria will be asked to complete an interview lasting no more than 1 hour in-person or through Zoom, depending on your preference. Participation is voluntary.

Ms. Devaney will also conduct participant-observation regarding general administrative/clinic procedures, not individual behaviors. Field notes will only be taken on administrative procedures, and no individual identifiable data will be collected. Grace Medical Home has approved this study.

CONTACT INFORMATION:

To learn more about this research, eligibility criteria, or to participate please contact:
Jacqueline Devaney, Principle Investigator, MA Student, UCF.
Email: jdevaney@knights.ucf.edu
Phone: (407) 766-0098

Or let the front desk know you’re interested.

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