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and the people within it, have affected and changed me for the better continue to surprise me. Thank you to all of the CEF advocates and all of the work they put into making CEF the organization it has been, presently is, and will become. Everyone's collaboration and compassion matters and is making a strong, positive impact on this community, one meeting at a time.

Finally, thank you to all of my friends and family for their support throughout this project, from their puzzled questions trying to understand exactly what I was doing, to encouragements to continue moving forward. All of these, and more, did not go unnoticed, and have not been forgotten.

Abstract

One of the most vulnerable populations in the United States today are those that are chronically homeless and those in danger of homelessness, such as the unemployed. During my freshman year at UNC-CH, I conducted a research project on a population of individuals that work with the nonprofit, CEF, to achieve a higher level of financial independence. This study focused on the primary factors that contribute to and perpetuate homelessness. This study along with others like it, have found that a primary factor contributing to homelessness and unemployment is an individual's personal health.

Following these findings, this thesis focuses on these individuals' interactions with health and healthcare resources. Based on the current literature regarding this topic, there appears to be a lack of information concerning how individuals within this population themselves perceive healthcare. Typically, the information available is represented by healthcare providers or members outside of this population. This thesis used interviews and focus groups to further the understanding of how individuals of this population use, access, and perceive healthcare related to their goals and daily life. This thesis is important because a stronger understanding of these areas can help healthcare policies and resources adapt to better fit the social and structural needs of these individuals. It is also important for this population to be given a voice and space to express their own opinions and perceptions rather than having outside sources represent them.

Chapter 1: Introduction

"Seventy percent of SSI and SSDI applications are denied the first time around." These were the words presented to a member during their CEF appointment with me. They had gotten their SSDI application results back and, true to the statistics, had been denied their first time. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are federal programs that provide assistance to people who meet certain federal requirements, such as the federal definition of "disabled." Such benefits can provide direct income when recipients need it most, and provide access to healthcare (Social Security Administration).

"Well what do I have to do now?" The member asks, still digesting the daunting statistic for first-time application denial. I did the only thing I could do, which was to tell them about the appeal process, offer to work with them through it, and recommend the legal services of a local lawyer firm CEF is connected with to help build their case. However, the primary issue was, on average, the first application decision likely took four to six months, and appeals usually take another few months to a year. All the while, the member most likely has been, and will be, struggling with their income and making ends meet with their bills, in addition to potentially paying for lawyers and subsequent doctor's visits. This is because those who apply for such benefits often have a new or old injury or disorder which hinders their ability to find or maintain employment. It could also be they meet other criteria, such as low-income, as defined by the eligibility requirements.

The primary reason for the application denial seems to be the ability to prove an applicant has a disability. This requires access to a primary care provider, medical records documenting

the disability, as well as other evidence to support their case for receiving benefits. The conception of proving a disability, and the assumed ability to access a care provider in order to diagnose and subsequently provide evidence for a disability, are problematic for such applicants. This is especially true first, in the face of stringent federal definitions of what constitutes a disability. This is also true due to barriers to healthcare that such individuals are faced with. Returning to the member, the next challenge was reconciling the future steps we should take to appeal the case, and prove the reality of the disability, which seemed all too obvious to us. From our meetings together, the case seemed open and closed. As an advocate, I could see how they were injured and how it hindered their daily functions, and obviously qualified as a disability to me, but the challenge was providing a solid case to prove it to the right people.

In situations where they have medical bills piling up, have limited or lost employment due to the disability, and then have to face the absurdity of having to prove a case that one deserves federal assistance, it can all be too overwhelming. "It's like man, look at my life right now and all that's going on, I need help!" they say with disdain (Member-advocate meeting July 2016). This story provides an anecdote of a situation which shows how the health and well-being of a person, in addition to processes surrounding health, can have direct effects on multiple aspects of their lives, such as employment, access to healthcare, and qualifications for supplemental benefits. Their story provides a case that comprises numerous ideas that will be addressed in the pages that follow. These include conceptions of health, barriers to healthcare, personal experiences with healthcare, cost and insurance, and how illness can have direct and deleterious consequences on someone's life.

Early Beginnings and CEF

Thinking back, this thesis was but a fleeting dream that started when I was a first year at UNC Chapel Hill. I was a member of the campus Living Learning Community, UNITAS (a group name that indeed is not an acronym nor does it stand for anything). Part of being a member in UNITAS meant taking two anthropology courses that dealt with learning about social justice issues. The primary focus of the courses was a capstone project based on ethnographic research in a local community organization. The topic for my project covered the factors that lead to, and perpetuate, conditions of homelessness among people, called members, who sought out the help of the Community Empowerment Fund, CEF. It was here that I found my beginnings as a developing anthropology student and eventually a social worker. It was an ethnographic study where I utilized classic anthropological methods of one-on-one semi-structured interviews and participant observation to inform my research.

After spending the spring semester of 2014 as a participant observer and ethnographer, I decided to continue working with CEF as a fully engaged advocate. Now, seven semesters and 140 one-on-one member-advocate meetings later, I have developed into a senior advocate and CEF admin leader as the Coordinator of the Savings Taskforce. During this time, I have worked with many CEF members and collaborated with them to achieve their goals, be it finding a better job, stable housing, or, interestingly enough, a chainsaw to support a startup landscaping business. Throughout these interactions, I continued to think about my previous research and how I could continue to invest my time in this population of people and further impact them. Soon, I began to notice that one of the things rarely discussed in member meetings was personal health or healthcare resources. Being a pre-medicine student, health is a topic that is forefront in my mind. It was a puzzle to which I sought answers.

My initial search began by becoming part of the CEF Health Committee. The primary duty of this committee was to compile and develop a research database related to local healthcare resources and make it available for both advocates and members to use. These included various clinics that offered free or subsidized healthcare to individuals. We made sure to include information from all service areas, including primary care, dentistry, optometry, and mental health resources. We also performed health check-ins with members, especially if they checked the "Better Physical or Mental Healthcare" goal box upon initial intake. This was all in an effort to increase member access to healthcare and help connect them to appropriate resources. Though we were satisfied with the progress made in sorting resources and developing the database, we struggled to formulate an effective means through which we could both inform members of the resource options, and have members actively engage with them. It is one thing to make resources available, but another thing entirely to actually connect them to individuals who need them most.

Following this, we developed an advocate training program to present at the monthly advocate meetings. In this way, we hoped to share what resources were available for members to use and hopefully strengthen their connections. We talked through the importance of health, how to bring up and effectively discuss health with members during appointments. Advocates seemed receptive to the information and voiced their agreement with the importance of the discussion of health. Some also described their own observations that few CEF mentioned their health during meetings. Even by a show of hands, it only seemed like a handful of people had been a part of an appointment where a member brought up their health or requested information related to health resources. So, other advocates had observed this trend as well, yet it had not been adequately addressed until now.

As an organization, we had taken steps to try to bridge this gap. However, I continued to wonder what else may be getting in the way of members and the discussion of health and healthcare resources. I decided it was time to take up my role as an anthropologist and officially research into the matter. And thus, with many years in the making, this research study was put into motion. As an advocate and anthropologist, I wanted to understand why health did not appear to be in the forefront of members' minds as evidenced by it rarely being addressed in member-advocate appointments.

Research Questions

Major Research Questions:

1) How do CEF members understand health in regards to their individual health, the health of those around them, and in relation to their goals?
2) Why do members usually not discuss their personal health in CEF meetings?
3) How do members use, access, and perceive healthcare resources?

The topic that I was first interested in was how members perceive their overall health. I wanted to determine if the reason members did not discuss their health in member-advocate meetings was due to their perception of their personal health. However, in order to understand this concept, I needed to step back and ask a deeper question, what does "health" mean to CEF members? Health in itself in a complex topic that can be approached from many different, and interacting, viewpoints. My understanding of health can be vastly different from the members I would engage with due to our different backgrounds and beliefs. Is health strictly physical, or mental, or perhaps social or economic? Is health a personal, secret matter, or something shared with others? How members gauge, interpret, and understand health, be it personal or even public

health, was an important benchmark to engage with first in order to better inform this issue of health and its absence during member appointments.

The next topic I was concerned with was why members didn't discuss health related topics with their advocates beyond their general understanding of health. Was it that they were not conscious of their health or not concerned with their health? Perhaps they were just not comfortable approaching advocates with these personal topics? Perhaps health just did not rank high on their goals or concerns compared to finding a job, or housing, or other issues they wished to address. Perhaps they were already adequately connected with healthcare resources and did not require advocate assistance?

Following these potential answers, I was still concerned with how members use and access healthcare resources. As with health, this topic could also be approached from many different angles. One angle is, what motivates people to seek out healthcare? What constitutes a need to actively pursue professional care? What has to "go wrong" or be wrong with a person's concept of health that pushes them to ask for help? How do individuals decide when it is time to see a doctor versus when it is time to go to the hospital or emergency room? What constitutes a medical illness or emergency? Do people always go to a doctor, or do they seek out advice and help from friends and family, or do they simply put off care? These could all contribute to healthcare resource usage patterns. These initial deciding factors that lead to the choice of health seeking behavior are key to understanding the issue of health resource utilization.

The next topic of interest was in regards to what stops or inhibits individuals from pursuing healthcare resources and treatment? Are there personal factors, systemic motivators or inhibitors, obvious or obscure influences? Do individuals simply not know when or how to approach conversations where they ask for help with their health? The primary barriers often

listed by the literature and policymakers are time, cost of healthcare, and lack of insurance. Are these the only factors, or are they just the ones that bear the most weight? Are there others that could be just as important in weighing out the risks and benefits of pursuing healthcare resources? I assert that approaching the issue from a different lens, one outside of economic and public policy fields, can help illuminate these hidden factors. Such factors could potentially be invaluable in the development of future interventions to help alleviate barriers and increase access of health resources.

I use the methods of structured ethnographic interviews, focus groups, and participant observation to answer these questions. I present an ethnographic case study of individuals in homeless and low-income situations, which work with CEF, during the fall of 2016. I use these research questions to attempt to show the merits of approaching this problem through the lens of the field of anthropology, particularly through ethnographic and qualitative approaches, rather than through a public policy or economic lens. I also hope to increase the scope through which these topics are reviewed in order to influence positive changes that will alleviate such problems of healthcare access and health disparities for homeless and low-income populations.

<div align="center">Key Terms and Definitions</div>

The following section is to help clarify key terms and definitions used throughout this study and its subsequent discussions. The terms for homelessness are derived from definitions from the Department of Housing and Urban Development of Orange County (HUD Exchange 2011). The definition of low-income was derived from the United States Department of Health and Human Services 2015 Poverty Guidelines (USHHS 2015).

1. Low-income
   a. Having an annual income that does not exceed 200% of the federal poverty guidelines: $11,770 for one-person household to $24,250 for four-person household.
2. Homeless
   a. An individual or family who lacks a fixed, regular, and adequate nighttime residence
   b. Acute
      i. Having experienced less than three episodes of homelessness within a twelve-month period
   c. Chronic
      i. Having experienced three or more episodes of homelessness within a twelve-month period
3. CEF Member
   a. An individual who engages with CEF programs and resources, such as member-advocate meetings or Opportunity Classes.[1] Individuals come from varying backgrounds, as well as economic, housing, and legal backgrounds. There are no eligibility requirements to become a member
4. CEF Advocate
   a. A volunteer who undergoes CEF program trainings in order to meet with CEF members and collaborate with them to achieve their goals. Majority of advocates are UNC Chapel Hill students
5. Conservative Model[2]
   a. An approach to homelessness that ascribes its cause to a personal pathology whereby homeless individuals are inherently lazy or have other negative characteristics. They are thought of as deviants who choose not to take part in the broader economic and social systems. The solution to homelessness from this model is to defund federal benefits programs and force such individuals to reenter and participate in job/labor markets
6. Disease Model
   a. An approach to the cause of homelessness that is viewed under a medicalized model where homeless individuals have a mental disability or addictions that lead to homeless situations. The solution to homelessness from this model is to both treat and prevent mental illness and addiction in order to alleviate and prevent homelessness

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[1] CEF Opportunity Class is a twelve-course program offered every Saturday from 9am-1pm. Their goal is to provide members with information which can help them transition out of poverty and homelessness. Such skills and information include budgeting habits, performing an effective job search, and building credit. What makes these classes unique is that they are taught by a CEF member who has been with CEF since the beginning. In this way, the information is more approachable, relatable, and empowering, since the instructor has experienced similar situations as members. The classes not only provide valuable information, it also provides a support system as members share their personal stories and experiences dealing with poverty and homelessness. There is also a Women's Opportunity Class catered specifically to women on Sundays. Members are able to attend classes at any time, they need only show up and start engaging.

[2] My descriptions of the models of homelessness are themes brought on by studying into the discourse of homelessness, and from Gowan (2000)'s "Excavating Globalization from Street Level: Homeless Men Recycle their Pasts."

7. Structural/Systemic Model
    a. An approach to the cause of homelessness which ascribes to a systemic/structural pathology whereby homeless individuals arrive into such situations not only due to potential negative personal decisions, but also due to broader social and structural systems which lead to homelessness. Such systems include racism, deindustrialization, and broader economic, employment, and housing practices and opportunities

Overview of Chapters

After reviewing the literature, previous studies, and methodology of this study, the heart of this thesis is reached in the research findings and discussion chapters. For the research findings chapter, I review the findings of the different research methods of the study. In the discussion chapter, I provide an analysis and review of previous studies related to healthcare access barriers. I also suggest a framework that can be used to organize, approach, and understand these issues. The framework categorizes the different barriers to healthcare under Individuals/Personal Constraints, Health Service Seeking Behavior, Structural/Social Organization, and Cost and Insurance.

I assert that the problem of healthcare access is not just cost and structure of public systems and services alone. The issue extends into personal experiences, perceptions, and understandings of health and health seeking behaviors. Following the understandings under the structural/systemic model for homelessness, the problem is a dynamic interaction between personal/individual and social/population level concerns and understandings of the meaning of health and homelessness (Gowan 2000). In essence, the problem will not be solved simply by increasing or diversifying funding to certain programs or organization, or by restructuring the delivery of healthcare and public services. Such interventions will require a collaboration of

these efforts, and more, coupled with a shift in social understandings of homelessness and duties related to healthcare. It is my hope that a mixed review of both my findings and others' will provide a comprehensive examination of these topics.

In the concluding sections of the discussion, I review potential interventions that could be used to alleviate the barriers to healthcare access. This includes a summary of what they are, their merits, and also their drawbacks. This is, once again, in an effort to provide a complete review of the issue, while also contributing solutions to the problems in addition to simply identifying its symptoms. Finally, I provide a review of the debate that I feel encompasses the motivations for researching into this issue of healthcare access. This is the debate regarding the right to healthcare. This debate contributes to explanations of why researchers and governmental leaders are concerned with understanding the health disparities experienced by certain groups within the population. While there appears to be a "common sense" moral understanding that health disparities are of public concern, the steps that would need to be taken to protect such a human right, if such a right was officially recognized, are of intense cost-benefit debate. It is such pivotal discussions and debates as these that are necessary in order to make large scale changes to address such high stakes societal issues. This will act as a closing thoughts section to help readers engage with one of the moral dilemmas for healthcare policy.

In order to solve a problem, one must understand the all factors that bring it into being. Without this understanding, interventions being implemented may not be comprehensive or effective enough to fix the problems which they seek to solve. The issue of health is important because the health of individuals has a direct impact on peoples' lives, not only biologically, but also socially and emotionally. It influences their ability to take advantage of opportunities they are presented with and can affect their subsequent financial independence. If issues of health can

be alleviated, individuals may be able to more comprehensively achieve higher standards of living. This is why research into health disparities and healthcare access barriers is important.

This study will provide a case study of a particular population in order to show the validity of past research findings and provide further examples to fill possible gaps and to expand information related to this issue. Following the subsequent analysis and discussion, a clearer understanding of this problem will have been reached and thus allow for potential solutions to be closer at hand as more sides of the problem are brought to light. This study can hopefully inform future interventions that can address the complex system of factors that intersect multiple aspects of these individuals' lives.

Review of the Health of Low-income and Homeless Individuals

"The quality of national healthcare may be measured by the care we provide to the most vulnerable among us (*NewsHour*, Jan. 21, 2002)." This is a powerful statement by former Surgeon General David Satcher, which highlights the importance of understanding the health disparities experienced by low-income and homeless individuals. Through many previous studies, it has become apparent that there are vast differences in health between homeless and low-income individuals in the US compared to the general population.

First, there are increased rates of infectious disease and chronic medical conditions (Wagner et al. 2014). There are also increased cancer related risks due to smoking, alcohol, and sun exposure. Not only are homeless patients admitted to inpatient units five times more often, they also generally have to stay longer than housed individuals.[3,4] People living with poverty and

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[3] Martell JV, Seitz RS, Harada JK, Kobayashi J, Sasaki VK, Wong C. 1992. "Hospitalization in an urban homeless population: the Honolulu Urban Homeless Project." *Ann Intern Med*. 116:299–303.
[4] Salit SA, Kuhn EM, Hartz AJ, Vu JM, Mosso, AL. 1998. "Hospitalization costs associated with homelessness in New York City." *N Engl Med*. 338: 1734–1740.

homelessness suffer from combined burdens of residential instability, poor social networks, and significant levels of physical and mental health disease (Schanzer 2007). Typical health issues cited are: hypertension, consequences of violence, chronic obstructive pulmonary disease (COPD), skin disease and acute infections, liver diseases, kidney diseases, and GI diseases (Wagner et al. 2014). In addition to this, other factors that are associated with homelessness include: being male, coming from African American descent, having a substance use disorder, and lacking Medicaid insurance (Folsom et al. 2005).

How exactly, then, can the environments these individuals reside in affect their health? In their study of the effects of socioeconomic disadvantage on the human body, Gruenewald et al. (2012) sought to find out. They too acknowledge the extensive literature documenting the association between socioeconomic status (SES) and health, such that lower SES is associated with greater risk of adverse health outcomes. They hypothesize that certain SES-patterned environmental exposures, psychological, social, and behavioral processes affect the functioning of biological regulatory systems. The underlying logic is that these factors place demands on these biological systems that lead to greater wear and tear over time, which subsequently enhances the risk for poor health and functioning. Indeed, they find support for an accumulation of risk over the life course due to certain pathways, such as experiences of higher allostatic load. This can lead to greater risk for morbidity and mortality in later adulthood.

In my search for further information regarding the health disparities of individuals similar to the population that interacts with CEF, my challenge was finding articles that considered individuals not only in homeless situations, but also low income or unstable housing situations. It seems that researchers often place these populations into a single category, rather than delineating their subtle, but significant differences. However, this is an important distinction

because low-income individuals, also referred to as the urban poor, those in unstable housing, and homeless individuals each experience differential environments and thus differential stressors. For homeless individuals in particular, this stress difference arises because, "losing a home has multiple negative side effects such as loss of security, stability, and increased stress and fear for the future," which can cause accumulation of stressors housed individuals, even those with low-income, do not experience (Wagner et al. 2014). As discussed by Gruenwald and colleagues (2012), these differences in stress can produce substantial differences in health between such populations.

A trend of increasing concern is the disparity between mortality and morbidity for homeless populations. In their study of a homeless population in Pennsylvania, Hibbs et al. (1994) matched individuals identified in their data system to mortality reports to make direct, calculations for mortality to the cohort that was studied. They found that age-adjusted mortality rate for the homeless population was three and a half times higher than the general population, while the age-adjusted years of potential life lost before age 75 was also over three and a half times higher than the general population. Their quote, "the nearly fourfold increase in mortality that we observed is an unacceptable human cost of homelessness that merits intervention," is a sobering key point that justifies research into understanding and remedying these health disparities (Hibbs et al. 1994).

Based on their data, they make the claim that this excess mortality is not explained solely by age, race, or sex distribution, nor any single identifiable risk factor (Hibbs et al. 1994). This study found that the top causes of mortality, in this cohort, were injuries, poisoning, liver disease, and things related to substance abuse. This is contrary to other studies that claim infectious disease is the primary cause of mortality. Infectious disease was actually the top 8th

cause of mortality in this cohort, below the ones previously listed. Given these results, they conclude that any purely therapeutic intervention is unlikely to affect the most common causes of death among the homeless. This point helps strengthen my claim that healthcare access is not the only solution to these issues of health disparities. There needs to be more integration of services to help address the true cause of the health problems, which include life situations and other socially relevant factors (Hibbs et al. 1994).

In the face of such morbidity and mortality for homeless and low-income individuals, the quality and types of healthcare services available are called into question. Perhaps if they were of a higher standard, maybe the health disparities could be diminished? Following the perceived prestige, power, and authority of the United States, many might assume it would be a world leader in healthcare quality, and thus spending. The assumption of spending is true, considering in 2010, the US spent $2.6 trillion on healthcare. Yet the irony, and mystery, is that despite spending twice as much on healthcare as other developed countries, the US ranked last in studies of quality, efficiency, and equity compared to other countries (Britain, Canada, Germany, Netherlands, Australia, and New Zealand) (Hellander 2011). Additionally, the US ranked 49th in male and female life expectancy combined, not due to smoking, obesity, traffic fatalities, or homicides. This means that the health of the general population, measured relative to life expectancy, is lower than other countries around the world.

The problems of homeless individuals accessing healthcare are exacerbated by existent problems in the US healthcare system such as rising costs, barriers to obtaining private insurance, as well as access to patient records and paperwork processing. Given the situations, social statuses, limitations, and barriers experienced by homeless and low-income individuals, it is not surprising that such populations have diminished health quality. If former Surgeon General

David Satcher's statement is a measure to be taken seriously, it is all too evident that something

must be done for the US healthcare system in order to address the health disparities faced by

homeless and low-income individuals.

Chapter 2: Contours of the Debate - Analysis of Existing Literature

Three Models of Homelessness

Anthropological work regarding vulnerable populations of homeless and low-income individuals has become increasingly prominent over the past few decades. This is especially true following the increased visibility homeless and low-income situations have obtained as growing social problems. An important transition in researcher and governmental perspective of individuals of this population, was from a personal pathology to a social and systemic pathology. This developed due to the formation of three models for understanding the causes of homelessness.

The first is referred to as the conservative model. In its early beginnings, it was the common view of that homelessness was caused by personal pathology. In other words, it was contextualized as being caused by moral or character flaws intrinsic to the individuals, whereby they were lazy, they did not want to find work, and/or they want to continue to live off of benefit programs, among other reasons (Gowan 2000). It is a viewpoint which is still of considerable prevalence within broader social understandings of the general public, as well as governmental and public policy discussions. The solution for homelessness was thus to take away enabling programs, such as federal benefits, and push adherent individuals into the public system and force them to rejoin job and labor markets.

The next model, called the disease model, succeeded, but did not entirely replace, the conservative model. This is a medicalized model which places homeless individuals under increased scrutiny and divides them into varying categories of perceived or prescribed disability,

such as mental illness, addiction, or even family dysfunction (Gowan 2000). The major issue with this model is that it hones in on the mental illness and substance abuse of the few and distracted from homeless situations which developed due to other factors, such as poor working and housing opportunities. The irony of these two model approaches is that the nature of the quality of the society the individuals live in is not called into question.

The solution, or treatment, for homelessness under the disease model was to provide services to intervene, prevent, and treat addiction and mental illnesses so that such individual pathologies would not lead to the kinds of behavior which subsequently lead to homelessness. This included providing systematic shelters, drug rehab centers, and even, arguably, prisons to "reach out" and help those who have reached this rock-bottom, assuming they are willing to acknowledge their "sickness" and take the approved steps to alleviate the situation (Gowan 2000). This approach is problematic in that it focuses too heavily on proximal causes of homelessness, such as depression or substance abuse, and overlooks broader societal structures, such as a diminished housing and job market and various forms of structural violence. As Gowan (2000) summarizes it, "such discourse renders natural and inevitable the grand social upheavals of our times." Essentially, such approaches overlook broader structural causes and render them irrelevant or potentially unchangeable because of their natural origins.

Despite these problematic outcomes, the initial intentions of the disease model can be observed as well-meaning. This model most likely arose from scientific and medical concern for the well-being of the homeless and low-income populations and related attempts to remedy the situation in as tangible a way as possible. These concerns were probably connected to the mission of healthcare professionals, which could bias them towards the disease model. Their mission is to focus on causes of health issues in populations and address them accordingly, given

their training and expertise. They could observe the direct correlation between mental illness and addictions as contributing to homelessness and low-income situations, and thus developed means to remedy these factors. In this way, the disease model is not wholly negative, it is grounded in certain truths and good intentions, but is limited in its scope relative to the spectrum of causes of homelessness for the entire homeless population.

Due to increased research and visibility of homelessness as a problem, researchers and leaders have started to view these issues of homelessness and low-income through a third viewpoint, the structural/systemic, model. This is a model which views the causes and perpetuation of homelessness as having less to do with personal issues alone, and more to do with social and societal structures and how they have contributed to these problems (Glasser and Bridgman 1999). Perhaps it was not that individuals did not want to find work, but that they could not, due to a diminished job market, or lack of transportation, or due to discrimination against homeless individuals and their perceived character traits? Perhaps they remain homeless because of other potential barriers that arose from a homeless status, such as poor credit inhibiting rental and homeowner opportunities or questionably unfair tickets or outdated criminal charges on a personal record. These are a few of the common reasons actual CEF members have faced regarding employment and housing barriers. Such a transition made it apparent that solutions to treat homelessness were not as simple as funding or defunding a certain program, or implementing "treatment" plans to fix those with a medicalized homeless pathology. It would take systematic and strategic interventions that addressed the multiple interacting factors contributing to homelessness.

Although I will address the effects and implications of these models of thinking regard homelessness, I will primarily focus on the structural/systemic model and will situate my

discussions within this model because I believe it provides the most accurate approach and captures a broader, more holistic scope of the problem. This model is also the most appropriate viewpoint to take in order to arrive at a comprehensive result for my research questions regarding CEF member conceptions of health related to their opinions of the broader causes of healthcare access issues, as well as reasons for not discussing their personal health in CEF member-advocate meetings. This is because the conservative and disease models would render such research questions pointless because their tenants already provide answers for such questions. My results thus can not only provide further support for the structural/systemic model, but also provide new avenues to continue to explore this complex issue of the causes of homelessness and healthcare access.

Anthropology and Homelessness

The field of anthropology was a strong contributor to the transition to the structural/systemic model due to its methods, theories, and modes of analysis. The hallmark approaches that make anthropology uniquely qualified to examine these issues through a novel lens are ethnographic approaches, participant observations, and cultural relativism. Even in its early beginnings of research into the homeless population, anthropology has utilized ethnographic approaches and participant observation to enter the worlds of the individuals studied. From Spradley's study of the nascent culture of a new alcohol treatment center (1970), to Estroff's review of the subculture of psychiatric patients related to deinstitutionalization and homelessness (1985), these approaches have been the cornerstone of such research.[5] The

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[5] Estroff's research with deinstitutionalized mental health patients, has connections to broader discussions related to how deinstitutionalization and the disease model influenced policies enacted in the 1960s in the US, which are often cited as a major cause of the increase in homelessness as the patients were displaced out of the system and were unable to adequately re-integrate back into society.

essential idea of what ethnographic approaches are, according to Spradley (1979), is working to describe the culture of individuals by not just studying them, but learning from them. In other words, it is, "understanding another way of life from the native point of view (Spradley 1979)." Participant observation is defined as actively engaging in the activities of the individuals being studied in an effort to understand their reality from the inside-out (Spradley, 1979).

The philosophy of cultural relativism is a crucial part of a larger whole that forms the intellectual underpinnings of anthropological homelessness research today (Glasser and Bridgman 1999: 6). It is defined as understanding how each element of a culture fits into the larger cultural context without passing moral judgments. Essentially, this means understanding the value of the smaller facets of a culture towards the whole of that culture in and of itself, without comparing them to the values of an outside moral system or culture.

As Glasser aptly explains, these three approaches, "are especially suited for uncovering the subtleties of problems that arise as societies adapt to the complexities of contemporary life (Glasser and Bridgman 1999: Preface)." These studies have helped to show that issues with homelessness and poverty are not acute matters brought on by personal choices alone, but are also an end result of decades of social policies that have ignored the deterioration of the nation's cities (Glasser and Bridgman 1999). It also became apparent, through longitudinal studies, that homelessness, rather than solely being an acute issue, has chronic manifestations as well, composed of a dynamic of episodic and recurrent circumstances (Hopper 2003: pg. 59).

This increase in incidence of chronic homelessness and poverty has led to growing concern for the health of individuals in these situations. As was discussed in the introduction of this thesis, many studies have found that the health of homeless and low-income individuals is significantly lower in quality than other populations in society. This is especially apparent for

populations of "poor plus homeless" individuals who experience a compounding or amplification

of such negative health effects. This created a push for research in order to identify the causes of

these differences (Ensign 1998; Folsom et al. 2005; Gruenewald et al. 2012; Hibbs et al. 1994;

Wagner et al. 2014). The conclusion reached by these studies is that the primary causes of this

health disparity, aside from the differential experience of daily stressors which have negative

effects on personal health, is significant differences in healthcare access due to a variety of

reasons.

One of the primary speculated reasons why individuals in homeless and financially

dependent situations may not have access to healthcare resources is in regards to the cost of

healthcare. This approach can be seen in the discussions and policies geared towards healthcare

reform, such as the Affordable Care Act, which often speak of controlling costs of healthcare in

order to make healthcare more accessible. The line of thinking regarding these discussions is in

regards to economically driven choices individuals make regarding their income. For example,

the case may be that there is conflict with other personal interests such as choosing between

healthcare, food, shelter, and some other necessity. An example of such a conflict is discussed in

the sixth chapter under "The Catch-22." However, an interesting story further develops if the

issues are approached by looking beyond economic considerations and into more socially-based

considerations. This is where anthropology, with its etiology and methods, takes its place as a

unique contributor to the understanding of this issue. The explanations for why these health

disparities and issue of access have developed may indeed move beyond the economic sphere of

influence, and into more biologically and socially relevant influences. As observed by Haley

(2007), perhaps other sources of access barriers are healthcare resource location, limited

transport means, lack of healthcare insurance, and negative experiences with the healthcare system.

It is often the goal of anthropology to examine problems and their standard or "logical" conclusions from a different perspective. That is, stepping back from the typical lens of viewing an issue, and looking for other explanations or perspectives. One such perspective is the biosocial perspective. This is a perspective that focuses on the notion that the health of an individual is not determined by their biology or genetics alone. In order to fully address health concerns and resources, one must also take into account the social determinants of health as well. Beyond this, it can often be fruitful to examine the structural, environmental, and cultural factors that influence health and its perceptions. In this way, a more holistic approach to health can be taken that better fits the needs of those in which the healthcare system serves. This is the approach that I advocate for in regards to researching the issue of health and healthcare access.

According to a review of various studies and papers associated with population health and healthcare access, there is a fair amount of data available regarding the homeless population's health disparities and problems accessing healthcare. However, in review of these sources, it seems there have primarily been studies that gather and report on many quantitative data and factors. Between the years of 2000 and 2005, there were eight published studies that used unique combinations of sample, study, design, and conclusions (Haley, 2007). However, there exists a limitation in the research. This limitation is that it often lacks qualitative information on the perceptions the individuals being studied have regarding their primary health and access problems. Their voices regarding their own experiences with healthcare had little attention. One of the primary factors that explain why this limitation has arisen is that typical health needs assessments rely on readily available health data, clinic-based reports, and visits to

speak with local health experts. These visits are often brief, biased by what health experts are able to see, and lack inclusion of the social contexts and participation of individuals targeted by the assessments (Ensign, 1998).

This lack of voice and first person opinion from the very individuals being studied is a crucial gap to be filled. Who better to ask and receive information from than the ones with the most expertise on the issue? This is especially true in the face of public, national, and international healthcare policy changes. The only way to guarantee effective and successful healthcare resources, treatments, and interventions is to identify the exact needs of the very individuals being treated and barriers preventing such treatment efficiencies. In this way, public health officials and clinicians can focus on ensuring that individuals of these subgroups receive healthcare through coordinated treatment and support designed for their needs, as suggested by previous studies (Hwang, 2005). The other strength to facilitating a space for such opinions and voices to be heard is that it can be empowering for the individual and community. It can potentially instill and rekindle a sense of independence, power, and autonomy that may be perceived as lessened or nonexistent in a disadvantaged population (Ball, 2013). Just as it has done in the past with homeless and low-income populations, anthropological perspectives have the capacity to fill this gap and further the understanding of this issue.

Healthcare Access Barrier Framework

In review of previous studies related to healthcare access barriers, I have developed the following categories and themes that can help form a framework of how to approach these issues of healthcare access. This framework approach can help to better organize the numerous factors that can influence healthcare access and perhaps facilitate an increased understanding of their individual interactions within and between groupings:
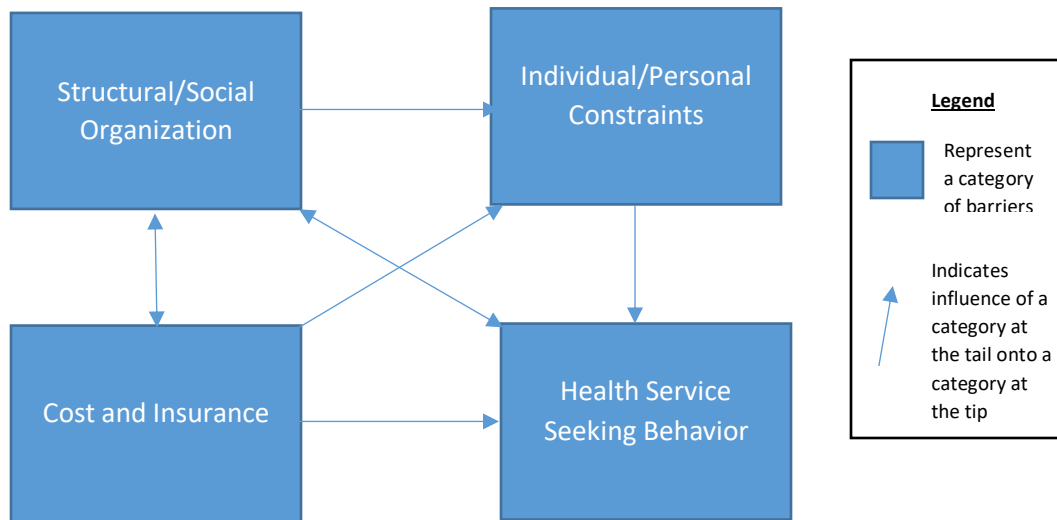
Figure 1a. Healthcare Access Barrier Framework

The first grouped theme is Structural/Social Organization factors. This is a category that includes the structural causes of poverty and economic inequality of wealth distribution within the US, social understandings of health, as well as the US healthcare system's organization and processes. The second category is Individual/Personal Constraints that includes factors such as time, personal goals, transportation, and personal priorities. This category is influenced by the Structural/Social Organization category by framing how individuals think about and approach their health as well as healthcare. The third category is Health Service Seeking Behavior, which includes the different factors that can influence an individual's criteria and decisions to act on a health issue by engaging with the healthcare system. This category is influenced by both the Individual/Personal Constraints and Structural/Social Organization categories.

An example of their combined influence is regarding personal identities of homeless and low-income individuals shaped by their experiences with stigma and bias regarding the characteristics of individuals within these socioeconomic categories. This category can also have a reciprocal influence on the Structural/Social Organization category as such behaviors can

reinforce perceptions and stereotypes of homeless and low-income individuals in broader social and healthcare settings. The final category for healthcare access barriers is Cost and Insurance, which includes all factors which control and affect the cost of healthcare and insurance processes. This category is influenced by the Structural/Social Organization category, and influences the Individual/Personal Constraints and Health Service Seeking Behavior categories. This framework of healthcare access barriers will be discussed in detail within chapter six.

In the face of all of these barriers within their categories, it begs the question of what interventions and movements have and are being implemented to lessen the strength or even remove these obstacles. In light of this, one of the last chapters of this thesis will provide a review of a few interventions or potential interventions to alleviate problems with healthcare access. These include topics of E-health, coordinated care systems, and insurance expansion options. None of these interventions are the perfect solution for this issue. They have their share of both pros and cons related to their effectiveness. However, the point is that a combination of multiple interventions is what is needed to address this problem.

Chapter 3: Research Methodology

Data Collection

Originally, I planned to use a mix of quantitative and qualitative methods in order to best represent the study population and fill the knowledge gap I discussed in the literature review. I planned to use interviews, surveys, and a focus group, because each of these methods have their own set of strengths, weaknesses, biases, and checks. When combined together, they would help display a more complete and unbiased set of conclusions which apply to this study population. These are not only the standard methods utilized by anthropologists as they approach this research topic, they are also inspired by the two main approaches that have been applied to international health assessments. They are the PRA (participatory rural appraisal) and RAP (rapid assessment procedures), as discussed in Ensign's 1998 study. PRA focuses on empowering local individuals by assisting them in identifying their own problems and developing solutions thereof. It also includes data collection focusing on visual aspects, such as community mapping, which help articulate and represent ideas in a way words alone cannot. The RAP techniques are similar, but focus on direct observations and in-depth interviewing (Ensign, 1998). By using these models of data collection, this study will provide its intended comprehensive and representative data.

The method of personal interviews was used because it allows for firsthand insight into the experiences and opinions of individuals within the study population. This type of data was crucial because it pushes beyond the quantitative numbers and into the qualitative aspects that require equal representation. It is one thing to simply distribute a survey, analyze data, and

extrapolate trends and form conclusions based on the responses. It is another to document,

analyze, and draw trends and conclusions from the individual truths held in personal experiences.

Specifically for this study, ethnographic interviews were utilized. An ethnographic interview is different from an ordinary interview in that its structure, flow, and direction are unique. In an ethnographic interview, there is an explicit purpose, turn taking is less balanced and skewed towards the interviewee, the interviewee is encouraged to elaborate, and ethnographic questions are used. These are types of questions that deal with describing one's own observations, feelings, or thoughts on the structural systems in place in a group, organization or society (Spradley, 1979). It is also important to note that there may not ever be an answer to a question, only theories or ideas.

An interview has its strengths in that the interviewer will often enter a discussion with the interviewee with a certain cultural orientation and set of questions, however, will end up coming out with a different point of view and set of answers than they began with. This can help keep in check the biases the interviewer may have and also expose areas for study not previously acknowledged. Interviews are also more beneficial than surveys since individuals can better answer questions verbally than in written form, as with surveys (Wagner et al. 2014). The main weakness to interviewing is the time and effort it takes to set up an interview, hold the interview, transcribe, and eventually analyze the resulting conversation. This ultimately limits the reach of the study in proportion to time allotted.

These interview limitations are why survey methods were originally planned to be incorporated. Surveys are a simple, yet powerful way to collect data from a certain population of individuals. From such responses, opinions and trends can be extrapolated and quantitative charts and representations can be drawn. Surveys can also be distributed online and in person, which

enables the researcher to reach a higher number of individuals who may desire to be part of a study, but who do not have time for a full, extensive interview. These are the main strengths of survey methods.

However, the weakness of surveying comes from the fact that the data can only be so informative or generalizable depending on the response pool size, as well as question and selection biases. This is why all data collected and trends formulated must be analyzed and reported with acknowledgment of their limitations, possible areas of bias, and their power for generalizability. One such area of bias, which is common for all surveys, is sample bias derived from the selectivity of respondents themselves. There can be multiple factors that encourage certain individual to elect to participate in a survey, and discourage others. This can range from access to survey materials and their submission processes, to personal connections or experiences related to survey content.

It is for these reasons that all conclusions and trends observed would be compared to interview questions to determine if the observed data is similar the individual responses from interviewees. Even with the confounding factor of individual uniqueness or outlier characteristics, with enough interviews, a common theme or conclusion can be drawn which should be supported in the quantitative data. Unfortunately, the survey portion of the study was unable to be followed through due to the inability to effectively distribute and recollect it from the study population. However, a copy of the planned survey is included in the Appendix for reference.

Finally, a focus group was utilized in order to expand the scope of the interview data. It consisted of leading a group discussion revolving around health and questions asked in the surveys and interviews. The groups were chosen using the members that were a part of two

groups within CEF: the CEF Members Alumni Advisory Council and "Talking Sidewalks." The participants were informed of the change in typical meeting content and were allowed to opt-in or opt-out of the experience.

The strength of this method is the ability to observe how the influence of multiple opinions change, strengthen, or weaken, the narratives the surveys and individual interviews tell. Group discussions can also encourage others to speak up more, or inspire memories or ideas participants would otherwise not recall in a solo interview, should a nonjudgmental, comfortable environment be in place. However, the weakness of focus groups is that one person may tend to speak up more than others, or a sense of groupthink or conformity may arise due to social group pressures. These pressures were minimized by introducing ground rules at the start of the discussion that facilitated an open and comfortable space for discussion, as well as the mediation of the discussion by the principal investigator.

From my past studies with this population, one of the key factors I observed were limitations in transportation and geographic barriers. To this end, I wanted to incorporate a "community mapping" activity into interviews and the focus group. Unfortunately, this also went unfulfilled due to time constraints of participants during interviews and focus groups. However, I will describe the process due to its utility for this and future studies related to this topic.

The community mapping activity was inspired by the design included in the Ensign study of Baltimore Homeless Youth (Ensign, 1998). Participants would be given paper, writing utensils, and other distinctive marking materials, and asked to draw a rough map of Chapel Hill. They would be asked to sketch out important buildings or locations they use daily, important streets, and locations of healthcare facilities. The hope of this method of data collection is to obtain a visual overlay of the space that individuals use and their knowledge of healthcare

resource locations. This data could perhaps shed light on hidden factors such as geographic barriers or transportation limitations that might contribute to healthcare access and use. It could also show how knowledgeable individuals are of healthcare resource options.

This study also incorporated analysis of demographic data provided by members to CEF when they first make contact and begin working with CEF. This information is given at the individual's discretion with a standard demographic survey intake form. The information is used to better understand the situation and background of the individual to initiate a plan for how CEF will help the individual and connect them to the resources that could be of use to them. This information is contained on a secure database that only CEF admin members and staff have access. I was granted access to this information, during my previous study, in the form of charts and graphs that show trends that represent the population of members that can then be analyzed to help contextualize the population. I gained access to this information once again for this study through my relationships within CEF and through permissions from the administrative leaders. Since the information is reported in the form of finalized charts and graphs representative of the entire member population, none of the information presented can be connected to any one individual and therefore confidentiality is maintained.

Finally, I used the classic anthropological method of ethnographic participant observation to inform my research. This is where the ethnographer is actively engaged in the activities of the individuals in the field site in an effort to understand their reality from the inside out (DeWalt and DeWalt 2011). Although I did not take any physical notes or make formal conclusions throughout my experience, I have worked with members and listened to their stories over the years I have been a part of CEF. I will describe and incorporate trends and stories I have observed in order to contextualize and discuss the results the other methods reveal. The strength

of this methodology is that participants are not directly influenced by questions that may narrow their views or answers due to their wording or the participant's desire to give the answer they believe is desired. However, it is also limiting in that observations may be taken out of context or be biased by the observer looking for certain actions, creating a searching bias. This can also be true if those being observed realize they are being observed and consciously or subconsciously change their behaviors, known as the Hawthorne effect (McCambridge et al. 2014).

Participant Recruitment

Members were recruited for this study primarily through posters, which were advertised throughout the CEF office in the waiting and meeting areas. The poster described the study, what participants would be asked to do, and explained the incentive[6] for participation in the study. Members were also passively recruited by discussing the project with them after their appointments and sending out information to advocates over the email listerv. The goal was for advocates and members to be on the lookout for potential individuals who would be interested. This was a form of recruitment known as snowball sampling. Despite initial intentions and plans to hold fifteen interviews and a single focus group, in the end, I performed a total of three interviews, as well as two focus groups of four and three participants. This represents a total study population of ten individuals.

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[6] Participants in the interview portion were offered, first $10, then $25 gift cards to Harris Teeter. This was a local general grocery store that was accessible to participants. Participants were retroactively incentivized when the amount increased in order to encourage more participants to enter the study.

Chapter 4: Subject Population Characterization

For the following section, I describe the demographic context of the CEF member population within the larger context of CEF as an organization.

The Community Empowerment Fund: CEF

The Community Empowerment Fund, or more commonly CEF, is a UNC Chapel Hill student founded organization whose goal is to facilitate a transition out of poverty and to guide its members to a life of financial independence (Community Empowerment Fund). The people who comprise CEF, are local individuals from Chapel Hill, Durham, Carrboro, and Hillsborough[7] who are experiencing homelessness, unemployment, low-income, and other forms of financial difficulties. These individuals are referred to as members, rather than clients, to produce an environment that gives them ownership over their interactions with the organization, and all programs they wish to partake in. This helps to give them back a sense of autonomy, which they may have experienced a reduction of, due to the experience of homeless and low-income situations. Together with student volunteers, called advocates, members collaborate on an appointment basis to set and achieve goals that will improve their life situations.

Member-advocate appointments are generally set on a first-come-first-served basis, with preference to schedule members with advocates they have been paired with. Implicit to this process is the ability for members to choose which meeting slot they prefer based on availability, date and time, as well as who the advocate is, be it because they know the advocate or even the

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[7] These are the surrounding cities and towns in proximity of the CEF Chapel Hill and Durham offices.

advocate's gender, should they wish. However, this last selective option of member pairings based on gender is not explicitly stated during appointment scheduling. There is no official policy or procedure regarding a member's ability to choose advocates based on gender, it is more implicit on a case-by-case basis. However, the idea for appointments are for members to feel comfortable working with their advocates, therefore few restrictions are in place for how members may choose advocates.

Although this study took place in the CEF Chapel Hill office, CEF also has an office in Durham. The CEF Chapel Hill office is located just off Rosemary Street, on Columbia Street, about three miles from the local men's and women's shelters, which are associated with the Inter-Faith Council for Social Services (IFC). It is also located along a few bus lines and has visitor parking available. The CEF office is wheelchair accessible and has clearly marked signs to guide members to the correct location, within the shared office building.

As mentioned in the introduction, CEF offers a variety of social work related resources from employment preparation, housing resources, legal services, banking and finances, personal document services, and everything in-between. CEF also partners with local organizations to provide an extensive network to help members succeed. Specific for healthcare, CEF offers assistance applying for federal healthcare benefits, such as SNAP, WIC, TANF, Medicaid, Medicare, and SSI/SSDI. It also offers connections to local programs, such as free/subsidies clinics and a program, Charity Care, which helps with medical bill and medication payments. In essence, CEF provides healthcare resources related to entering into the healthcare system itself, such as finding ways to get around or reduce cost or insurance barriers, filling out paperwork, or acquiring documentation. This is the extent that it can legally operate as a non-profit social work organization outside of the healthcare system.

Overall the environment within CEF is quite inviting. It provides a safe space for members to come in and complete the work they have tasked themselves with and ultimately work towards achieving their goals, one meeting at a time. A key feature that makes CEF unique with its service is the distinct relationships between advocates and members. There seems to be an inherent feeling of trust, security, hope, goodwill, and compassion between both parties. Whether it is a member or advocate, everyone who comes to CEF is there to help and learn something new. Everyone learns and grows together as they travel through their experiences. It is this mutualistic, cooperative team framework that makes CEF a unique and successful organization. It is also these relationships that produce powerful influences on the social power dynamics at play.

What is an Advocate?

As described in the first chapter, majority of CEF advocates are UNC-CH students, although there are a few full-time staff members, admin leaders, and front desk managers. Along with the members CEF serves, advocates can also be considered the lifeblood of CEF, which it could not function without. As an organization, CEF strives to recruit and train exceptional advocates, ones with the right motivations and ones who will continue working with CEF during their time at UNC. This is because advocates act not only as a helping partner for members throughout the process, but also a physical body of continuity, solidarity, and support for members who may need such stability.

The motivations of advocates for doing such work are key. Those with shallow or selfish motivations for joining CEF simply to add community service hours or pad their resume typically do not last long. This is due to the time investment, stress, and emotional strength it takes to continually work with members and see them through to their goals. Without strong

convictions and motivations, it is all too easy to get burnt out or quit after numerous housing or job search dead ends, denied applications for benefits, legal battles against decades' past criminal charges, and frustrations against broader social structures which make such homeless and low-income situations so difficult. It is a humbling note for advocates, in comparing just how much more tiring, stressful, and frustrating it is for the members to deal with their pressing life issues, than it is for advocates. Following this member-advocate structure, some may wonder how such interactions could be functional or create positive impact, given the differential powers and social realities the interacting parties face. However, as I reflect below, such seemingly incompatible relationships can be seen as powerful resources.

Given that essentially all advocates are college students, it is a safe assumption that they come from a socioeconomic class that is higher than those to which members belong. That is not to say that some advocates may not be within the working or low-class bracket, such as those studying on academic scholarships, grants, and financial aid. That is also not to say that some advocates may have never experienced homelessness in their past. However, in their present state with a college student status, they have opportunities, socially-derived privileges, and identities which are different from the members with whom they work. Given such differences, it may be surprising that such relationships are sustainable or effective in meeting CEF's mission. However, hidden equalizers are found within their status as students.

The first is that, as students, advocates are expected to be intelligent, but also willing and motivated to learn to reach their goals to better their future. Although members have different short-term and long-term goals, members are also willing and motivated to learn and work to fulfill their goals. This commonality of motivation can be channeled into member-advocate interactions and accelerate a sense of trust through an understanding of relatively mutual interest

in achieving goals. Second, since they are college students, they are also not officially educated and licensed social workers. Advocates only have their previous experiences, official CEF trainings, and CEF resources to guide them. This means that, aside from access to resource information and varying proficiencies in navigating and executing such resource processes, they are arguably near or on the same knowledge level regarding how to achieve member goals.

However, one of the advantages to this arrangement of informal positions is that advocates are trained to be non-judgmental and provide spaces that cue to members that they will judge neither them nor their situation. They will also not argue with members regarding what members believe is an important step or what they believe they need. In this way, their informal positions as advocates allow them to enter into a genuinely collaborative relationship with members and gain members' trust in their ability to help them. This is an equalizer that can make advocates more approachable and "levels the playfield" for the differential social powers at work. Such relationships are thus able to effectively provide a collaborative support system in order to strategically work towards member goals. The unique relationships CEF provides is something members recognize as special and actively relate to other people they meet who need the help CEF can provide. They know CEF is helpful and will not turn people away compared to other organizations.

"When I see someone that needs help I tell them, go to CEF. I go there because I know I can get help (Age 72, African American, male, homeless)."

In order to make member appointments both productive and comfortable for members, all new advocates go through Advocate trainings where they learn, not only about CEF resources and processes, but also go through "sensitivity training." These are trainings that review CEF's mission and philosophy towards its services, and provide tools to help advocates learn how to

approach members during meetings given the differences in privileges, life experiences, and perspectives they might encounter. These tools include discussions, roleplay scenarios, and instructional modules related to how word choice, connotation, and language can affect member-advocate relations during meetings. This includes learning about social justice issues that members-advocate relationships interact with. These include racism, sexism, gender and sexuality identities, ability/disability, as well as differential economic and social realities that produce diverse individuals. In this way, CEF strives to prepare advocates to make positive impacts during member-advocate appointments and ensure both productivity and comfort for members.

<div align="center">Member Intake, Demographics and Logistics</div>

One of the important processes that CEF performs with every new member is gathering their background information. They perform this task by filling out a "Member Introduction Form" typically during the Member Orientation, or during the first meeting with the new member and their advocate. Not only do the forms ask for standard information such as birth date, racial identity, gender identity, marital status, education and contact information, it also asks about current housing status and sources of income or benefits.

The most important part is actually the backside of the form. This is the "Goal Setting" section where members are given a list of items in the form of a checklist where they specify if they have or need the item listed. They are later able to rank these goals to prioritize them for future meetings. These include various documents of identification, higher education, a cell phone, employment items such as a resume or cover letter, a list of government assistance/benefits, goals to quit smoking or other drugs, and even questions about their voter

registration status.[8] It also lists the programs CEF offers and description of what they are to help

them decide if they want to be involved in certain CEF programs and receive more information

about them. This step in the introduction form is often the place a member's experience starts

because it helps them form a list of goals they need or want to achieve. It also opens up options

they may not have thought of before.

Once the forms are filled out, advocates then input the information into the online

website, ConnectCef, which acts like a database for CEF. The helpful part about inputting the

information into ConnectCef is that all the information can be compiled into different graphs that

CEF can sort and create based on the answers given. This is helpful with checking CEF's

progress, plan future programs, and to provide data to enhance grant applications. It was through

this system that I requested and was able to see certain graphs of the information provided by

CEF members. The trends they show are revealing. The graphs themselves are included in the

Appendix. This data set will help to contextualize the population of CEF members as a whole in

relation to the participant pool of the interview and focus group portions of this study.

The total population the CEF member intake data set comprised was 339 members. These

represent members who only engage with the CEF Chapel Hill office. Of this population, 55%

identify as male and 44% as female, with the remainder identifying as other or declining to

answer. Of these groups, 51% identify as African American, 31% Caucasian/White, 5% as

American Indian, Alaskan, Native Hawaiian, Pacific Islander, or Asian, 4% as other and 9% did

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[8] Voter registration is important to CEF as it tries as an organization to increase community collaboration and action during elections to have bills, bonds, and other programs, which benefit the community, passed. This is typically through awareness campaigns, organizing member-advocate groups to attend local town meetings, and giving members opportunities to tell their stories to local policy and lawmakers. An example of this process in action was during this past election year with the 2016 Affordable Housing Bond of Orange County, where CEF members and advocates organized a member-advocate community choir, which performed at such meetings and other community functions, to spread awareness about the bond. This is one of the many ways in which CEF works to advocate for broader structural changes.

not respond. The age of members range from twenty-one to seventy-three, with a median value of fifty-one and average of fifty. Majority of members are in their forties and fifties while the smallest percentage are in their twenties. Of these, 18% have some high school education, 22% have High School Diplomas, 12% have their GED, 7% have Vocational/Technical Certificates, 8% have a 2-year degree, and 7% have a 4-year degree. Finally, 44% live in a rental home, 18% in a shelter, 6% in transitional/recovery housing, 12% with friends or family, 8% outdoors or an abandoned place, 2% in public housing, 2% own a home and 8% in another form of housing.[9] These trends in gender and racial identities, as well as age range, are similar to those described by Folsom and colleagues (2005) discussed previously in relation to homeless and low-income situations.

When looking at the Member goals, CEF offers help with obtaining physical and mental healthcare. This goal is listed as the "Better Physical Healthcare" and "Better Mental Healthcare" goals. For this population data, 187 (~55%) have added the "Better Physical Healthcare" goal and 119 (~35%) have added the "Better Mental Healthcare" goal to their list. These numbers mean that in some capacity, majority of members are concerned about their health enough, and have concerns regarding assistance getting connected to healthcare services of some kind, that they are willing to consciously acknowledge this and physically mark an intention to engage with such resources. In regards to my second research question, such data points represent the potential for members to bring up health concerns in a regular CEF meeting with an advocate. Unfortunately, these numbers only reflect members who have added the goal to their list. I was unable to obtain data on the number of member who have checked-off or completed these goals.

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[9] Graphical representations of the intake data have been included in the Appendix "CEF Member Demographic Charts and Figures" section.

This means I cannot provide definitive analysis of the proportion of members who have followed through with a discussion of health with their advocates.

It is interesting that only 35% of members marked that they desire to be connected to better mental healthcare resources compared to 55% who marked a desire for better physical healthcare. However, it is difficult to draw appropriate conclusions from such a number due to the response bias of individuals in their self-reflection, which is inherent in an intake form, as well as the lack of definitive clarifying criteria members used to decide to check or not check the goal. This number could represent that only 35% of CEF members have a mental health condition or illness, or perhaps only 35% of those with a mental disability wish to receive better mental healthcare, among other conclusions. However, such definitive conclusions cannot be drawn due to the variety of personal definitions individuals may have ascribed to the goal and missing context of such a goal decision.

Another reason for such a low number could be related not only to social stigma which accompanies mental illness, but could also indicate that a rational decision making strategy known as the "Economy of Choice" or "Rational Choice Theory" could be at play. This is a theory that describes the thought processes and cost-benefit analysis individuals use in order to make decisions. The typical assumptions of the theory are that individuals have preferences and constraints which they must balance in order to maximize the outcome of a choice (Opp 1999).

For members making the choice to add this goal to their list, they may be faced with a fear about future mental illness, but may be hesitant to mention such concerns. Reasons for such hesitations could be due to fear of the threat to self-identity mental illness has, or even problems dealing with a mental illness may impose, such as increased medical costs. The concerns may be, "I cannot afford for someone to diagnose me and give me another thing to deal with," therefore

they triage the concern for the time being and deal with more pressing issues. Such fears can bring about a denial or unwillingness to acknowledge help one may need and result in integration of their symptoms into their daily "normal." These forms of decisions are discussed in further detail in the Catch-22 and Individual/Personal Constraint barrier category sections of chapter six.

I was also hoping to obtain data on the number of individuals who use certain government benefits programs, such as SSI/SSDI, SNAP, WIC, and TANF, as well as those which have Medicaid and Medicare for insurance. CEF asks for this information when members are building a budget and when assessing their financial situation in order to connect them to certain services. However, at this time there is not enough accurate information that could be pulled together into a representative report. This information would have been able to contribute to the discussion regarding homeless and low-income individuals' utilization of federal benefits programs as well as access to healthcare related to insurance coverage, such as that provided through SSI/SSDI.

<div align="center">Interviewee Demographics</div>

As with any research study in any field, there were multiple setbacks, both foreseen and unforeseen throughout this project. Looking back, I am thankful they happened. Where's the adventure in something going exactly as planned? Ironically, I do not think my study would have been nearly as revealing nor as enriching had it not been for things straying from the original plan.

Admittedly, one of the struggles of this study was recruiting members to participate. It was not for a lack of trying. I received a certain mix of excitement and disappointment seeing that people had taken the small slips from my recruitment fliers every time I came into the office. I was excited because people were obviously interested in the study, otherwise they would not

have taken the time to take the slips. However, I was discouraged because there was not nearly as much follow through with their interest because I had not received calls of inquiry. I hoped to increase interest follow through by including an incentive, once I received funding, of ten dollars for interview participants. This resulted in a couple participants in the interview portion. I later increased the incentive to twenty-five dollars towards the end of the study to further motivate participants, while also retroactively reimbursing past participants. By the end of the study, I had gone through 15 fliers, each with seven information slips, with a total of twenty-five slips taken by individuals. Despite my efforts at recruitment, I was only able to successfully perform three ethnographic interviews with CEF members.[10]

Of the three interviewees, all three were male African Americans of the ages 55, 60, and 64 years of age. Two of the participants had apartment rental leases and one was homeless. They all have been working with CEF between four to five years. One works at a part-time job while the other two have disabilities that prevent them from working, therefore their primary income comes from federal benefits, such as SSI or SSDI. Their educational backgrounds also range from some high school to an Associate's degree. They all have some form of a chronic illness, such as diabetes, PTSD, hepatitis C, or arthritis or some other joint condition. Despite this small sample, the interview participants represent the majority of CEF member demographics when compared to CEF intake demographics previously discussed.

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[10] A copy of the interview schedule has been included in the Appendix "Methodology Materials" section.

<u>Survey Demographics</u>

As was mentioned in the methodology, due to issues with distribution and intake, I was unable to perform the survey portion of this study. However, a copy of the survey that was intended to be utilized has been included in the Appendix for future use.

<u>Focus Group Demographics</u>[11]

As it so happens, despite my initial "bad luck" of sorts with one-on-one interviews, my first hard data for my study came from holding the focus group sessions. I decided to reach out to the Members Alumni Advisory Council of CEF in hopes that they would be interested in my research topic. The Members Alumni Advisory Council is a group within CEF comprised of various members that have worked with CEF over the years. It was created by Maggie West, the Program Coordinator and co-founder of CEF. Maggie created the group in order for members to have a say in how things at CEF are ran in order to be beneficial for current and future members. Maggie selected the first group of members from CEF graduates (members who have graduated from Opportunity Classes), who attended regular meetings with their advocate and were goal oriented.

Since then, a new member is selected by asking a CEF graduate if they want to be on the committee, or if the CEF graduate might show interest in being on the committee. Advocates can also suggest members and the alumni committee elect members through an unbiased interview. They are a group that acts as representatives for the rest of the members of CEF. This is why I felt they would be an apt group to interview in order to answer the questions of my study. Upon

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[11] I have to extend a thank you to my original thesis advisor, Dr. Mark Sorensen, for inspiring me to incorporate focus group methodology into this study. My original plans did not include a focus group portion. At the time, I did not think I wanted to undertake the logistics of coordinating a group of people and hold a discussion. I was confident I could handle one-on-one interviews, but did not foresee myself facilitating and mediating a discussion between multiple people. However, I saw the value in them and knew it was worth stepping out of my comfort zone in order to access this unique opportunity. This decision would prove to be quite fruitful for this study.

meeting with their leader/coordinator, and her then pitching the idea to the group, they were more than happy to help and be participants in a discussion on health-related topics. After an extended time of playing phone-tag and getting in touch with the ten members of the group, we set a date and time to hold the discussion. Being my first experience finally holding a session that would contribute to my thesis data, I was excited and nervous to see what the discussion would produce.

As with any group function, and research in general, there were setbacks off the bat. This included people being late, and subsequently the discussion starting a full hour later than originally scheduled, and only four of the eight people which comprise the group showing up for the discussion, with one leaving early from the discussion. I just went with the flow and knew the discussion would be fruitful regardless of the turn-out. Any data was better than no data. The day would not be wasted. Just before the group started, I received a confidence boost from our office captain and front desk worker who came by and asked was what going on. "Look at you facilitating," she said with a reassuring nod. I then saw, even more so, how far I had matured as a researcher and grew in confidence in my abilities as a blooming anthropologist.

The second focus group of the study was from the Talking Sidewalks community group, which CEF helps facilitate. Although it has changed in numbers, function, and leadership over the years, the general goal of the group is to allow members of the homeless community to come together and discuss various topics. The media utilized include general group discussion, free writing, art, or watching video clips. Majority of the group is composed of homeless individuals from the local men's and women's shelter who engage with CEF. However, CEF advocates often join in on the group's meetings to meet new members and get more involved with the CEF community. I felt that this group would be immeasurably helpful with my topic. As such, I

started going to their weekly meetings, became engaged with their conversations, and pitched the idea of facilitating a focus group with them. They were more than happy to help out with the project and agreed that this was an important topic for discussion and research. While the normal group size is approximately ten people, due to the weather and transportation issues on the day the focus group was held, only three people were able to make it to the discussion.

Of the combined focus group population pools of seven participants, two were female and six were male, five were African American, one was Latina, and one was Caucasian. The ages ranged from forty-three and seventy-two, with a median of fifty-three and an average of fifty-four. The time spent working with CEF ranged from three to six years. Two of the participants lived in apartment rentals while four were homeless. With the exception of representing a higher proportion of the homeless member population, this participant pool is fairly representative of the majority of member demographic trends discussed previously.[12]

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[12] A copy of the focus group script has been included in the Appendix "Methodology Materials" section.

Chapter 5: Member Conceptions of Health

The following chapter provides an analysis of the responses obtained from participants in order to contextualize their understanding of "health."

<u>Review and Analysis of Member Responses and Quotes</u>

For the interview and focus group portions of the study, I started out by asking questions that would help to reveal how the individuals think about and understand "health." This was an important step to begin with in order to contextualize people's responses, due to the vast definitions and understandings of health that exist. Health, like many other words, is complex with multiple facets, connotations, and approaches to contextualize what it truly means. Ask anyone about health and their mind can jump to numerous topics, some directly related to health, and others distantly related many levels away. The term related to this phenomenon is "spreading activation" where one word or phrase can spark trains of thought that explore the multiple connections a person has made to that word or phrase (Colman 2015). Following this, I decided to begin with this question to set up a baseline list of criteria of what people included in their understanding of health. This would hopefully shed some light on the initial concerns the simple word "health" can activate. When asked, participants agreed that they did indeed think about their health fairly often.

My first question to participants was in regards to what the term "health" meant to them, or what first came to mind when someone said "health." When thinking about health, people generally thought of their diet, what they were eating, the way they felt physically or emotionally

as well as their lifestyle or behavior, things they neglected, or simply getting needed help from doctors. It seems each of these traits are compared to, or measured, against common understandings of what is "good" versus "bad" contributors to health. In other words, what a good diet is, what feels good physically or emotionally, or what lifestyles or behaviors are good.

When it comes to diet, people focused on the content of the food. Buzzer words included protein, vitamins, calories, minerals, and food groups like vegetables and fruits. These words and associations are expected given the nature of public health educational movements, which began during the first half of the 20th century decades in the United States, related to what is considered healthy food based on its content (Bryant 2003: 65-72). Other important topics included self-care related to not only physical or emotional health, but also psychological health.

"Good health means not worrying about things you don't got to worry about, because if you worry about things that you don't have, you don't need them. Worrying is bad. I spent a long time while I was out there (referring to living on the street), what am I going to do today, what am I going to do tonight (Age 72, African American, male, homeless)?"[13]

What this participant is describing, as I interpret it, is that good health is minimizing the things you worry about because such extra worries will only add to the stress of life. They say that there is no need to worry about things you don't have, since you don't have them, and worrying about them won't help anything. This can relate to the Economy of Choice discussed previously about individuals prioritizing goals in conflict and setting others aside to make do with what they have and can control. Such defense or resilience mechanisms could be key to maintaining mental and physical health, which are affected by stress and worrying. However, the implications of such a strategy could have negative, though ironic, consequences if these

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[13] From here on, such parenthetical citations denote a study participant's age, racial identity, gender, and housing status at the time of their interview or focus group.

strategies make discussions and interventions regarding health fall to the side, in an effort to improve or maintain health by triaging worries and goal conflicts.

Following such discussions, the question remains, who sets the standards for good health? One interviewee had an interesting perspective concerning if people can really tell if they're in good health.

"Well you don't really know if someone is good health or not unless you're with them all the time. They don't even really know theirself, unless the doctor and them have gotten along and talked about it. I thought I was in A1 health. Then I had a stroke (Age 72, African American, male, homeless)."

To this interviewee, a judge of good health takes time and observation to compare to an understood normal. The judgment of a doctor also seems to have strong influence on the judgment of someone's health. This is not an uncommon viewpoint. People have to find their reference point somewhere on what constitutes good health, be it a doctor, or common sense brought on by experience, education, or public knowledge.

"I remember when I was going to school, umm, and I was in elementary, uh, one of the programs that they were doing, as far as health-wise, that were, with kids, was that, they would help us to realize how important dental, like, doing, just, being hygienic with your, with your dental. And, you know, that just kind of resonated with other things, you know, as far as when I grew older, to, you know, be mindful, of certain things (Age 46, Caucasian, male, homeless)."

These were responses that I expected due to the present culture of health and fitness inspired by various government and community movements in the United States. These ideas are mostly likely transmitted through parental teachings, health education in school, and even the general media or public health projects. However, a particularly interesting topic that came up in both focus groups and one interview, was preventative medicine. As one interviewee stated:

"Preventative maintenance…what's going to happen? How can I avert problems that anyone my age is certainly going to deal with at some point (Age 54, African American, male, writer, homeless)?"

Based on what I has been discussed in the literature, I did not expect for preventative medicine to be of such concern to my study participants. Preventative medicine seems to have only recently started to become of higher priority in the past few decades, especially with the current generation. I did not expect my participants, who were in their early-forties to early-seventies, to show as much concern for prevention. This was also true due to a theory that those in low-income and homeless situations may suffer from a myopia of sorts, in regards to their future. This is said to be due to them having to focus more on survival and current needs, and having to put off future concerns as a result.

This myopia theory is attractive, especially because it takes into account the stress of such social and economic environments individuals may find themselves in. However, it is problematic because it assumes that, while homeless individuals do have the ability to juggle and micromanage their issues of today to survive relatively well, or as best as can be expected, this ability becomes nonexistent, or severely diminished, when related to future endeavors. In order for this to be true, it would seem those that support this theory would need to account for reasons as to why individuals would lose their ability to apply such skills to manage concerns for the future.

Even if homeless individuals may not have the time or resources to act on such concerns, there does not seem to be a definitive reason as to why they would not have the same capacity to look towards the future as a housed individual. Based on participant responses, this theory loses its strength. Participants do indeed have the capacity to engage with concerns for their future, be it with goals or health concerns related to preventative measures. Perhaps, then, the issue is not a myopia of looking towards the future, but the ability to act on such concerns and visions into the

future. Despite this weakness, I discuss reasons why theory of myopia may be attractive further, and why some suggest it may arise, within the later "Personal Constraints" section.

This issue of preventative measures was of particular interest to a fifty-nine-year-old female Latina participant in a focus group. She recalled how in other countries, there are public radio and other broadcasts about preventative medicine and measures, such as reminding people to wear warm clothing in the winter. They also try to remind people of things, such as handwashing or covering your mouth when you cough of sneeze. She says it's a small, almost ridiculous sounding thing, but they make a big impact on public health and in big groups of people. "*But here in the United States, I hear this far less. However, now I do hear it more than thirty years ago.*" This increase in public consciousness of prevention could account for why these individuals were so conscious of prevention.

If prevention was such an important topic to these individuals, then what inhibits them from receiving the preventative care they are concerned with? From their responses, it seems that cost, being on a fixed income, and insurance availability or restrictions/limitations, are key factors. As one interviewee stated:

"I live on a fixed income and I really can't afford to get the necessary things, preventive things done, that I need to (Age 63, African American, male, apartment rental)."

I tried to delve deeper into the topic by asking about the different types or components of health. At first, participants listed the standard physical and mental health that one would expect to be mentioned. Mental health is a subject of particular interest for researchers of this population, due to the fact that there are typically a higher proportion of individuals in low-income and homeless situations with mental and physical disabilities (Schanzer 2007).

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"There's mental health, and there's physical health. I often compare mental health, a person's mental health, as being underweight, or possibly overweight. And, that's how I try to describe it to people who question my decision to pursue mental health options. I say, well just like my physical, my physical weight can be in great shape, but my mental health can be really out of shape (Age 54, African American, male, writer, homeless)."

However, when asked if there was anything else beyond what was mentioned (physical and mental health), they listed social, financial, spiritual, and even environmental and community health components. It was quite apparent the individuals I interviewed were aware of the many aspects of health and the different areas it encompassed. Despite a potential assumed agreement or obvious answer, I asked participants both if and how these components are related to each other. One analogy I found particularly salient, was explained by a focus group participant in response to this question:

"Well they're actually separated, like all parts of the body, members of the body, and stuff. Like there are arms, legs, and stuff like that. You gotta have all of that to be a complete person (Age 54, African American, Male, CNA, homeless)."

When asked about how they would rate their overall health, participants gave a range of answers. For those that rated their health to be higher, they explained it was because of actions they took related to their conception of what brings good health. It was because they ate the right foods, stopped worrying about things out of their control, and practiced as much preventative measures as they could. Another qualifier was because they had seen a doctor recently and been told they were healthy. This included one participant who regularly donated blood and gauged their health based on that. This is because they check certain vital signs, such as blood pressure, pulse, protein levels, and hematocrit to determine if donors are fit to give blood. This was an interesting avenue for an informal check-up I had not considered. Perhaps not the best way to gauge overall health, due to the lack of rigor in examination as would be found from an actual physician's visit, especially related to chronic conditions, but perhaps better than nothing?

For those who rated a lower health status, it was typically due to the fact that they had some form of chronic or infectious disease, such as diabetes, obesity, or Hepatitis C, conditions that arose from aging (such as arthritis or swelling) or knowledge of family history they were concerned with, such as cardiac arrest or cancer. As could be expected, individuals seemed to be aware of their current health status, though it seems those with lower ratings may potentially have more concrete reasons, such as diagnosed conditions.

When asked about what illnesses they've noticed people around them tend to have, the ones listed included COPD, HIV, hepatitis C, diabetes, high blood pressure, as well as drug and alcohol abuse. Another area many were concerned with or touched on was mental health issues and illnesses they either had or knew someone with them. These observations are similar to health trends observed in other homeless and low-income populations, as discussed in the introduction (Wagner et al. 2014; Schanzer 2007). When asked about the health of those around them, and trends they'd notices over time, one participant responded, "*it's scary.*" Others in the focus group agreed as well:

"Because, umm, the reason I say it's scary is because, umm, like this year, uh, it might be alright to do a lot of exercise or like...and then you find out next year, that, the very exercise you're doing is, could be damages to your health. Because, somewhere, I heard something about the, umm, smoke...uh...ahh I can't remember... [a friend] was talking about the umm, about smoking, and sitting, and that sitting is just as bad as smoking in some kind of way...(Age 54 African American, male, homeless)."

So it's scary how much and how fast medical knowledge can change over the years as people try to live healthy lives based on these standards. This is not an uncommon statement and feeling. My own parents often have dry humor about scientific breakthroughs and publications promoting healthy or unhealthy foods or lifestyles. "I guess it's okay to eat eggs again, they keep changing their mind on them." "Better go ahead and eat that while it's still healthy for you."

"Who knows, at this rate they might find that exercise is actually bad for you." The sentiments go on. Such uncertainty can potentially be of increased concern and fear for such a population which already has so many other balancing concerns and uncertainties to handle. When even more uncertainty is added to such a socially visible, and often moral obligation, as health, such expressions of fears can be understandable. Unfortunately, it seems the fear will continue as people try their best to do what's right for their bodies with the most accurate knowledge they have.

Despite the varying perspectives on what's healthy, one that people do seem to agree on is how easy it is to form habits, both good and bad, depending on what is invested in.

"The more you put yourself in a relaxing situation, and you get comfortable with where you at, you'll tend to do a lot of habit…there's a lot of things in this world that distract people from getting out there and getting active (Age 43, African American, male, homeless)."

One of the distractions which they go on to cite were people not being informed about risk factors for certain diseases, such as genetic, environmental, and social risk factors. Others share in their concern for people ignoring symptoms and not getting informed about their own health by going to a health clinic. One participant spoke of individuals they knew who were averse to going to see a doctor altogether, yet are slowly realizing the benefits of going because of a desire to take care of their bodies. This is especially true, as one participant explained, as people start to age, and begin to require visits from multiple medical professionals:

"Yeah, but the growing old thing is scary though. You can do that (see a doctor), and still be sick, or die, because our, our doctors, and stuff, where we used to just go to one that take care of it all, we got separate doctors. And 'bout time you go all around, one of the ones that you're not taking care of could be the one to kill you...the sicknesses, and stuff (Age 54, African American, male, homeless)."

So there is also a fear of aging and keeping up with all of the body's needs as things seem to stop working as well as they once did. This becomes an amplified problem for those in low-

income and homeless situations who need to see multiple doctors, but may have to choose which ailment must be attended to or put off with currently available resources. It can almost become a constant losing cycle:

"...'Cause I know with myself...I was, uh, I was diagnosed with, umm, with diabetes and blood pressure (I assume he means high blood pressure). The diabetes override the blood pressure (in terms of personal concern/ranking), and I messed around and, and, I umm, and was so concerned about my, umm, diabetes, I didn't treat the blood pressure. And I got very bad off sick. And then, it switched over (laughs), I was more concerned about the blood pressure and messed around and the sugar went about 400 and something (normal: 70-140 mg/dL). See, it's something else with health, because everything that's bothering us, it goes back and forth, back and forth (hand motions like turning a wheel), back and forth...you think you got one controlled, the other one goes (motions a balancing scale tipping)...and it's hard...it's hard. And then you can't afford your medicine... (others agree) (Age 54, African American, male, homeless)."

Once again, it becomes clear that individuals of this population are not oblivious to healthcare concerns, nor do they ignore the health of those around them. Despite the negative outlook of others regarding changes in health trends, others spoke in a more positive light. They spoke of people becoming more conscious of their health and choosing to actively engage with healthy activities:

"I have noticed a kind of fashion in the last few years, like they come back to the early years...more herbs, organics, or whole foods. The stores are more expensive but I have noticed the people are getting more healthy. They are models for people to be more concerned about their diet, eating, and how they eat every day. They get more...they really care about themselves (Age 59, Latina, female, apartment rental)."

Thus, it seems that these individuals have a broad understanding of health, rather than a narrow outlook, which some might expect due to the myopia theory discussed previously. These individuals understand that there are multiple facets to health, which each interact to form the greater whole that forms "health." This includes the important social and community portions, which can also affect individual health. It seems the primary fears are in regards to sticking to "good" health habits, especially in the face of changing public opinion on what is healthy. There

is also anxiety in regards to preventative care, especially as they experience the effects of an aging body. Their understandings of their current health statuses are based on these ideas of health, as well as the opinions of those around them, but primarily a healthcare provider. With this understanding of health in place, it is time to proceed into a deeper discussion of CEF member experiences and conceptions of health as they relate to discussing their health with CEF advocates and the various barriers to healthcare they are faced with.

Chapter 6: Member Discussions of Health

Given that members do indeed have a solid conception of health, what represents good health, and have strong concerns about preventative measures, why is it that members do not bring up their health in CEF meetings with advocates? From participant responses and discussions, it seems that they have similar models and approaches to health as the general population within the broader biomedical healthcare system of the United States. Essentially, living in low-income and homeless situations has not seemed to change their fundamental ideas regarding health. So why is it that they do not seem to bring up health discussions in advocate meetings?

The first obvious reason may be that they are not comfortable talking about their health with a stranger. A person's health is personal and contains both private and public ramifications. Some aspects of health, be it good or bad, are relatively easy to spot, given the common notion of what good health and hygiene, a connected topic, represent. This puts pressure on individuals to create an outward appearance of health for the public eye. Such portrayals can thus be created which misconstrue the person's private, or actual health domain. In essence, people can sometimes be pressured to hide their health problems for one reason or another. This also has connections with perceptions of gender roles, where men may feel pressured to conform to the male role where they are not supposed to openly discuss their feelings or complain about their health problems, but rather deal with them on their own. This is contrasted to the gendered female role where is it typically more acceptable for women to discuss their feelings or health

complaints openly.[14] At least, this is in regards to gender roles one may find in the Western society of the United States.

Moving deeper into this subject of gender, another factor that could influence if members bring up their health is in regards to the gender of the advocate a member is meeting with relative to their own. This can be true in terms of more personal health issues, such as those dealing with gynecological, urological, or even STD concerns for both males and females. Members may find it easier to discuss such personal matters with advocates that match their gender identities. Such selection policies do exist, however, they are merely implicit at this time on a case-by-case basis. An example case is where members may choose advocates who have been "Safe Zone" trained.

This is a training that provides advocates with knowledge and skills in order to create a safe space for those with gender or sexual identities outside of present societal norms. In general, members are not discouraged from meeting with advocates for any reason, unless a previous action has created a need for intervention. Such an example I was made aware of recently, was where a certain member was barred from meeting with female advocates due to circumstances which were not explained, though it was probably due to a past meeting issue (CEF advocate announcement January 2017). Aside from such cases, a member is implicitly able to request a meeting with an advocate, with whatever stipulations they wish, and CEF will follow through. In order to facilitate a comfortable environment for members to express such concerns, perhaps a more explicit process for members to choose advocates based on certain criteria, such as gender similarity, should be implemented and actively advertised to members.

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[14] These are admittedly broad generalizations that reflect stereotyped conceptions of masculinity and femininity as they could be applied to discussions of health. Their influence and pressures may be experienced along a spectrum depending on the individual and their personal beliefs and concepts of identity. For more information see: Aston, J. M. and Vasquez, E. 2013. "Social Issues, Justice and Status: Masculinity and Femininity: Stereotypes/Myths, Psychology and Role of Culture." Hauppauge, US: Nova. ProQuest ebrary.

Another reason for member not bringing up their health is that perhaps they feel a personal fatigue, annoyance, or even reluctance to discuss their health because they perhaps see themselves as being cast in a medicalized position. In the biomedical society of the US, among others, there seems to be a moral obligation to maintain one's health. Aside from connecting to topics in the previous paragraph, this obligation can put individuals in uncomfortable or recurring situations when their health is brought up. Therefore, they may develop an aversion of sorts towards discussing their health outside of a medicalized setting, to avoid such uncomfortable, annoying, or tiresome conversations.

This is especially true of homeless and low-income individuals who are applying for certain programs or benefits. These resources often ask about the individual's health during the initial application or intake forms. After going through the cycles numerous times, and repeating their stories and histories over and over again, they may reach a saturation point of frustration or fatigue where such dialogues are no longer welcome. It could also be that these repeated discusses have changed their self-identity to where they feel reduced to their health issues or disorders, rather than being an actual individual.

For those in homeless and low-income situations, where stigma and public perceptions can chip away and reduce a person to narrow views is rampant enough, such additional reductions due to a medicalized position can add to the negative influences of such circumstances. Although I have not experienced this in a member-advocate meeting regarding healthcare resources, I have seen an immense fatigue build up in filling out multiple job or housing applications over many months. This is because they request the same information over and over again, and it never gets any easier or less tedious to fill out than the hundredth time before. It can be challenging to keep members actively engaged in such repetitive processes

without losing hope. It is not too much of a stretch to see how this same fatigue/frustration can happen with health and access discussions.

Another reason could be the fact that there is typically a significant age gap between members and advocates. This is because majority of advocates are in their late-teens to early-twenties, which majority of members are in their late-forties and early-fifties. How could such young college students, who have barely even begun their own lives, nor have they experienced all that their members have, possibly be able to help members achieve their broader life goals, let alone help them navigate the healthcare system?

This is a fact I myself as an advocate have struggled with as I continued to meet with members over the years. It has also been voiced by other members, though admittedly it was often due to them expressing their own frustrations and directing them onto advocates "*What can a twenty-year-old possibly help me with? I used to teach kids just like them back when I taught high school. What can they do that I haven't already tried* (CEF waiting room, February 2017)?"

Another reason an age gap could be an issue is potentially due to generational concerns, where it is perceived as inappropriate for an older adult to impose their own problems onto a younger individual when it is their own responsibility to handle their problems. These factors may be true, however another equally true fact is that advocates are there, willing to help and apply what they do know from their experiences, and will fight alongside members, and scour every network they have access to, in order to help their member. It's not perfect, but it definitely seems to work, given how long CEF has been around and has continued to grow.

Perhaps members do not bring up their health due to the fact that advocates are not doctors? After all, CEF is not a clinical space. Multiple participants voiced their inherent trust in a healthcare professional and a generalized requirement for patients to be open to discuss their

health and concerns with medical professionals. Doctors are inherently trustworthy to members, and arguably the general population, due to their status within the biomedical system that has proven its effectiveness and garnered the trust of those who participate in it. Perhaps CEF advocates have not earned member trust to a degree where discussions of health are achievable? This is a valid point, especially given that some members see multiple advocates during their interactions with CEF. This is due to the fluidity of advocate presence because of their status as students with fluctuating schedules and commitments.

Perhaps it is due to member ranking of who they go to for health advice? The common consensus of members seemed to be that they first go to health professionals for health advice, then family and friends or even the internet for health research. This can extend back to trust, with family and friends having stronger trust ties than an advocate a member maybe engages with once or twice a week. Perhaps advocates have not breeched these categories of trust with members until after a significant amount of time has passed, or until situations "force their hand," such as with applying for benefits, which often involve disability or health status qualifications, or something directly medically related?

However, long-term relationships are a primary focus of CEF and its program structure with Member-Advocate pairings, where advocates and members agree to work together exclusively for an extended period of time. This means that this potential issue of trust could be alleviated. Over this time, advocates could slowly integrate themselves into the member's broader trust network and may finally reach a level where such health discussion can thrive. However, over this time, the member may have achieved many of their goals, and feel they are in a good place, and may thus slowly detach from CEF as an independent individual before they feel it necessary to bring up their health.

Further still, maybe the reason members do not bring up their health in advocate meetings is due to their perception of good health, given their understanding of health, and their focus on other, more pressing goals which they perceive as needing greater attention or intervention at the present time? During this time, they might be attending to their health in the best ways they know how through self-medication, talking with friends or family, or seeking advice from other sources outside of CEF. This means that it may potentially be up to the advocates themselves to initiate the conversation about health.

Whatever the reasons are, be it the ones I have reviewed, or others I have missed, it is apparent that, as with anything of social basis, there are many factors that can influence peoples' decisions to engage with another regarding their health, be it due to personal experiences or understandings, or broader societal processes, expectations, and understandings. Following this, the next question is that, even if members do bring up their health in advocate meetings, will such discussions be useful? In other words, even if members discuss their health, will they be able to utilize the resources which advocates connect them with? This is a question connected to the issue of healthcare access, and the barriers that prevent the utilization of such resources. As with this discussion of reasons why members may not discuss their health with advocates, the reasons and types of healthcare barriers are also numerous.

Chapter 7: Healthcare Access Barriers

"Losing a home has multiple negative side effects such as loss of security, stability, and increased stress and fear for the future. Access is limited because of stigmatization, shame, isolation, and fear of bureaucratic hurdles, along with lack of knowledge of legal and insurance processes, payment/cost, and not recognizing their own poor health status (Wagner et al. 2014)."

Throughout the literature and this research study, multiple reasons and factors have been found that can inhibit an individual's ability to access healthcare. In the remaining section, I synthesize my work with previous literature findings to provide a comprehensive review of the barriers to healthcare. I use my proposed framework to organize and contextualize these factors. The framework categorizes the different barriers to healthcare under Individual/Personal Constraints, Health Service Seeking Behavior, Structural/Social Organization, and Cost and Insurance. These are derived from the overarching themes in which the various barriers can be grouped. It is my hope that providing this framework will help readers and future studies better understand these topics and perhaps organize them in such a way that they can inspire future research directions and approaches.

Individual/Personal Constraints

One personal constraint is time. There's a common saying, "there's only so many hours in a day." This saying becomes an all too real fact of life for the many homeless and low-income individuals in society. In these situations, time transforms into even more of a luxury and commodity with which to invest. With such limited, fixed amount of time in a day, every second

spent must be carefully calculated and used appropriately, or certain needs may go unfulfilled.

The primary resources that must first be dealt with are food, shelter, and a place to rest. The fight

to obtain these necessities alone seem to amount to significant time and energy costs for

homeless and low-income individuals (Nickasch et al. 2009). This struggle is supported by

Maslow's Hierarchy of Needs (1970). This is a systematic ranking of human needs that are

ordered in such a way that higher needs, such as esteem or self-actualization, can only be

satisfied once lower, more basic needs, such as food and warmth, are met.

"Yeah, and then when I got without it [insurance], you, you then, you, when you have a finance problem with it, you, you gotta, know if you wanna eat, sleep, or whatever, or take your medicine. So, some months it's, it's, you try to stretch it out, and you get sick anyway (Age 54, African American, male, CNA, homeless)."

However, it is also important to note that time constraints are sometimes not a major

factor for everyone, as one interviewee mentioned:

"Not too many things get in my way. I don't allow too many things to get in my way. I craft my schedule around doctor's appointments and things of that nature (Age 54, African American, male, writer, homeless)."

With my initial research into CEF, I asked questions related to reasons why there were

differences between the numbers of men versus women that came to CEF for help. My initial

theory was that it was related to systematic factors and trends related to gender and situations

that led to homelessness. Typically, there are more homeless men than women in a given

population. However, it is important to note that this trend can be different in certain areas

depending on the population demographics. Nevertheless, this was true for the CEF population.

Despite other suggested reasons, through further research and conversations with members, I

discovered another possibility as to why CEF served more men than women.

The issue was a spatial disparity in the distance between the CEF office and the women's and men's shelters. The men's shelter was closer to the CEF office (0.2 miles away) than the women's shelter (2.6 miles away). This substantial difference in distance made travel to CEF a significant factor because of transportation requirements. Though this difference can be mitigated by the reliable, and free, UNC Chapel Hill public bus system, there is still a significant difference in ease of travel to the office, such as simply walking versus navigating the public bus system. Following this case of how transportation can affect resource utilization and access, I decided to research into topics related to spatial arrangement and transportation needs related to healthcare service utilization.

When asked about barriers to healthcare, multiple interviewees mentioned transportation as a major factor, especially for those who did not have a car, a license, or easy access to public transportation. Transportation needs are an interesting subject related to healthcare access. It seems to be further down on the list of barriers commonly cited, yet can be a key factor when it comes time to actually seek out care. Multiple studies have touched on the issue of transportation for individuals in low-income or homeless situations (Nickasch et al. 2009; Rae et al.2015; Yeboah 2014). These include not owning a car, issues with public transportation due to personal constraints or physical disability (e.g. wheel chair accessibility), or having to rely on a friend or family member. Solutions to issues of transportation are to connect individuals to sustainable, and accessible, modes of transportation. This can include connecting them to resources related to local public bus schedules and routes, as well as help with paying for bus passes or fees. However, it should be acknowledged that this potential solution is limited and less viable for more rural populations that may not have extensive infrastructure for a robust public transportation system.

For my population of individuals, there is a potential source of reliable transportation already at their disposal. They have access to the public transit bus system that is provided, free of charge, around the UNC Chapel Hill campus, and local communities. It runs daily, Monday through Friday, from 6:30am until 7:30pm, at regular intervals. There are even buses that run on weekends depending on the route. This means that they have potentially one less barrier to healthcare access than other communities without such transit systems. However, even this system has issues of its own, as one member reviewed:

"Well for me, it's down to transportation. So, since the bus system here only runs to a certain point, I have to walk the rest of the way there, and I have to walk the rest of the way back. You know, so I have to walk out, to where ever the bus stops, go to my appointment, then, you know, from my appointment, I have to, you know, walk back after I'm done with my appointment, back to the bus stop. And, I mean, so it's in proximity, I mean I guess it'd be nicer if there'd be a way to get some, you know, some arranged transportation or something, I don't know. Because they say I'm healthy, I can't get uh, what's it called...Easy Ride? Yeah, I can't get anything like Easy Ride, which will take you to a place like that. I have to petition people to either help me, you know, make my way up there, and a lot of the people I know are, you know, usually professional workers, you know, they're working between, anywhere between seven and...some of them are students, and stuff like that, and so it's like, you know, when I have to do stuff like that, I have to plan it out. And it, it might take me, you know, a half hour to get from where the bus stops, to you know, that place (Age 46, Caucasian, male, homeless)."

So, in this case, transportation intersects with multiple areas of influence, including time and social networks. Other issues for public transport include bus fees for certain routes and times, as well as varying handicap accessibility levels for the buses and bus stops. As an organization, CEF is able to help relieve this issue of cost by providing a program that helps members obtain bus passes.

Another viable option would be to connect individuals to resources where they can obtain their own personal automobile. There are definitely many factors to take into account with this solution, such as initial cost, continued maintenance and upkeep, as well as the cost of gasoline, but it is a valid option depending on the financial circumstances of the individual. Investing in a car can break down multiple barriers, not just with healthcare, but also employment and housing

options. Reliable transportation is truly a source of increased personal liberty and independence, as long as certain sequences of events occur to make the option available and sustainable.

Beyond time constraints and transportation, some final issues participants mentioned included weather, personal aversions to doctors, and what they described as the "White Coat Phenomenon." They described this as the situation where patients may have a medical concern or symptom, yet when they go to see a medical professional, the symptom goes away. It is as if just by entering the medical setting and seeing the white coats of the providers, they were cured. Multiple members agreed that they had experienced this one time or another. Upon further research, it seems there are other forms of this white coat phenomenon, including what is known as "white coat hypertension," where a person's blood pressure reads higher in a medical setting compared to another setting. It is believed it is connected to anxiety towards the healthcare process (Mankad 2014). It could also be considered a form of placebo where just going through the motions of seeking out a health treatment can make someone feel better. It seems that how individuals perceive and approach health services can also affect their healthcare access.

Health Service Seeking Behavior

One of the primary issues with homelessness and low socioeconomic situations are negative perceptions and stigma related to individuals in these categories. The feeling of hopelessness, marginalization, and internalization of a subhuman status are major barriers that I addressed in my initial research with CEF members. It is an all too prominent reality and fact of our society that homeless and low-income individuals are perceived and treated differently than others in society. This is due to preconceived notions of what kinds of people end up in such situations and the questioning of their character and work ethic, such as those that follow the

conservative model of the causes of homelessness. The common characteristics attached are that they are dirty, lazy, or criminal, to name a few.

The quick fix, according to this model, would be if they just put the effort in and found a job. The problem is that the solution is not that simple. There are multiple compounding factors that sometimes can be so numerous that it may seem that a solution is impossible to be conceived. This idea is partially caused by the myths of meritocracy and equal economic opportunity that create a misunderstanding of the situations these individuals find themselves in. This negative image and treatment can take away the humanity and self-worth of the people that are affected by it. This can cause them to lose hope, trust in others, and the motivation to better themselves. The effects of these perceptions on mental and physical health were touched on by an interviewee discussing social health:

"You know...but that can, that can affect you physically, and it can affect you mentally. I think mostly, when you see such things going on around you, and you want to be social with that, sometimes it can affect you mentally. You know, you feel like, you know, you're not part of that, society, and when that society starts to erupt, you got all kinds of ingredients in there like hate, or, you know racism, uh, you know, any kind of form, and you in that environment where, you're not all of that, you know, you being humble. You know, it's like, you're a rat trapped in a trap, you know, you got all of this coming at you, and when you faced with that, with that adversity, it feels like you, you, you just feel so terrible. And you feel like you want to do something, and you know, what can we do about it? You know, because it effects, you know, as you being a human being, we're all human being, we all human beings, so we do have certain types of, umm, behaviors. You might feel some type of way and another person might feel some type of way, and when you see that going on, you feel like you're trapped, and you want to do something. 'Hey look, I'm sick of this. Let's do something about this (Age 43, African American, male, homeless).'"

This pervasive reality of stigma and marginalization is just as powerful in creating a barrier for healthcare access and utilization. Researchers from the Wen and colleagues (2007) study have aptly approached this barrier by examining the perceptions of homeless individuals with their encounters within the healthcare system. They specifically focused on the individuals' feelings of "welcomeness" and "unwelcomeness." After performing seventeen in-depth interviews with homeless individuals and organizing their transcriptions, two interesting themes

emerged. They described these themes through the individuals' use of I-It and I-You constructs or statements of understanding.

These two constructs of understanding are related to theoretical notions of how people perceived their experiences. That is, whether they felt like an object without power to define their existence or function, essentially, control of their situation (I-It), or whether they felt like a person or dynamic being who has a say in defining their essence (I-You). They found that feelings of unwelcomeness stemmed from feelings of being ignored, rushed, treated rudely, or discriminated against because of being homeless or of a low social class. Interestingly, however, they observed that these feelings were in response to perceived negative attitudes of health personnel, rather than actual verbal interactions. These experiences can have a negative effect on their willingness to seek out help in the future. Following these results, they suggest future research into the perceptions of both homeless patients and healthcare providers to address this problem of misunderstanding and contradicting experiences, or unintended negative interactions. This speaks to the importance of investigating into barriers than can be found throughout any step of healthcare utilization.

For my participant population overall, a sense of welcome was not a deciding factor that affected them. Some did acknowledge that they sometimes had issues seeing a new doctor because they still needed to build a trust and get to know them. However, they said this should not get in the way of the visit itself.

"Uh, feeing welcomed...umm...not so much an issue. Umm, I'm, not so much a reactionary, you know. Most healthcare providers have a professional demeanor, that, you know, includes, uh, is inclusive (Age 54, African American, male, writer, homeless)."

"Oh it's very important to me. I finally found a doctor. We talk, we have rapport, we have time, unlike my experience with UNC where it felt like herding cattle. You don't have the time no more...it's like they're just trying to make more money (Age 60, African American, male, rental apartment)."

"Even as good as that profession is, you're supposed to feel comfortable telling them. I mean, you supposed to. I mean they're there to heal the world. I mean that's what they're there for. And if you have any type of symptoms and stuff, you shouldn't be afraid to tell them (Age 43, African American, male, homeless)."

A response I found particularly salient as an argument for how to combat negative feelings towards a healthcare provider visit was having an open and empathetic mind towards the health professionals:

"And then, then another thing, we have to remember these doctors is human. He might have just left a patient that is about to cross over, and then he got to change [wooshing noise and hand motions head to toe] quickly before he come in your room, you know, you examine room. So yeah, the, uh, take a lot of stuff in perspective with this doctor and patient relationship because you never know what, what happened before he saw you (Age 54, African American, male, CNA, homeless)."[15]

This is an important outlook that I think is important to take into account. The interactions go both ways and the demeanors of providers can be affected by how their day is going. However, they do their best to make every patient encounter the best it can be. While my participants did acknowledge that welcomeness and previous experiences could potentially be a real worry, my participants' primary concerns were in other areas, specifically about the efficiency and outcomes of their treatment. For one, it was the extra steps they had to take with referrals, specifically to other professionals when their primary care provider did not have the equipment or facilities to perform a treatment or procedure.

One participant went to the ER because they had cut their arm by accident. The ER physician assessed the injury, dressed the wound, and referred him to a physician for follow-up. The issue was the referred physician requested the patient rush to see him to have the injury reexamined and assessed for surgery. Instead, they seemed to do the exact same thing the ER

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[15] Due to this participant being a CNA, I was not surprised that they voiced this grounding reflection. Having been a care provider, their perception of this issue of welcomeness, and the negative factors which can diminish it, comes from experiences as both patient and healthcare professional. It is interesting to reflect on how such a perspective has influenced how they approach other issues of health and healthcare access.

physician performed, which seemed to the participant like they were second guessing the work

and qualifications of the ER physician:

> "*I was like, why was it necessary for me to, you know, to do that. And that's, that's kind of...I felt like he was trying to pad the bill a little bit, and, you know, I mean, I don't know why, I mean that's kind of how I felt. But I mean, I didn't understand the reason why he, you know, it was like he kinda, was almost second guessing the ER doctor's, or the ER physician's, you know, diagnosis. And that was something I was kind of like, just question mark, question mark, question mark. (Age 46, Caucasian, male, homeless).*"

These situations of confusion or frustration with repeated care and mistrust of the utility

and ease of referred care can have negative impacts on the health seeking behavior of

individuals. Concerns for the benefits of referrals and in regards to unnecessary care which "pads

the bill" are directly related to personal constraints and concerns related to both time and income.

This is an example of how each of these levels within this framework of understanding

healthcare access issues interact with each other and further show the complexity of the problem.

Another deciding factor for health seeking behavior is personal perceptions of what

constitutes a medical emergency or symptoms that need to be addressed by a medical

professional. In truth, an individual's perception of their health and what is a serious illness or

symptom has direct impacts on if they feel the need to seek out professional help. In their study

of preventive healthcare services in homeless women, Yeboah (2014) found such perceptions

have key influences. It seems many individuals stated that they often delayed treatment unless

serious symptoms developed that interfered with obtaining food and shelter. This shows a

dynamic interaction between perceptions, health, and personal priorities, as discussed under the

personal constraints category of barriers. Such interactions have serious consequences, especially

in the face of chronic illnesses, which can have strong influences on individual morbidity if not

treated. Yeboah (2014) stresses the importance of preventative measures in keeping people

healthy, and allowing them not to have to seek out help as often. Prevention is especially

important for homeless individuals who have higher morbidities and comorbidities due to their living situations.

In my study of CEF members, similar sentiments on what constitutes an emergency and delay of healthcare behavior were found. The primary measure of an emergency was based on personal experiences, a certain level of unmanageable pain, being afraid, or a gut feeling:

"When the pain is unbearable. I had diverticulitis, twice in my life, and the pain was so great that I did not have any other choice. I needed something...you know...and I didn't know I had diverticulitis, until I went. I just knew I had real, just stomach pain that was just, scary (Age 63, African American, male, apartment rental)."

"...from a past experience, with an appendix, that became inflared...but I came home, and I was lying on the bed, and it was just aching...this was so uncomfortable, that I cannot lie, lay on my bed, and rest. I was just weighing the odds, I was like, well if I can't get any rest at home in my bed, I probably need to go to the hospital (Age 54, African American, male, writer, homeless)."

"I guess the human instincts. Alert. Your inner, when you cannot, when you are in danger. You really feel it. When I feel it, I go right away, I wait for nothing. I mean, something I cannot control, oh my gosh, I go right to 911. But thanks God, I pray a lot, I go to the church, I keep, he help me a lot, and I control many things, and I am so grateful of my faith, because I know every moment more, myself, and thanks God, I can control my many things, myself, and I take care of myself (Age 59, Latina, female, apartment rental)."

These measures of an emergency and flagging signs of when to seek out health are important, and can often mean the difference between catching an illness before it progresses to a morbid state. One participant expressed their gratefulness for listening to their personal voice of reason that something was wrong. In this case, they noticed unusual swelling, which they did not know of its cause. This prompted them to ask about it at their next visit, where the doctor performed a test for diabetes and found that he had a "low case," which the participant understood as a case that could be treated and essentially cured.

Unfortunately, not all cases of human instinct produce satisfying results, as another participant explained:

"But I didn't feel okay. So, I'm like, you know, how am I supposed to resolve the, I don't feel okay, and they're, you know, the doctors are saying, I am, or whoever's attending, and, you know, and I'm feeling they should be qualified to know if I'm okay or not, though I don't feel okay. So, how do I still explain to them, I don't feel okay, you're saying I'm okay, everything seems normal, but I don't feel okay? You know, I kind of walked out feeling, like, I didn't feel okay afterwards, and I still didn't, I mean I went in because I didn't feel okay, and they said I was okay, but I still didn't (Age 46, Caucasian, male, homeless)."

Coming into this experience, he had experienced a change in his overall feeling of what was normal. He couldn't identify what could be causing it, but he had a feeling something wasn't right. However, upon eventually going to the doctor and having tests done, the doctors could not find anything specifically wrong. This feeling of contradiction between the diagnosis and personal feelings, which creates significant cognitive dissonance, can have profound effects on future health seeking behavior. It also reveals the issue of who has the authority to determine if an individual is truly healthy. The foundations of the healthcare system are a trust in the providers and the knowledge they use. Yet how does one reconcile what they feel?

"And then, you know, this is later now, this is a year later, and now I still feel like there's a problem, though they've said it's okay, you know like...so I'm not trying to second guess them because, like, like everyone else, I know they've had educations, I know that they've, you know, treated patients upon patients, I mean, and I'm sure they've been in the profession for a while. So, I mean, I'm not trying to, like, say they're wrong and I'm right. I know how I feel, and I'm kind of like, okay I know how I feel, yet you're saying I'm okay, so I'm kind of like, I don't know. I still feel like I've got some problems with it, not as much as I used to have, but I still have some problems with it. Though I'm, I basically feel like I deal with it. I just deal with it, so...(Age 46, Caucasian, male, homeless)."

These concerns are related to the discussion of who truly has the authority to tell when someone is healthy or not. The general consensus for who determines if someone is healthy was that the person themselves usually can tell, or a health provider, like a physician. Health was determined based on comparison to a normal state they considered healthy and knew when something was wrong if they felt outside of that normal. Despite the physician's training, knowledge, and authority, a patient may still continue to be adamant that something is wrong. This situation is a common issue where someone does not want to second guess of distrust their

physician. This can lead to patients simply dealing with the problem, internalizing it, and potentially accepting it as a new normal for their health. In other cases, a patient may decide to seek out other sources for guidance or treatment.

When participants did not want to, or could not go to, a healthcare provider, they listed other means of receiving health advice. The primary outlet was from friends or relatives, especially parents or grandparents. This discussion of health advice from family actually sparked an interesting conversation about alternative medicine and home remedies. Others relied on their own training, such as one participant who had experience as a nursing assistant, and another, who preferred to self-medicate with herbal remedies.

"Sometimes I try to medicate myself as best I can. But I don't use drugs. Like when you eat toxic meat, or something bad and get intoxicated...and I try just to clean up with dandelion, I have a bit of a natural resources, because I am allergic to many medicines, conventional medicine. Dandelion for liver, to clean up, chamomile or mint, or lettuce or garlic and lemon. I try to do what I can and bring only the necessary things to the doctor. I really only go to the doctor when I see something really, really, I cannot control (Age 59, Latina, female, apartment rental)."

Others were not so keen on self-medicating and preferred to only take medications specifically prescribed by their physician:

"For me, I don't like to take medicine no way. I only take what is prescribed for me. Don't come to me with nothing that ain't prescribed to me. You don't take someone else's medicine because it's not prescribed to you, because it's the strength. I've had people come up and say give me something, it's the same thing. Yeah, it might have the same name, or number, but they stronger or weaker. It won't do you no good if it's less than what you need (Age 72, African American, male, homeless)."

In light of what symptoms influence "when" individuals seek out health services, another issue is where they go for care. In regards to a general health issue, the options most frequently utilized include primary care facilities, such as a primary care physician, emergency departments, and hospitalizations of varying degrees of inpatient care and length of stay. It has been found that homeless populations chronically overuse emergency department services which are often overcrowded and an expensive part of health delivery facilities (Schanzer et al. 2007).

Although each of these facilities provide care to patients, they each have their own unique care focus and specialized forms of treatment.

Primary care facilities are concerned with patient first contacts, continued care, and preventative methods. It is highly relationship and long-term-based. Emergency rooms, alternatively, are concerned with crises and life threatening situations. They are not as concerned with continuation of care or preventative measures. These facilities also present with differing costs and time commitments related to waiting to be seen by a care provider and follow-ups. One of the primary complaints by many individuals, including the participants in this study, is the perceived excessive waiting times for emergency rooms. All of these factors have direct and indirect influences on health service seeking behavior, as well as on individual health in short and long term intervals.

Members of CEF had both positive and negative reflections regarding experiences and thoughts on the emergency room:

"I used to watch this show, about the ER, people come to the ER, it was on cable, and they treat everybody. I don't care if they acting up, been drunk, been whatever... but people shouldn't, they kinda have that reason, they ain't got no money, and don't go to the doctor, that's just...(Age 52, African American, female, apartment rental)."

"Uh, what I've done in the past is, like, is what most Americans have done, or a great percentage of Americans have done, is the ER, the Emergency Room. I really don't like that because, umm, when it comes to aftercare, it just leaves...either you go for the aftercare, or you decide this will pass. Which is not a comfortable position to be in. That's actually what happened with my hernia. I had a follow-up with radiology, I just didn't follow up, largely because of cost and not wanting to be a burden on the system (Age 54, African American, male, writer, homeless)."

"See then my problem went from not having, to having, and now I got this thing, I got this fear of I don't want to milk the system. You see I get Medicaid, and, and, I don't want, now I'm in a fear that, if I go to the doctor too much, it might be milking the system that somebody else need. I mean, I left one fear and went to this fear, and stuff like that about my health (Age 54, African American, male, CNA, homeless)."

"I don't like going to the emergency room unless I feel like it's an emergency, like, I need to go to the emergency room. So, to me, unless it's, and I don't know if that's good or bad, I feel like I don't want to squander something, you know, when I don't feel like...You know, my problem's not that bad, you know, it's bad enough that I feel like I do need to go see a doctor, but I don't feel like worth, you know, to the

point where I need to go to the emergency room because I'm just not feeling it (Age 46, Caucasian, male, homeless)."

The primary concerns for these individuals seems to be a conflict between knowing they need help, or feel they need help, but not wanting to either milk the system, or squander resources. This leads to debates about if a condition is serious enough to go to the ER, or put it off, especially if they cannot afford to see another health professional. There is also concern for the quality of care administered by the ER. It is acknowledged that they typically do not, or cannot, turn a patient away, but there is only so much they can do. This is especially for conditions that require follow-ups, and referrals to other healthcare providers they may not be able to follow through with. These concerns help show that the decision to seek out a certain portion of the healthcare sector, even in an emergency, can be problematic.

In 2011, a study conducted by Small, sought to find out what factors influenced the utilization of different sectors of healthcare, from physician utilization, emergency room use, and hospitalization, among vulnerable populations. This study utilized the Behavioral Model for Vulnerable Populations in order to understand the various motivations that influence utilization of discretionary (physician exam) and non-discretionary (ER and hospitalization) health services by vulnerable populations. The population studied was considered vulnerable if they had substance abuse disorders, were homeless, has mental health problems, were victims of violent crime, were diagnosed with HIV/AIDS, or were public benefits recipients. Interviews were held with 1,466 participants on their utilization of these services within the past 12 months (Small 2011).

They found that these vulnerable characteristics, and combinations thereof, influenced the frequency of use of these different types of health services. Their analysis showed a direct and almost linear relationship exists between increased vulnerabilities and use of non-discretionary

healthcare utilization. This is an issue since, "chronic use of emergency rooms and hospitalizations are a costly alternative to primary care (Small 2011)." The researchers state that this is especially true because, "primary care allows for proper screening of chronic disease and reduction of financial burden that tertiary care places on medical and health delivery sectors." They also saw that other factors, such as gender, marital status, perceived health status, and insurance coverage, affect which sector of healthcare the individuals would use (Small 2011).

<u>Structural/Systemic Organization: Healthcare System Organization</u>

As with any service industry, be it food service, cosmetics, or hospitality, the structure and organization of the business affects how easily patrons are able to use the service. These truths apply to any healthcare system as they provide a service to the public. In fact, the way the system is set up and functions can be a source of potential barriers related to access, as evidenced by Rosenheck et al.'s (2001) study into health service delivery issues with individuals that were homeless or had a mental illness. This article discussed how the organization of sites and how clients are engaged with can become barriers to homeless persons with serious mental illnesses. Such barriers included, not knowing where to go for service, not being able to afford care, experiencing too much confusion, hassle, or waiting, and being previously denied service. They found, as with other literature (Fitzpatrick-Lewis et al. 2011; Nickasch 2009; Rae et al. 2015), programs that couple treatment with services to provide housing, substance abuse care, and income support, may help overcome homelessness and achieve substantial improvements in their lives.

Other barriers they identified were variances in services used because of differences in funding, the location of services relative to areas frequented by homeless persons, and friendliness of services. They stress the value in inter-organizational relationships and networks

of agencies and providers to improve patient outcomes and access. This was exemplified in their

findings that community outreach efforts can facilitate access to services and help personal

barriers to be overcome. Such findings indicate the importance of sustained outreach efforts to

underserved people, and others in severe need of help, especially those in nontraditional

locations for entry into services systems. There is also a need to understand and optimize the

workings of the service systems health resources are deployed by (Rosenheck et al. 2001).

Some of these sentiments from Rosenheck et al. (2001), were discussed by my study

participants. One such theme was in regards to healthcare access related to the general size of a

city:

*"I feel like that it is very accessible, umm, has been more so here, in Chapel Hill, than for
instance, Durham, or perhaps even Raleigh. I, uh, have a variate of, varied experience, you know,
regarding life, and places that I've lived...exposure, I can say that, the smaller, umm, the community, the
easier it is, or has been, for me to navigate certain systems. I think the system, navigating the system here,
is, uh, tremendously easier, than navigating the system, than say, for instance, Durham, whereas
navigating the system in Durham is tremendously easier than navigating the system in New York
City...so, despite the size, the monstrous size of it [the healthcare system], I do feel like there is, uh, some
kind of interconnectedness, that doesn't allow you to get lost, so much in the system (Age 54, African
American, male, writer, homeless)."*

By expanding upon this idea that the healthcare system is not a singular entity, but is

actually broken into smaller segments demarked by city limits, helps to reveal potentially hidden

influences on healthcare access. In particular, segmenting this system into these smaller entities

helps to show that, despite similar means, goals, and trainings, healthcare centers can have vast

differences, even between local cities. This is due to the diversity urban centers have based on

local policies, approaches, and cultural composition. Though Durham is only a few miles away

from Chapel Hill, the resources available to members of the community, especially the homeless

and low-income individuals, are surprisingly different. This is a fact that CEF as an organization

had to reconcile and overcome as it officially began working in Durham in 2010 and opened a

second office in Durham in 2014. To this day, it still takes continuous effort to collaborate while also filling the diverse needs of the two communities. In the same way, it is no surprise that healthcare systems can vary in the accessibility between individual cities.

When asked about what was wrong with the healthcare system, the following quote was the most eye-opening:

"I mean, I think that, the healthcare seems, again, systemic. And, you know, it seems to work a certain way, and the thing about that is, it's just like, a lot of times I just feel like a marionette. You know, I feel like I'm the, you know, they're kind of like the puppet masters and I'm just the puppet. And the thing is, you know, I don't like feeling like that, you know, I feel like, as far as a fair right to, you know, equality for the healthcare sure. It kind of, like, it seems like they've almost come in, like, you've got a fore[16] doctor, a shady doctor, or dodge doctor, and it's just like, you know, who do I go to because, it's, you know, it's all competitive now. It all seems very competitive and it's just like, it seems like they've made a lot of...that healthcare has become out of reach for, you know, people that either can't afford it or, you know, low-income, or no income, and stuff like that, so, I mean, how do you solve that problem (Age 46, Caucasian, male, homeless)?"

It is concerning, to say the least, for a participant to feel as though they are not in control of their healthcare experiences, as though they are being controlled by those which provide it. It is a patient's right to be informed on any diagnosis and treatment, as well as alternatives and be allowed to make a decision based on what they feel is appropriate. For patients to feel as though they are not in control of their healthcare experience and are not given equal treatment in the health facility due to their income, shows that there is something deeply wrong with what the healthcare system has become. Yet if it is apparent that something is wrong, what can be done about something as monstrous in system and influence as the biomedical health system?

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[16] This is indeed the word they used during the focus group discussion. However, I am uncertain exactly what they mean by the adjective "fore." A search of its use showed it could be related to "before," which could relate to uncertainty experienced by seeing a perceived "pre-doctor" as if they are being screened before seeing a "real" doctor. They could also mean "fore'," an abbreviation for foreign, which could relate to uncertainty experienced by patients seeing a perceived "foreign" doctor. A foreign doctor could mean a new doctor or a doctor born outside of the country. However, I cannot substantiate such speculations at this time.

When asked how we could improve the healthcare system, participants responded with these thoughts:

"Well, me, myself, and I, I think if we, the politicianers, and stuff, quit taking insurance bribes, and all those things, that we could have, everybody could have the health that they need. 'Cause, it has been other countries that, uh, all that resources right there. And, like I said, we take the ten quick, 'cause most the doctors, if they write a 'scription, they get a perk off of it. So, if you take all those perks away, and go back to the olden times, we would get more better health than we do now. 'Cause it done got worser now, 'cause everything is dollar signs. You gotta make the quarter (Age 54, African American, male, CNA, homeless).

It seems that one of the primary issues of the healthcare system, as reflected by participants, is an overall trust in the system, and a belief that the providers have the interests of the patients in mind, rather than dollar signs. This and other problems are in need of addressing in order to lessen this barrier's effect and hopefully increase patient trust in and access to healthcare resources.

By zooming in from the overall structure of the healthcare system and into the employees themselves, the physicians, another barrier to access can be found. This is a particularly interesting and potentially less studied level of healthcare within the wider discussion of healthcare access and reform. Asgary and colleagues (2016) performed a study that looked at this commonly overlooked area. They argue that current medical school curricula does not allow for adequate training of physicians to administer primary care to individuals experiencing homelessness. They claim that there are certain skills needed to address the unique healthcare needs of the homeless because of their social conditions that affect their clinical encounters. Furthermore, structured and formal integrated curricula to specifically address the primary care needs of the homeless, with their specific challenges and barriers, often do not exist. Therefore, they propose a designed health disparities clinical and population-based curriculum that would better prepare medical students to address the multi-level barriers to healthcare among the

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homeless. The article goes on to describe the development, implementation, feasibility, and assessment of efficacy of such curriculum.

Having reviewed this study, I was interested to see what members thought about their health professionals. In general, members did not mention themes that Asgary and colleagues (2016) touched on regarding a physician's ability to cater to homeless and low-income individuals. As discussed in previous sections related to welcomeness, members were relatively positive about their encounters and for the physicians themselves. Many responses spoke to the importance of listening to one's doctor and their health advice. Others spoke of the importance of being able to trust one's doctor. They also emphasized how medical professionals are humans too and the need to acknowledge this fact during a visit. Such sentiments were, ironically, summed up in particular by one participant:

"And of course, doctors get sick too [everyone laughs and agrees] (Age 43, African American, male, homeless)."

Cost and Insurance

When people are asked about barriers to healthcare, one of the first things they usually mention is the high cost for healthcare. It is true, healthcare costs can be exuberantly high. In 2010, the total medical cost for a typical American family of four was $18,074, which translates to over one-third of the median household income of $50,221 of 2009. The retail price of 217 most popular brand-named drugs also increased 41.5% over a five-year period (Hellander 2011). This increase in cost is coupled by a growth in socioeconomic inequality in the United States. Income inequality was at its highest in 2009, since 1967, and was highest among Western industrialized nations. In 2009, 14.3% lived at or below the poverty line, defined as a family of 4 with income of less than $21,954 (Hellander 2011).

In 2010, the average annual premiums for employer-sponsored health insurance were $5,049 for single coverage and $13,770 for family coverage. Since 2000, average premiums for family coverage have increased 114 percent, while the amount of the premium paid by employees with family coverage has increased 147 percent, as firms shift the cost burden (Hellander 2011). Between 2001 and 2006, insurance premiums actually rose 73%, compared to wages which only increased 15% (Clemmitt 2006). Such high costs help explain why fewer employers may be willing to offer health insurance to employees.

With socioeconomic status and cost of insurance trends like these, it is not surprising that in 2009, 50.7 million Americans (16.7%), including 7.5 million children, were uninsured (up from 15.4% in 2008). This trend was due to decline in people with employer-based coverage (from 64.2% to 55.8%). The increase would have actually been greater had it not been for expansion of public coverage, Medicaid, which now covers 15.7% of the population (Hellander 2011). This issue of insurance coverage disparity has real consequences on health outcomes. A sobering research finding of discharge data by Hellander (2011) found that uninsured non-elderly patients hospitalized for heart attack, stroke, or pneumonia are more likely to die than those with private insurance. In 2006, economists estimated the US spent more than $2 trillion on medical care, about $6,830/person, or 16% of the nation's GDP. This is compared to Switzerland with $3,446/person and Norway with $3,093/person, which are the next largest per-capita spenders (Clemmitt 2006). These cost of treatments and insurance were on the forefront of participant's reflections on their experiences with healthcare:

"Yes, when I was having seizures, I realized that sometimes I don't have to go to the emergency room. I also told my family don't call 911 when I have a seizure, but they are scared not to call. And I'm telling them not to call, let me sleep. Then I will wake up and feel better. And 911 costs so much money (Age 52, African American, female, apartment rental)!"

"I called the ambulance from that shelter over there and to the hospital [a 1.5-2-mile trip]...cost me $350, and insurance doesn't pay for it (Age 72, African American, male, homeless)."

This issue with cost is especially a problem for people in low-income, unemployed, and homeless situations. Personal income must be invested appropriately, and often skillfully, so that it can be stretched to fill the needs of the individual until the appropriate time in which it is obtained once again. In other words, budgeting out personal income is a crucial skill, be it in hard copy on paper or theoretical in the mind. The items that make the top of the list are usually the basic needs for survival, food, water, shelter. Once these needs are fulfilled, only then can an individual begin to act upon their other needs. Just as with time, Maslow's (1970) hierarchy of needs come into play with budgeting finances.

Unfortunately, personal health can rank further down on the list than personal income can reach. This leads to prolonged absences of health check-ups, screenings, and delay of treatment and service seeking behavior for potential health concerns. The key feature to this pattern of behavior is that individuals are often indeed conscious of their health needs and have valid health concerns.

"I'm like, I'm having problems though, you know? I'm, and that's one of the things, like, even lately, I'm, I've felt like, you know, I still can access Carolina.2, you know, I can do that. Though, it's been, I'm like, you know...every time I've tried to think about it, I'm usually back where I'm staying, you know, laying down, and I'm like oh I didn't do that today. You know, kind of, how do you say, dropped it off my list, or didn't worry about it (Age 46, Caucasian, male, homeless)."

"There's a lot about my health that I need to take care of. Like, I mentioned dental, that's one thing that I need, but I don't have dental insurance. My Medicare doesn't cover it, so it can be real expensive just to go, a visit alone can cost you over a hundred dollars, two-hundred dollars. Just to be there, not including the X-rays and all that. I just can't afford it right now. So that's, I have to do that, and that's when I have...when I do it, it'll probably be when I have to do it. You know, if you have a tooth ache, and you let that teeth go without anything being done to it, over a period of time, it'll get to the point where you won't be able to not have something done to it (Age 63, African American, male, apartment rental)."

The issue is not ignorance or obliviousness to the issue, but rather the strategic, though potentially reluctant, choosing of what is most important to address at a particular time and moment. As these decisions and rankings of needs are performed, "disease and resulting

restrictions they involve simply become integrated and normalized into everyday life (Wagner et al. 2014)." This normalization can have dire consequences in the long run. Yet, this is not an uncommon trend. It is a commonly held view that the uninsured often foster ineffective, excessive spending because they wait until their health condition reaches a critical stage and end up in the emergency room, instead of getting more cost-effective preventive care in a physician's office (Clemmitt 2006).

However, there are alternatives that can allow for individuals to access healthcare without having to worry about cost. A public health program, which has become popular, is to bring the healthcare system to people. This can arise from local groups with a desire to improve the health of their community. These come in the form of community health fairs. One such fair, Operation Breakthrough, was described by an interview participant:

"It's an event they have out at Lincoln Center, maybe once or twice a year, something like that. They have different organizations that come in, to help you with different programs, housing, stuff like that. They'll check your eyes, blood pressure, AIDs, feet, eyes, they'll give you a haircut...they do a lot of stuff over there. So, I was able to go through them. They had a program that, if you needed dental work done, they would send you to the clinic (Age 63, African American, male, apartment rental)."

These community fairs have increased in prominence around Chapel Hill, both through local community groups and churches, as well as through student organizations. Typically, the vendors in place volunteer their time to offer care to those in need because of a belief in the benefits of such interventions. While maybe not the best solution to the problem or a substitution for a consistent primary physician, it seems to be better than no healthcare treatment at all. This is especially true in the face of the issues of cost.

Another more prominently discussed intervention to address this issue has been the development of insurance programs, both through public and private institutions, through governmental intervention. These are available to those that can afford the costs, or meet certain eligibility criteria, and can cover various portions of the healthcare system depending on the

plan. However, there are multiple issues with insurance including coverage, eligibility, cost, and funding. So many issues in fact, that I have decided to dedicated an entire upcoming section to review the issues with insurance, and a review of possible solutions to the problem.

<u>Insurance: The Biggest Barrier to Healthcare?</u>

The institution set in place to help remedy this issue of cost discussed in the previous section is insurance companies, which offer health insurance plans. Yet, this solution to help individuals pay medical bills has proven to not be enough and has major gaps in its structure when it comes to eligibility and coverage. In fact, a contributing risk factor for being homeless is lacking Medicaid insurance (Folsom et al. 2005).

Ultimately there are two standard approaches used to help those that cannot afford healthcare. These are public insurance, such as Medicaid, or direct support by safety net institutions. Each target low-income individuals and have their merits, issues, and state or federal funding. Both face difficulties with economic and political environments that change and challenge their effectiveness. Often, when the budget is strained, states opt to edit the eligibility requirements, thereby leaving many people without Medicaid because they do not meet a certain requirement.

This leads to gaps in coverage and individuals falling into categories where they make too much to qualify for Medicaid, but too little to afford private insurance for healthcare (Weissman et al. 2008). Indeed, Weissman and colleagues (2008) found that access gaps between high and low-income people due to cost are significantly smaller in states with the broadest Medicaid coverage compared to states with narrowest coverage (Weissman et al. 2008). This trend in insurance access subsequently affects both general healthcare and preventative medicine utilization.

In 2010, the Affordable Care Act, or Obama Care, was enacted to help solve the issue of insurance coverage related to Medicaid. It was an attempt to provide health coverage to many more Americans and to contain the insidious rise of healthcare costs. Yet, it was not an easy decision to make. What duties does the state have towards its citizens? How much should the state do to ensure the well-being of its people? What benefits do citizens have a right to expect from a government that's supposed to promote the general welfare? It was an ordeal, to say the least, to have it pass Congress due to the discussion of these questions and the high-stakes regarding such fundamental philosophical questions. Five of the primary provisions of the law are as follows (Vaughn 2013):

1. Most individuals will be required to have health insurance beginning in 2014.

2. Individuals who do not have access to affordable employer coverage will be able to purchase coverage through a Health Insurance Exchange with premium and cost-sharing credits available to some people to make coverage more affordable. Small businesses will be able to purchase coverage through a separate Exchange.

3. Employers will be required to pay penalties for employees who receive tax credits for health insurance though the Exchange, with exceptions for small employers.

4. New regulations will be imposed on all health plans that will prevent health insurers from denying coverage to people for any reason, including health status, and from charging higher premiums based on health status and gender.

5. Medicaid will be expanded to 133% of the federal poverty level ($14,404 for an individual and $29,327 for a family of four in 2009) for all individuals under age 65.

However, according to a 2011 poll, 40% of Americans think the health reform law does not go far enough to change the health system while 20% believe the federal government should not be involved in healthcare according to a new Associated Press poll carried out by Stanford University researchers (Hellander 2011). Yet, just as interesting, if not ironic, is that the same polls found that around 90% Americans agree that the healthcare system should be changed from what it was like before the legislation passed. Their primary concerns were, "making sure that more Americans get the healthcare they need," and, "reducing the amount of money that patients pay for healthcare (Hellander 2011)." So it is apparent that people can see that there are issues with the healthcare system, but disagree on the best methods to solve them.

After its passing, the ACA has had mixed reviews and reactions from people for various reasons. Shartzer et al. (2016) reviewed the Health Reform Monitoring Survey data to address the changes in access and affordability for nonelderly adults since the program started. Overall, they found strong improvements in access to care across income and state Medicaid expansions. This included adults from low and moderate-income levels. Despite the progress, there are still large gaps in access and affordability in existence, especially in low-income adult population. There is also an issue of people potentially needing to learn how to use their new insurance coverage and need to change their care-seeking patterns and behaviors or may run into provider capacity issues as they seek care.

An interesting point that was also brought up is that there was concern that the ACA's rapid expansion of health insurance coverage would strain the health system and have detrimental effects for those already "in the system." However, the data shows measured improvements holding steady for all of the subgroups examines, which suggests gains of low-income adults have not detracted from health access and affordability for other adults. They also

acknowledge that other factors, such as changes in economy, individual mandate, and enhanced coverage for preventive services, could contribute to the observed gains to access rather than solely being from the ACA alone (Shartzer et al. 2016).

So why did health insurance gaps arise? Originally, when the ACA was going to be passed, it would require all states to expand Medicaid. However, the Supreme Court ruled that this was unconstitutional, and had the act changed to make the expansion optional. When the act passed, twenty-six states, and Washington D.C., expanded Medicaid under the ACA. The remaining states, including North Carolina, did not expand Medicaid under the ACA. Now, people above 100% poverty eligible for premium subsidies to purchase private plans in the marketplaces, but those under 100% poverty in states not expanded, do not have access to Medicaid or subsidized private coverage. This left nearly five million uninsured people at risk of falling into a coverage gap in states that did not expand. States that did not expand also missed out on millions of federal funding to support the expansion (Garber & Collins 2014).

In their reviews of the Behavioral Risk Factor Surveillance System (BRFSS), which is an annual survey conducted by the CDC in partnership with state governments, both Hayes and colleagues (2015) and the National Women's Law Center (2014) found interesting trends related to insurance and healthcare access. Historically, black and Hispanic working-age adults are far more likely than White/Caucasians to be uninsured, to lack a usual care provider, and to go without needed care because of cost. It was also observed that insurance has a large impact on whether adults have a usual source of care and could afford care when needed, even when adjusting for income, age, sex, and health status.

The results of the survey showed that being insured did indeed reduce disparities between whites and racial and ethnic groups. This was promising news for the potential for programs that

promote access to insurance, such as the Affordable Care Act, which will help to improve access to healthcare and reduce likelihood of going without. However, the results also show insurance coverage alone will not eliminate disparities in healthcare access. Although it may help level the playing field, there are still other issues that affect equity, such as historical inequities and pervasive cultural barriers that the healthcare system alone cannot address (Hayes et al. 2015; National Women's Law Center 2014).

In regards to their experiences with insurance, participants had different opinions about insurance. For those that had insurance, be in Medicaid, Medicare, or private insurance, they remarked that accessing healthcare was usually relatively easy, or at least easier. However, not having insurance presented as a major issue:

"Yeah, insurance is an issue there. Umm, maintaining it became a challenge when I became homeless. So, you know, it lapsed, I have still yet to get it back. Well that would be a big obstacle. Obviously, they could always, there's always room for more employment. So, umm, what, yeah just a lack of insurance is an obstacle (Age 54, African American, male, writer, homeless)."

"The doctors and nurses take an oath. You gotta help people, no matter what. But you go to some offices and they won't do it. Most of the time it's because you don't have insurance (Age 72, African American, male, homeless)."

"Well my situation, it was no insurance. So you said your prayers and hoped you was living the next day (Age 54, African American, male, CNA, homeless)."

This last response was particularly salient for the issue of insurance related to healthcare access. For some, it seems the issue is not only having insurance, but also what kind of insurance one has:

"Like, it's like when they notice this Medicaid, they try to make you a little bit out of the category, you know. When, because, probably, we get in the social disadvantage, because we don't have the social status, like other people have, with Blue Cross Shield, they pay, they pay more rich or so a month more than we do. But, I mean, it's still, we are the same category in human being in a war, when we were in a war, we don't make an exception of people when we offered our services in the war. We attend to all title of people when we was young working for the community American services here. So we usually request to get equal service and insurance, health insurance, whatever we have (Age 59, Latina, female, apartment rental)."

As this one participant put it, they feel they do not receive the same kind of treatment as another person who has private insurance, versus insurance provided by the federal government. This is not necessarily on purpose, but because of a potential stigma or category people may place people with Medicaid in. They go on to suggest that we need to discuss with the administrators of these insurance programs to cover more healthcare procedures, such as chiropractors, dentistry, and physical therapy. Yet, this perception of differences in care and requirements based on insurance type is not an isolated incidence:

"With the Medicare plan, I can do just that. I mean, my doctor can refer me, but I don't have to be referred with Medicare. But, my roommate, has a plan, she has Medicaid, and her restrictions are a little different than mine. They prefer her to see a certain hospital or doctor. If she does otherwise, I think she'll have to contact them, and let them know she wants to see. But, the difference may be that I pay for my insurance, she don't. See the government pays for her's. If I wasn't disabled, then it would probably cost me twice as much. So I am, so I do consider myself getting help (Age 63, African American, male, apartment rental).

While this is more a misunderstanding of the different types of insurance and health plans available, such as with HMOs and PPOs, this idea that a patient may be treated differently based on their insurance type is a concerning phenomenon which may benefit from additional focus for future research. However, this issue might actually be connected to a general mistrust or misunderstanding of how insurance works, as another participant reviewed:

"So, I mean, I guess, I don't know, I'm not into...having insurance that I understand is part of it. You know, not having something that is understandable, because, it seems to me that they try to keep you not in the know about stuff like that and, I don't know, it's just kind of like...it's almost like they want you to be clueless on the part to pay, but, you know, they want you to still come in and see them, and, you know...(Age 46, Caucasian, male, homeless)."

Another experience related by a member interview shows how even in situations where having insurance isn't an issue, other factors within the framework can have negative influence on health. For this member, because they were a diabetic, their doctor prescribed them medication in order to prevent future complications, like heart attack or stroke. However, as the

months passed, they started to experience terrible health problems, which they didn't know

where they were coming from.

> *"I was thinking they were coming from anything but the medication. So I kept taking the medication, and I kept experiencing problems. Kept going to the ER, getting picked up by EMS, and driven to the ER, and released and still taking the medication (Age 60, African American, male, rental apartment)."*

This continued for many years without relief, despite lifestyle changes and various

intervention attempts, until they finally decided it had to be the very medications which were

supposed to be helping them. After discussing it with a friend of his, a UNC professor, he

discovered that his symptoms were potentially due to the medications being generic.

> *"He told me that generic medicine, is like a knock-off medicine, it has the particular drug in it, and then it has other things in it, like fillers, and things of that sort. And I'm thinking well my god, I'm allergic to those certain things like that. And I'm taking that medication because my insurance would only pay for generic…they would not pay for brand. I'd taken the brand name medications in the past when insurance did cover it and didn't experience these side effects (Age 60, African American, male, rental apartment)."*

Within three days of stopping them, they felt completely transformed as the health

problems disappeared.

> *"The side effects are so terrible, I can't get nothing done. I'd be lethargic, I'm dragging, I'm getting depressed, and this is not profiting me any bit to be on the medication and be able to live life, not to have a life, not to have any joy. So, I stopped the medication and told the doctor, and I began to see substantial improvement in three days. I had my energy back, my thoughts came back, my strength came back, I started feeling youthful. So, I said that's what it was, it was the medication, so I emailed my doctor and told them I'd stopped the medication and asked for any other options (Age 60, African American, male, rental apartment)."*

Unfortunately, this situation occurred due to the good intentions of the doctor and

member trying to prevent future complications (Structural/Social Organization), the member's

low-income status (Personal Constraint), and insurance which would not pay for anything other

than generic. This is one of many unfortunate stories where inability to afford healthcare coupled

with insurance coverage issues can have drastically negative effects on an individual's health. As

members discussed in chapter four, it's also scary *"...to see how the present healthcare system can harm you if you don't watch out what you doing. If you don't look and take heed to who the doctor is, and what medication you're taking (Age 60, African American, male, rental apartment)."* In order to solve this problem of insurance, issues of eligibility, cost, coverage/policy content, and social views of the insurance programs will all need to be addressed.

<u>The Catch-22</u>

The following section is an excerpt from the discussion I had with the Talking Sidewalks focus group. This dialogue contains deep narratives that provide grounding examples of situations experienced by individuals navigating the healthcare system. It provides stories that highlight key elements that will be discussed in the following sections, which describe healthcare access barriers. This discussion is an appropriate introduction to these themes and will facilitate a deeper understanding of these barriers by providing a real example with which to apply these ideas.

D: *As my situation here, umm, I needed physical therapy, and uh, occupational therapy, and speech therapy. Each one of those, they take the Medicaid. But then you got a copay, so I thought the CharityCare [a program which helps patients that qualify pay for health services and medications] would pick it up, but it was a no. So I was in a limbo. I was saying, okay, now, umm, how am I going to give you the $20, when I don't, when I don't have a permanent space to live? And they wanted the $20 each visit. So I had to, uh, I had to just quit taking up, don't go there no more. And see that's what I feel is so bad when it come down to the healthcare. All those things change...there's so many changes of hands, that, that people are not getting the right care. Even though we getting called, they say all the health is getting more, you know brilliant and able to reach out and take care of big large things, and the little things is just falling underneath. You know it's because a poor person can't pay that copay, they can't go to the doctor because they don't want to, all of it going to the, umm, because when they tell me that, that if I didn't, they'll charge it so long, and then it will go to my credit records, and then I'm saying, [frantically] wait, wait, wait, let's, let me stop come no more. And see, I'm denied taking those therapies and stuff that I need because I don't have the copay, and that's when it really get bad for us little, little people (Age 54, African American, male, CNA, homeless)."*

C: *And the thing about that, now, is just, when they put it on your credit report, if you're trying to look for work that's suitable, sometimes, [D: Apartment], well that too, so, so the things that they*

kind of tax you under, or the things that they have set up, is like that, like I can't pay for it. Now, you're going to a collection agency now, it's not good, and you know, it's not like I go out there and do it on purpose and go out there and just like, 'oh I'm going to create a bill I know I can't take care of, though I know I have a problem.' So, you know, when that happens, it's just like, I have to kind of keep on keeping on because, you know, if I do this, it's going on my credit report, which, mind the fact, you know, a future job that may come up, I don't know, because some people do, they look at that as whether or not you're going to be a good employee. And so now my health might affect something that futuristically I might get employed at because if I can't go to the doctor, then, you know, then...or if I go to the doctor, then they put it on my credit report, you know, say, you owe, and employers can see that, then, you know, or futuristically down the road, I might have to, like D said, just deal with it, and then, well, if I deal with it and then still get a job, then I'm still dealing with being in the situation that I was, and having a job, but then I'm going to have to go hope, you know, being with them for a certain amount of time until such time that I could probable start going to see a doctor, and you know, affording the care that they're sharking for.

D: *It's a lot of stress 'cause, see, if you don't see a doctor, you die, you don't even have life insurance either. See there is so much, it's just so bad, that they need to shake it down and look at the uh, uh, unprivileged people because so many people getting their pocket greased, that they not, they not paying us no attention. And we the ones scrubbing they floors and doing the little minor things keeping things beautiful.*

Interviewer: *Gotcha, was there any other comments, anything?*

A: *That's connected to another thing called financial health. You feel like you can't afford healthcare, so any other...it comes to the point where, it even make you more sicker. Then you get depressed because you cannot pay all these certain bill that you got coming at you. You know, because you, you're sick, you can't go to the doctor, you can't go to the doctor because you can't afford it, or the quality insurance that they have, so, so, you ain't go no choice but to do, you know, go to work sick. You know, and then, on top of that, you're gonna have even more problems because you sick, you can't work. Then the person that, you know, that's employed you that is at that job, looks at you and see how sick you are, he's going to tell you, hey look, we don't want that kind of mess over here, we're gonna have to get rid of you. And then there you go, you lost your job. [Everyone agrees] And then, you know, the thing happens.*

L: *That's such a cycle too [others chime in agreement] because then you lose your job, and then you really don't have money to pay for the doctor visit, and then it just like...*

D: *It's Catch 22.*

A: *It's a Catch 22 cycle*

This particular narrative is in regards to what is described by members as a Catch-22 as they interact with the healthcare system. In general, a Catch-22 is a situation in which an individual is faced with a series of decisions, which have their own set of diverse outcomes.

However, the problem is that none of the decisions have desirable outcomes. There is also no optimal strategy available to discern the best option. In the end, no matter the decision, the outcome is a losing result.

What these members are describing is the very dilemma Bateson and colleagues describes as a double bind situation in their classic 1956 study of schizophrenia. Since this study, the double bind has been described in many other populations and situations, including those related to family structure and multicultural dilemmas, as well as homeless individuals navigating public spaces (Campbell and Handy 2011, Nagle 2008, Snow 2001). The present double bind, or Catch-22, being described is in relation to paying for needed medical treatment and for other necessities, such as food or housing. However, in this case, it seems that each dilemma leads to another, until the members enter a constant loop of double bind decisions.

In situations such as these, the issue is blatantly obvious: these individuals do not have the money or resources to take part in the systems and processes meant to help them. There is no doubt that, given the appropriate situation, resources, and factors, the individuals would wholeheartedly take part in the treatment plans and healthcare system. Yet, the issue is that they must take into account all of their other needs, such as choosing to pay for healthcare, or another bill, or for food. While these are decisions any individual of the general population may face at any given time, the stakes are significantly higher, as one negative outcome may lead to another, and thus a negatively reinforcing cycle may ensue.

It seems that individuals within the homeless population are at increased risk for entering such cycles, due to their lack of security and safety nets in multiple areas beyond just finances. As participants discussed, the issue of paying for healthcare and income is also connected to employment. In fact, the inability to pay for healthcare, which is connected to diminished health,

can have negative consequences on employability, or even maintaining current employment. This is not to mention the damage to personal credit of an individual chooses to take on the medical bill, but falls behind, which thus has a negative effect on their future employment and housing endeavors.

Such situations seem to produce, both real and self-induced, increased pressures and expectations for individuals to be "hyper-rational" in their decisions compared to the general population. Some may even consider it a character flaw held against someone who cannot take and act on the appropriate solution to the dilemma. This can be considered the "Double Whammy" of a double bind situation, where in the cycle of the double bind, they experience a character assassination, whereby their character is called into question, as in certain conservative media generalizations about the poor.

Even when at a disadvantage, they are almost expected to be better than human. This is a common dilemma in and of itself for those within the homeless community: "how can I be just as good and competitive, or perhaps better than those around me, despite the disadvantages and barriers I face?" In such situations, as participants described, it seems the only route they have to take is the option that, although may still hurt them in the near or distant future, saves them, even temporarily, until the next Catch-22 arrives. There is thus a differential outcome between what they are expected to do, what they know they should do, and what they ultimately end up doing, due to the circumstances they are presented with. Unfortunately, it seems that individuals of this population are faced with many Catch-22 scenarios throughout their daily lives, which puts them in a constant trade-off bind to choose the lesser of evils.

Applying the Healthcare Access Barrier Framework to the Catch-22
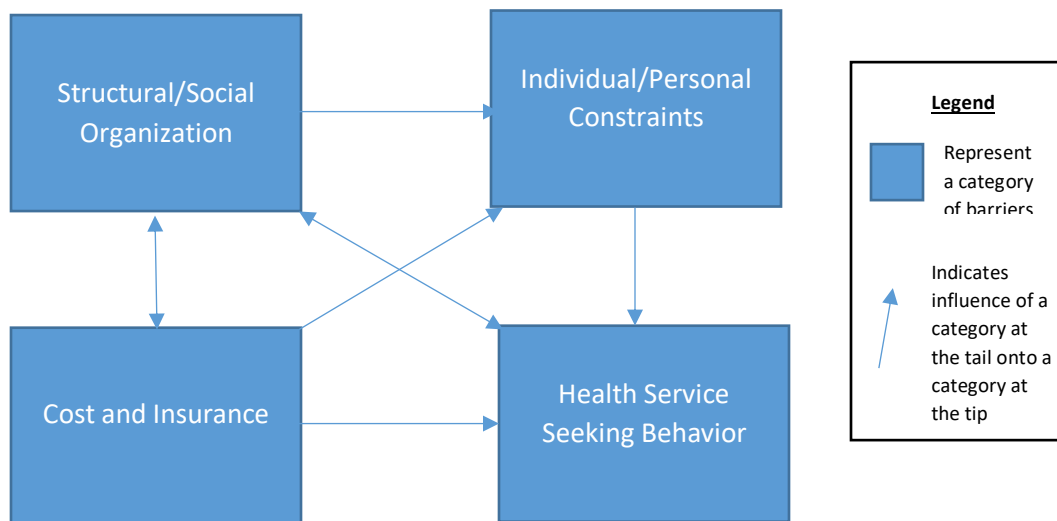

Figure 1b. Healthcare Access Barrier Framework

Following the discussion of the Healthcare Access Barrier Framework and the Catch-22,

I would like to discuss a situation where both a Catch-22 and the Healthcare Access Barrier

Framework apply to a participant's story in order to show just how complex such situations can

become. Here is a review of a participant's story described previously:

"...'Cause I know with myself...I was, uh, I was diagnosed with, umm, with diabetes and blood pressure (I assume he means high blood pressure). The diabetes override the blood pressure (in terms of personal concern/ranking), and I messed around and, and, I umm, and was so concerned about my, umm, diabetes, I didn't treat the blood pressure. And I got very bad off sick. And then, it switched over (laughs), I was more concerned about the blood pressure and messed around and the sugar went about 400 and something (normal: 70-140 mg/dL). See, it's something else with health, because everything that's bothering us, it goes back and forth, back and forth (hand motions like turning a wheel), back and forth...you think you got one controlled, the other one goes (motions a balancing scale tipping)...and it's hard...it's hard. And then you can't afford your medicine... (others agree) (Age 54, African American, male, homeless)."

The first category of Structural/Social Organization influences this situation in regards to

conceptions of health, organization of available healthcare resources, and the moral obligation of

individuals to remain healthy. These have influences on the individual through the

Individual/Personal Constraints category where the member is choosing which health concern to focus on at the time, potentially by using an Economy of Choice model, given their resources and needs at the time. This in turn affects the Health Service Seeking Behavior category where they choose which health issue to treat, while triaging the other for another time. These decisions are influenced by the Personal Constraint category, but also the Cost and Insurance category, which may be limiting their ability to address both health issues, especially in regards to paying for medication.

This personal anecdote has connections to the Catch-22, double bind, discussed previously where the member is having to choose between which two health issues to take care of, when both can have their negative outcomes if delayed or ignored. This is a novel case of the double bind where the decision is not only between healthcare access, cost and something non-healthcare related, but also between two chronic health conditions. The double bind continues to crop up in multiple areas of members' lives in ways that may not have been addressed in past studies. Not only do members have to deal with healthcare access barriers as described by the framework, but also a compounding problem of the double bind, which further amplifies such barriers. When such situations have complex interactions between concepts of Healthcare Access Barriers, the double bind, and Economy of Choice, it may seem nearly impossible to produce interventions that can have positive impacts on these populations. However, rather than being discouraging, it really just shows how it will take more than one intervention in order to solve such problems.

Chapter 8: Interventions to Improve Health and Healthcare Access

After discussing the many different obstacles that can influence and inhibit healthcare access, I believe it only fair to, in turn, review different suggestions for interventions that can help to alleviate, or even remedy, these barriers to access. It is important to note that this is neither an exhaustive review of interventions in existence, nor are they by any means perfect. However, it is important to start somewhere when seeking inspiration for future interventions.

<u>Coordinated Care</u>

One form of intervention, which I am a strong advocate for, is creating a collaborative network between social work facilities with the healthcare system. It is not enough for physicians to simply treat the acute symptoms and illnesses patients present with when they come into a care facility. There must be treatment for systematic and social factors that underlie the conditions they present with at these fragmented and interspaced physician visits. This is where the aid of social workers and case management workers can be of substantial help. Interventions of this form would help address the Structural/Social Organization and Individual/Personal Constraints categories of the Healthcare Access Barrier Framework and their resulting influences on other categories (Figure 1b, 92).

Following their study on mortality of a Philadelphia homeless population, and resulting evidence of health and mortality disparities, Hibbs and colleagues (1994) concluded that any purely therapeutic intervention is unlikely to affect the most common causes of death among homeless. This point strengthens my claim that access to the healthcare system as it presently

exists, is not the only solution to the problem. There needs to be more integration of services to help address the true cause of the health problems, such as life situations, homelessness, and other socially relevant factors.

One such study that highlights the merits of continued care beyond physical health needs is found in Fitzpatrick-Lewis and colleague's (2011) systematic review. Their review focused on literature related to the effectiveness of interventions to improve the health and healthcare utilization of people who were homeless, marginally housed, or at risk of homelessness. They evaluated eighty-four relevant studies for their quality of intervention effectiveness. It was found that, for homeless persons with mental illness, provision of housing upon hospital discharge, as opposed to simply sending them back to the same environment they were in previously, was effective in improving sustained housing in the future.

For homeless individuals with substance abuse issues or concurrent disorders, provision of housing was associated with decreased substance use, relapses from periods of substance abstinence, and health services utilization, and increased housing tenure. Abstinent dependent housing was more effective in supporting housing status, substance abstinence, and improved psychiatric outcomes than non-abstinence dependent housing or no housing.[17] Provision of housing also improved health outcomes among homeless populations with HIV. They also found that health promotion programs can decrease risk behaviors among homeless populations. Indeed, it seems that looking beyond physical ailments, and seeking potential root causes of illness, such as socioeconomic circumstances, can have positive influences on health and healthcare utilization.

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[17] Abstinent dependent housing is a form of transitional housing where abstinence from certain behaviors, such as drug or alcohol usage, are a requirement in order to be admitted into such housing programs (Fitzpatrick-Lewis et al. 2011).

These sentiments are aptly summarized in a letter to the *Science Letter* journal by Dr. Stephen Hwang (2005). In the letter, he discusses his conclusions that challenge public health officials and clinicians to focus on ensuring homeless individuals receive healthcare through coordinated treatment and support designed specifically to their needs and that addresses the specific subgroups that comprise this population, such as homeless or runaway youth, families with children, and homeless women. He also reviews how case management coordinated with other available series effectively improved situations, especially with individuals with mental health issues. However, it is important to keep in mind that such coordinated care can produce its own irony.

Schanzer and colleagues (2007) address this irony in their review of the health statuses of the homeless population in New York in relation to the effects of socioeconomic status on health status, regardless of housing status. What makes the homeless shelter system in NY special is they have primary care and mental health services available on-site in some shelters. This can help explain why some individuals have improved health and access despite the typical statistics that are contrary to this. They also have case workers and benefits counselors who may aid individuals in gaining Medicaid/health insurance and/or other social service benefits. This seems like a positive solution for policymakers to explore. It makes sense to bring the needed services directly to the homeless individuals. However, the irony arises in that it is a shame for people to have to enter the shelter system first, before they finally experience improvements in health status and increased access to healthcare. These services should become available to individuals before they reach this state (Schanzer et al. 2007).

<center>Cost and Insurance</center>

Following the issues of insurance and cost, there is hope. After the passing of the Affordable Care Act of 2010[18], the resulting gap in coverage was noticed by states that did not expand. States have thus begun to take steps to address this gap. One option they have is to submit a "Medicaid Expansion Waiver," which, once approved, would give them access to federal funds to create their own custom expansion plan. States that have approved and implemented such custom expansion plans include Arkansas, Iowa, Michigan, Pennsylvania, Utah, and New Hampshire (Garber & Collins 2014).

One of the primary, and arguably intuitive, methods to solve the issue of cost is insurance reform specifically related to coverage criteria. In 2011, Meng and colleagues produced an article that details the various strategies that governments have used to help expand insurance coverage to targeted populations of vulnerable groups. These groups include rural and low-income populations. They followed a framework to organize documents found from numerous databases and created inclusion criteria to help focus the information. Ultimately, they found six common categories for strategies that were often used to expand coverage to individuals. The primary limitation of this study is that it is only preliminary research into what strategies exist. It does not discuss the effectiveness of the strategies or evaluate which has had the most impact. It does, however, help show that interventions that were reviewed have a positive effect on expanding the coverage of health plans. This is key to providing evidence that the problem of insurance coverage can potentially be fixed if the right strategies are implemented.

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[18] Effective as of the final version of this thesis, the ACA was still active. However, it was being debated for repeal in the spring of 2017. If the ACA is repealed with no substitute for dropped Medicaid coverage that the ACA made possible, we can predict a deterioration in the health status of homeless and other low-income populations in the affected states.

The six common categories for strategies used to expand coverage to individuals were as follows: 1) Modifying the eligibility criteria. This means increasing income threshold for entering into health insurance and expanding the categories of eligible population groups, such as to include refugees, immigrants, and other vulnerable populations. 2) Increasing the awareness of schemes and their benefits. This is typically achieved through mass media campaigns that specifically address the changes and benefits available to target populations. It also seems worthwhile to cover specific venues and locations target populations congregate (e.g. churches, homeless shelters, social services offices). 3) Making the premium affordable. This could be through the use of subsidies or setting suitable levels to make insurance affordable for eligible populations. This would work if the government or another organization would directly or indirectly contribute all or part of premiums for eligible population. These contributions could consist of paying premiums, offering tax credit to subsidize eligible populations indirectly, or even donations to pay premiums for those in need. Another method could be sliding scale premiums, where they are set based on income level of the target population (Meng et al. 2011).

4) Simplifying enrollment procedures (forms, policies, requirements), and integrating sources for enrollment through partnerships with other organizations to facilitate enrollment. 5) Improving healthcare delivery by covering a wide range of healthcare, controlling price of services covered, and improving quality of care. This includes adjusting the co-payment, deductible, and adjusting cost ceilings. 6) Improving the management and organization of insurance programs. This includes improving information systems for measurement of eligible population, enrollment, and management of schemes, along with improved staff training for more effective outreach and running of programs. It may also be beneficial for insured

population to engage with the design of insurance schemes to ensure their effective administration (Meng et al. 2011).

While each of these strategies have been utilized in some capacity of another by different governmental bodies, it seems that the most common combination of these strategies used are strategy 3, 5 and 6. These trends make sense because they work with patients by making insurance more affordable, while also increasing the coverage and procedures they offer. This makes insurance more appealing, accessible, and worthwhile. It is also important as they streamline the information processing systems related to enrollment, outreach, and implementing insurance programs to ensure their effectiveness.

This argument for insurance coverage expansion is also in agreement with the findings of the National Women's Law Center review of the Behavioral Risk Factor Surveillance System (BRFSS) survey (2014). They concluded that low-income women's health could be dramatically improved if all states would expand Medicaid coverage. Cost is a major barrier that prevents women usage of preventative services, health screenings, and regular check-ups, which all contribute to better health outcomes. Without these resources, women's health can worsen because these services help catch illnesses early, treat and cure them, while also connecting patients to appropriate specialty services if they need them. Uninsured, low-income women, without a regular health service provider are often disconnected and have increased difficulties accessing the healthcare service network as a result.

While it has been observed that there is a relationship between this issue of homelessness and lack of Medicaid insurance, it is important to stress that the solution is not as simple as fixing insurance coverage issues (Folsom et al. 2005; Hayes et al. 2015). This is due to the numerous factors and barriers that reach beyond the economic realm. Many have been discussed

previously in former sections. It is a complex issue that requires more research. Folsom and colleagues (2005) suggest a potential avenue for solution development is to test the effects of specific interventions designed to treat patients with dual diagnoses and to assist homeless persons with serious mental illness in obtaining and maintaining entitlement benefits.

A participant also had an interesting idea related to insurance, or at least another way in which it could work:

"Though I know with insurance, you're paying X amount of dollars I guess into it. So, I mean, I'm kind of, like, you know, as much as you pay into it, I guess, it seems like, it should almost be like a bank account, sort of, like you building up, saying, well, you have X amount of dollars that, that you build up, and, you know, your bill was this, so we can alleviate this amount. As, you know, because this is what you basically built up to (Age 46, Caucasian, male, homeless)."

While this method has issues of its own, and would definitely change the general function of insurance, it is an interesting way to imagine insurance, and perhaps may contain a novel way to bring the systemic problem towards a more holistic solution.[19]

E-Health

With the constantly advancing and changing technology of this age, it seems only natural that healthcare would take on a virtual aspect. In their 2008 study, Baur provides an analysis of this new form of healthcare, called E-health, specifically related to its merits and disparities. E-health is essentially the availability of health-related information over the Internet and in digital

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[19] There are actually programs similar to this idea available called "Flexible Spending Account (FSA)" and "Health Savings Account (HSA)." FSA's are provided by employer health plans and are used to, pay for copayments, deductibles, some drugs, and some other healthcare costs. Using such accounts can also reduce an individual's taxes. The primary restriction is that the funds must be used within the year the funds are set aside. HSA's are savings account which allow money to be set aside, on a pre-tax basis, to pay for qualified medical expenses for those with high deductible health insurance plans (U.S. Centers for Medicare & Medicaid Services). The inherent issue with these accounts are that they require either employment or health insurance, which makes them potentially inaccessible to low-income and homeless individuals. Further still, even if individuals are able to open the accounts, they may not have sufficient funds to invest in such savings accounts because they have to spend them on something else they need in the present. These are additional examples of programs which give preference for those in higher socioeconomic situations which is inaccessible to certain populations.

forms. This can be in the form of individuals performing search engine inquiries or individuals

coordinating with medical professionals through online accounts and accessing their patient

histories. Such developments have the potential to have positive effects on the

Individual/Personal Constraints and Health Service Seeking Behavior categories of the

Healthcare Access Barrier Framework, in addition to their resulting influences on other

categories (Figure 1b, 92).

A number of participants mentioned that they had used the internet to look up different

symptoms for an illness of advice on a certain health concern.

"I have done that, yeah. I do, I'm just starting to do that. Actually, I do look up a lot of stuff online. That's what occurred with this question about is this my kidneys, or what not. I actually went online and looked up symptoms for kidney failure (Age 54, African American, male, writer, homeless)."

"I thought I wasn't one to, umm, get diabetes, because I'm also a diabetic, umm......I didn't realize that I had it, but, normally, I umm, was looking at my left foot, and it was getting swollen, and swollen. I don't know what the cause of it was, or what it was, because normally, you know, when I do my research, you know, mostly I didn't really read about diabetes, or anything like that (Age 43, African American, male, homeless)."

"My sister started having problems with diabetes, so I looked on the Internet, and I saw that lemons help with diabetes, or help to stop the diabetes. So, I told my oldest brother and my sister to drink lemonade with honey (Age 43, African American, female, apartment rental)."

The primary problem is equitable access to technology and the Internet. This is

commonly known as the "digital divide" which has sparked many "digital inclusion" movements

with efforts to broaden access to populations with targeted interventions. However, another

disparity is health literacy, where even if people have access to health information, less than half

of all adults can understand or use the information. Despite the disparities, e-health has the

potential to empower individuals and communities to take responsibility and control of their

health and safety by providing them with the information they need to understand their health

(Baur 2008).

The healthcare system today is information intensive with exchange between patients, consumers, healthcare providers, and public health systems. This movement coincides with public policy pushes for communities and individuals to take greater responsibility for their health and safety. This is especially true considering those with the most limited understanding of their health information also have the highest levels of poor self-reported health (Baur 2008). In essence, as Baur (2008) put it, "meaningful access and health literacy share a fundamental principle: people have the right to the technology tools and information they need to achieve their goals."

It seems that the primary limitation for E-health is lack of resources and knowledge to obtain and maintain technology. This includes not only physical access, but also skills and knowledge of technology. Nearly a third of the adult population does not live in a household with Internet access, nor use it anywhere else. This can be due to not only cost, but also lack of experience with technology, or even negative attitudes towards the technology. This can also be related to limited knowledge on how to navigate the systems, filling out forms, literacy, language barriers, and interpreting search result reliability.

The secondary limitation, again, is with health literacy, or the ability to obtain, process, and understand basic health information and services to make appropriate health decisions (Baur 2008). Indeed, there seems to be demographic factors of age, race, education, and income that influence health information seeking behavior. It has been observed that 70% of women versus 57.5% of men and 55% of postgraduate versus 23% of high school graduates seek out health information (Baur 2008).

Although health information and services are still primarily accessible in non-digital forms, I still wanted to cover this emerging field of medicine because it is a growing option for

healthcare interventions. This is especially important as it is anticipated that the entire population

will eventually need to engage, on some level, with e-health to participate in the information-

intensive healthcare system (Baur 2008). It has its own merits and issues that I find interesting.

Members in my focus group talked about learning about health issues, and remedies, by

engaging with media and online searches. Therefore, I believe this to be a relevant topic to cover.

Chapter 9: The Right to Healthcare

Why am I, along with other researchers and policy makers, concerned with identifying barriers to healthcare? I believe it is rooted in the debate regarding how a fair healthcare system could exist where everyone has equal access to services needed. Perhaps it is a belief in a duty to provide healthcare to all and subsequently the right to healthcare? If such a thing exists, it is important to discuss the responsibilities we have for protecting it, and the consequences and costs thereof.

To close out my discussion of results and research, I wanted to provide a review of this controversial debate that is intimately related to this study. This debate is in regards to the existence of the right to healthcare. I use the information from the eleventh chapter, "Dividing Up Health Care Resources," of Vaughn's *Bioethics* (2010), to inform my discussion. My point is to merely raise awareness of this issue, rather than weigh in on the debate itself, in order to continue the discussion by inspiring readers with an overview of the conversation. This is an interesting controversy because, although it seems many people think people have a right to healthcare, they do not know exactly how such a system could be implemented or work.

The first question this topic is concerned with is, "are the needy due only the healthcare they can afford?" Is it fair and just for the cost of the services of healthcare to be the deciding and limiting factor for if people are able to use said services? Even if what they can afford is nothing? Some would say that this is not morally acceptable, and is an injustice. If this is so, then is society obligated to provide more? What exactly are individuals entitled to then? Perhaps there

is a decent minimum? It seems the issue boils down to whom should receive healthcare, who should provide it, and who should pay for it.

It is also a truism that cost does in fact restrict how much can be delivered and how much can be obtained. So how much would it cost to provide universal health insurance in the US? In 2006, one estimate was that it would cost about $48 billion per year to extend coverage to the nation's 46 million uninsured (Clemmitt 2006: 297). The good news is some economists argue that majority of the bill could be alleviated by other economic gains and that continuing to cover only a small number of the uninsured could be costlier.

Despite this, some argue that universal coverage would increase demand for services and result in increased spending. Yet others disagree, arguing that universal coverage would free up tens of billions of dollars of funding once programs that specifically fund uninsured care, were dismantled. These funds could then be redirected to subsidizing universal coverage and reducing spending. An expert government panel estimated that covering the uninsured would create $65 billion to $130 billion worth of improved health and productivity annually, more than enough to make the cost of coverage worthwhile (Clemmitt 200). Indeed, every country with universal coverage spends less on healthcare than the United States because their governments have incentives to keep costs low. This is accomplished by only paying for effective treatments and negotiating price cuts from suppliers and health providers (Clemmitt 2006).[20]

Ultimately, every participant voiced an agreement that such a right to healthcare exists and should be guaranteed. This is because of the belief that people should not be allowed to suffer or continue to be sick, especially due to financial reasons.

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[20] Boychuk (2009) provides a comparative analysis between the United States' and Canada's healthcare systems, where Canada developed a universal single-payer system of national healthcare, while the United States took on a dual system of public health and private insurance. They describe the background histories which led to these policies and how they have affected social and political structures of the countries.

"Yeah, I think so. Certain plans that you're in, you're restricted to who you can see [HMOs and PPO] or what hospital you can go to. I think they should do away with that. I think that you should be able to go to any hospital, see any doctor you want to see. So that's my view, that's the way I think it should be (Age 63, African American, male, apartment rental)."

"I feel like, you know, in the context of the first world, or you know, humanity, umm, people have a right to healthcare. Umm, you know, uh, in a first world country like this, umm, with so much wealth, certainly people's healthcare should be utmost concern for everyone involved. A right to not suffer with, uh, problems because financially they're strapped, or because they're intimidated by overwhelming system, umm, yeah. I feel that people have a right to healthcare...it's better, it's better for everyone, if, umm, healthcare is, umm, aggressively, umm, at the forefront of everyone's minds. It's just better for families, households, and general well-being (Age 54, African American, male, writer, homeless)."

"All the medical organizations, I guess, they have a kind of financial aid, or kind of organizations, where they can help too, to get human health. So there's a right public health. The humans, we have a rights to be in the health service (Age 59, Latina, female, apartment rental)."

For many people, it seems all too logical or almost unquestionable that such a right exists, yet why is this so? Some call this an issue of justice. Justice, in the most general sense, refers to people obtaining what is fair or what is their due. Essentially, equals should be treated equally, unless there is a morally relevant reason to be treated differently. How this should be carried out often depends on which group philosophy one chooses to align with. From a libertarian perspective, healthcare should be distributed fairly through fair workings of a free market, where the government has no obligation to distribute benefits, and individuals are responsible. Essentially, people are equal in rights and worth, but they are entitled to fair, not equal, distribution of society's benefits.

For libertarians, there is no right to healthcare. This is similar to support for John Rawls' principle of "fair equality for opportunity," which states that, while everyone is entitled to an equal chance to obtain the basic goods of society, there is no guarantee of an equal share of them. However, it begs the question how absolute this viewpoint is, such as when dealing with children's rights to healthcare, considering they cannot control the parental socioeconomic situations into which they are born. Yet, if they accepted this exception, it would be problematic

to place an age limit on a right to healthcare in light of the daunting task of choosing agreeable criteria to demark such a hard line. Further still, it can be argued that healthcare preserves for individuals the range of opportunities we would have, were we not ill or disabled, given our talents and skills. Since people are entitled to fair equality of opportunity, and adequate healthcare protects/restores normal range of opportunities, they have a positive right to adequate healthcare. But what would this right include?

From a utilitarian point of view, there should be a just distribution of healthcare that maximizes the net good (utility) for society. In this way, some of society's resources are more beneficial overall than others. Just allocation of healthcare alone can take several forms depending on the factors related to society's resources, needs, and likely effects of policies and programs. A utilitarian may endorse universal healthcare insurance, or a qualified right to healthcare, or two-tiered plan. The latter is one in which government supported health insurance is combined with the option of privately purchased health coverage for those who can afford it. This is similar to how the US healthcare system currently functions.

Finally, from an egalitarian perspective, important benefits and burdens of society should be equally distributed. They are also not averse to mandating changes to the distribution of society's goods or to interfering in the workings of a free market to preserve equality. This means that it is not inappropriate for a government or power to intervene or provide benefits or assistance. An egalitarian would approve of systems that give access to legitimate forms of healthcare, offer guaranteed minimal level of healthcare for everyone, or that provide care only to those most in need.

Some reject the idea of a bare minimum. However, it must be acknowledged that the option is attractive. This is because it initially makes sense that not every service is needed by

everyone all the time, and a limit must be placed somewhere because of limited resources. The issue is where to place the floor, rather than the ceiling, on services. What is a decent minimum then? It is apparent that universal access to all available resources at all times is not economically feasible. Perhaps a decent minimum which could be publicly available and supported, and guaranteed for all first-tier services while the remaining second or higher tiers could be reserved for additional services and non-essential therapies?

People can agree, it would be good for everyone to have adequate healthcare, or that beneficence may justify society's providing healthcare to the neediest, or that making particular kinds of healthcare available to certain groups may produce a net benefit for society. These programs or policies which create a net benefit for society are actually called "Positive Externalities," where certain actions can cause positive effects external to the intended effects of the action. This concept has been shown to be active in multiple disciplines, including economics, public policy, and the social sciences (Brose at el. 2010, Cheung 2013 and Yamamura 2011).[21] However, some take it a step further and call for a right. The issue is that rights impose duties on others. These duties include not interfering with that person's obtaining of something and duties to help that person in their efforts to obtain something.

Perhaps there is no right, but there is still a societal duty to provide a decent minimum? Perhaps there should be a forced tax to provide to the poor, not in the name of egalitarian justice, but for the simple sake of beneficence? This is especially due to, as Allen Buchanan put it, "healthcare's good in producing productive labor force and improved fitness of the citizenry for

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[21] Brose et al. (2012) discusses the environmental and socioeconomic externalities that arise from agricultural bioenergy. Cheung (2013) found a positive externality from public policies implements in Hong Kong increased social inclusiveness due to the perceptions of the population regarding the policies. Ironically, Yamamura (2011) found positive externalities in traffic congestion which lead to increased physical activity and decreased chronic illness in the Japanese population.

national defense (Vaughn 2010)." Whatever the answer to these philosophical, moral, and ethical dilemmas are, it is clear that there is a lot of work to be done and decisions to be made whether a right to healthcare is established or not.

This is an incredibly controversial matter due to the implications of the implementation of both sides of the argument. Here, without being able to resolve all of these issues of a universal right to healthcare raises, I will only express my values that, with all of the resources, knowledge, and aspirations of the populations which reside within the United States, we owe it to ourselves to provide our inhabitants with healthy bodies and environments. We therefore should not continue to endorse a system which limits who can utilize it and essentially chooses who gets to be healthy, and who does not, without having to vault over so many barriers.

Whether it's through public health awareness campaigns, investment into preventative care measures, environmental health programs and education, or increasing access to healthcare, everyone deserves to be able to take on any dream they have, and be unhindered by the states of their bodily health, as long as we have the means to intervene. Regardless of rights, debates, opinions, or laws, issues of health disparities have indeed been identified and well documented for multiple groups and populations inside the United States. Therefore, it is our responsibility to work towards alleviating these differences and solving the problems that cause them. It will not be easy, but something must be done about it.

Chapter 10: Conclusion

CEF Member Discussions of Health

Following this discussion about the broader implications of healthcare barriers within the US Healthcare system, why does it matter how members perceive their access to healthcare or how often they bring up their health in meetings? The answer lies in where CEF fits into this dynamic system. To its members, CEF acts as a gateway and collaborative hand to help members achieve their goals by providing them with information, resources, and connections necessary to make such goals obtainable. It is not a paternalistic relationship, but a mutualistic relationship, one where members make their own decisions and choose which paths to take, with the advice and support of advocates. These approaches and actions are taken to make the services as accessible as possible and make the results that much more fulfilling for the individuals which reach their goals. It is truly the members, not the advocates or some other beneficent power, which achieved their goals.

This is in contrast to the healthcare system that is inherently paternalistic due to the knowledge, reputation, resource, and social power differential between healthcare providers and patients. This is not necessarily a completely negative reality, it just has its problems related to accessibility, welcomeness, and health literacy. When individuals enter into the healthcare system, they can potentially lose their autonomy and identity as they are medicalized, and the outcome, positive or negative, is attributed to the medical personnel's efforts, and not the

patient's.[22] CEF is a free, non-profit organization, which never turns away any individual who is willing to make the commitment to work towards their goals. This is in contrast to the healthcare system, which understandably cannot be instantly made free to consumers without considerable change in policy and the reconciling of controversy. Unfortunately, such a system may turn away individuals who need help due to cost, or may even inadvertently worsen their social or economic health due to debt and damage to credit.

By providing such a system which has fewer barriers, and an empowering model for member-advocate relationships, and a social network which connects members to the resources they require, CEF stands as a place of hope and support which members may begin to use to improve their lives. Understanding how members perceive their health, healthcare access, and why or how they discuss their health in meetings can potentially help show the difference CEF is making regarding member health and healthcare access. By supporting members, not only by providing them with resources and connections to overcome bureaucratic hurdles, but also by increasing their autonomy and empowerment as individuals with positive identities, perhaps CEF can, and perhaps does in fact, affect members' health identities within the broader healthcare system and facilitate an increase in healthcare resource utilization by increasing direct access by removing personal constraints and increasing health service seeking behavior.

<div align="center">Research Limitations</div>

The primary limitation for this project is the overall size of the participant pool, which was comprised of nine members of CEF. This means that potentially not all possible viewpoints

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[22] Such issues of paternalism and loss of autonomy have lessened in their effects as stricter guidelines regarding patient rights and autonomy have been established. However, even these efforts are limited if patients are not aware of their rights, or do not understand their rights when faced with such power differentials listed above. The practices and discourse within healthcare facilities can work to lessen such negative consequences.

and perspectives held by members regarding the issue of healthcare access were able to be included in this analysis. There is also room for questioning how generalizable the responses of the nine individuals are to the general population. However, as I have described throughout, participant responses were similar to those found in other homeless and low-income populations in studies performed by other researchers.

Another limitation is that this study was unable to perform a thorough mixed methods analysis of both qualitative and quantitative data regarding the issue as planned. Originally, the survey section was going to further support the interview and focus group responses and create a larger model of the CEF population. It was also going to support the CEF intake statistics through comparative analysis to the survey results. However, as previously described the survey portion was unable to be completed due to unforeseen circumstances and complications. It is for this reason that a copy of the survey is being included in the Appendix for reference and use in future studies regarding healthcare access.

Another limitation is that this study was unable to determine if there is a difference in how those in low-income and homeless situations perceive their healthcare access and their experience with the healthcare system. This was due to the demographics of the small population studied. However, this is a serious gap in the literature regarding this issue of healthcare access that should be addressed. This is because not all low-income individuals are homeless and thus they are two distinct groups that may potentially have different experiences and views on the healthcare and their relative access to it.

<u>General Conclusions</u>

Despite these limitations, this project was successful with many of its goals. This study was able to determine and describe how members of the nonprofit, CEF, use, access, and

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perceive their healthcare access. This was through the use of a framework to organize the different levels of the healthcare access process that could affect individuals' ability to engage with health resources.

Access problems often began at the personal level with a conflict between time and individual resources, such as income, and social networks. These were followed by differing perceptions of what symptoms or illnesses require a visit to a medical provider, to a relative or friend, or are simply incorporated into a sense of normal. Other reasons included a sense of welcomeness in a medical setting due to past experiences and perceptions of discrimination and stigma against an individual's situation. The next level of problems was with the healthcare system organization itself and its processes, such as paperwork, information exchanges, and professional school curricula, which can inhibit a person's ability to successfully enter and navigate the healthcare system. Finally, as most politicians and policymakers make clear, cost of healthcare and insurance were powerful barriers to healthcare.

Following these, this study also compared CEF member responses to the other studies and projects which have delved into this issue in order to show that multiple populations around the US do indeed have similar issues with healthcare access. This is not an isolated incidence, nor has it been solved yet, despite the efforts of policy and lawmakers. This is where the final sections regarding potential interventions and solutions came into play. They are suggestions and potential avenues which could be explored, individually, or in tandem with one another, to try to make progress towards alleviating the barriers found throughout the experience of negotiating the healthcare system. These range from expanding health insurance program eligibility, investing in E-health, adjusting the healthcare system organization in regards to paperwork and health costs, and coordinating care between health and social work facilities. However, this is not

an extensive list. Regardless, the point of the intervention section was to give hope in the face of all these obstacles that prevent equal access to healthcare.

It will not be the wave of a wand or the passing of a single law that will solve healthcare access disparities. It will be through the collaborating efforts of those that are willing to uncover, understand, and use this growing body of knowledge to implement new and effective programs to ensure that every individual can enjoy the benefits of healthcare. This will be accomplished through, not only policy and law changes, but also social changes. This is because there are systemic problems at the governmental, administrative, and social levels of healthcare, which all need reform.

Perhaps it will come as a reform through making universal healthcare a reality? Maybe it will be done by reconciling with and ensuring a right to healthcare? Whatever form it may take, the first step is identifying and understanding every angle to the problem so that a holistic and entirely inclusive body of solutions can be established. No one should be allowed to slip through the cracks or be left in a coverage gap which makes it impossible to access healthcare. It is a daunting task, but I believe we have the potential, and the responsibility, to make it happen.

<div align="center">Directions for Further Research</div>

One area of study that could follow this project is a comparative analysis to determine if there is a difference in how those in low-income situations, but in permanent housing, perceive their healthcare access and experiences with the healthcare system compared to those who are low-income and homeless. There is a serious gap in the literature regarding the differences in experiences between these two populations because they are often pooled together into a singular group. This is an important area in need of research because not all low-income individuals are homeless which means that the two form distinct groups and therefore may potentially have

different experiences and views regarding healthcare and their relative access to it. These differences could complicate certain efforts to alleviate barriers to healthcare access. They could also reveal additional barriers, or caveats to barriers already identified, which can ultimately develop a more comprehensive representation of the issue as a whole.

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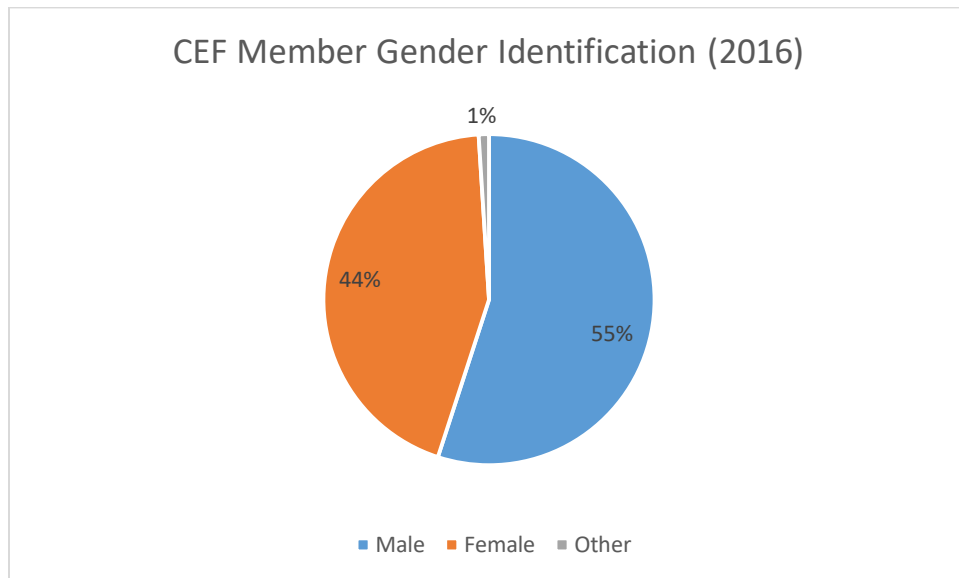CEF Member Demographic Charts and Figures

Figure 2. The figure above displays the gender breakdown of the reported gender identification of CEF members based on their initial intake forms that are administered when individuals first decide to actively engage with CEF. (N = 339).
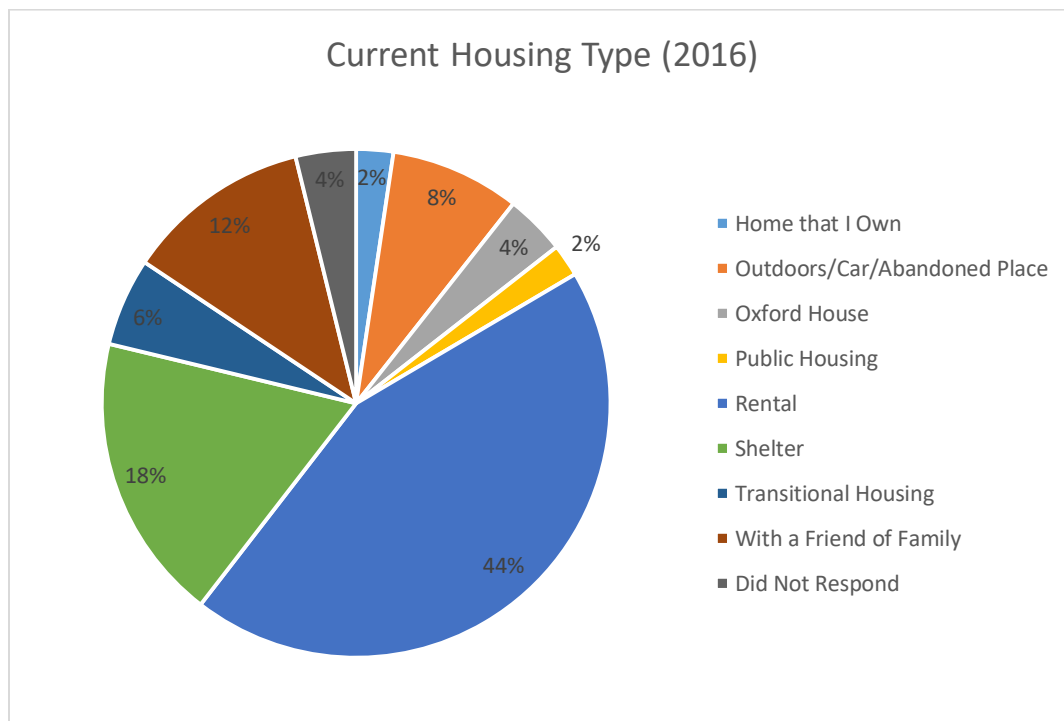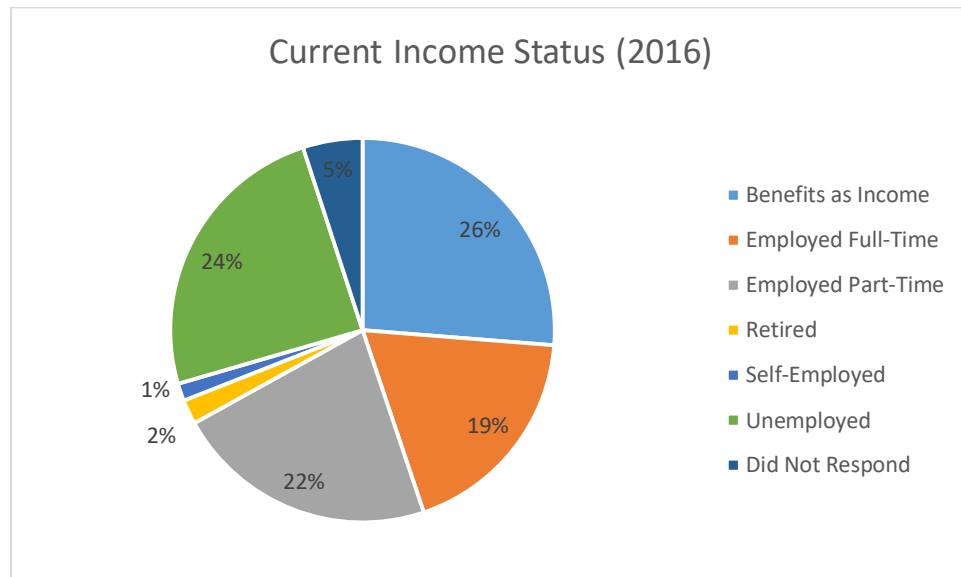

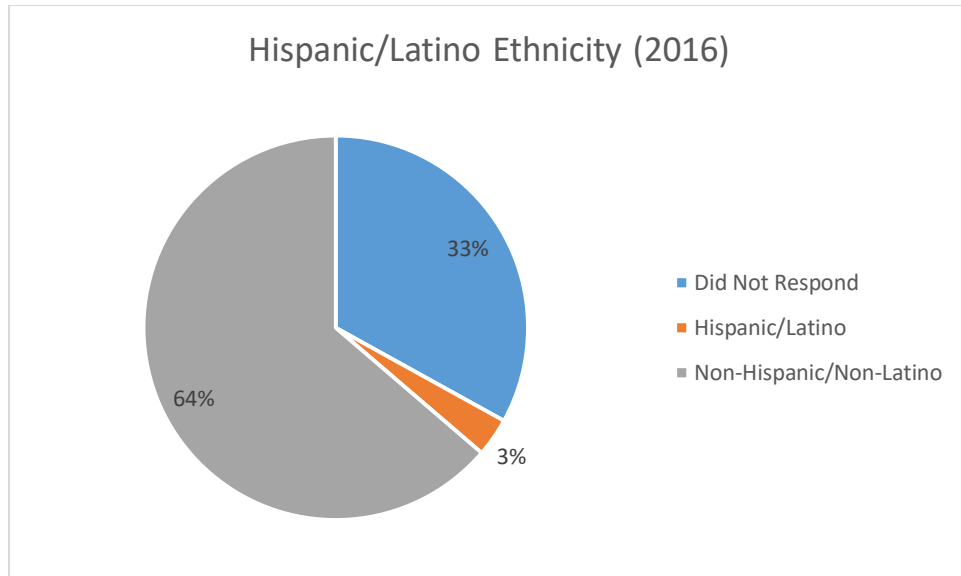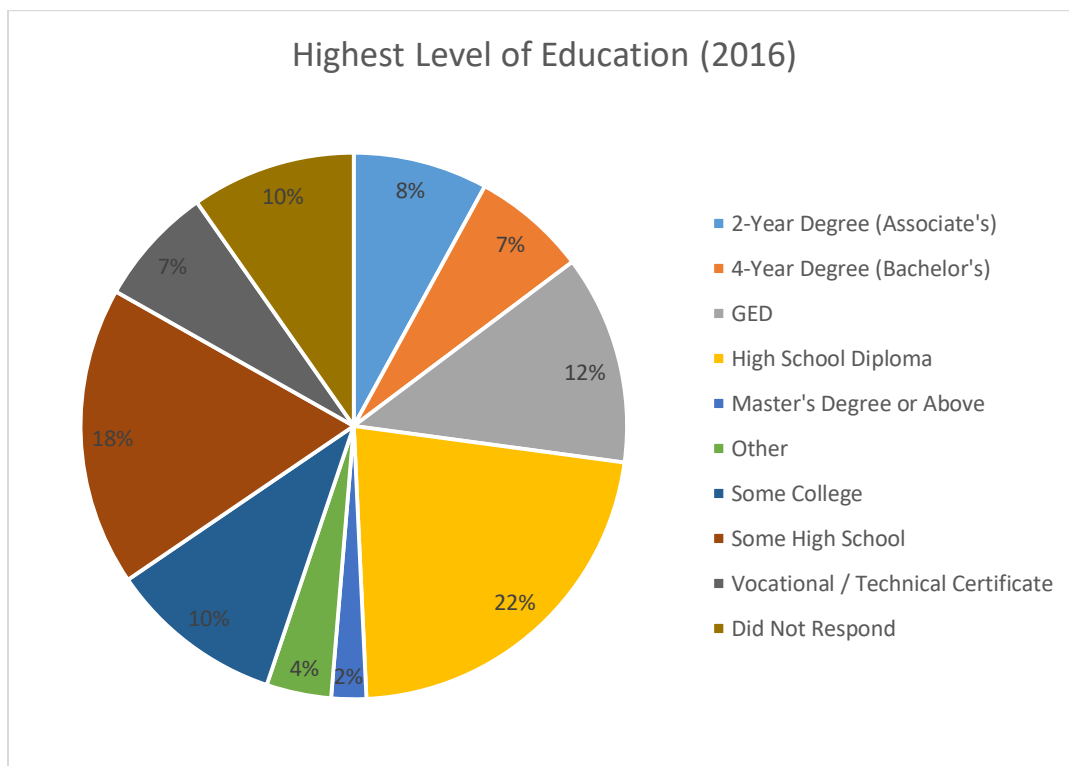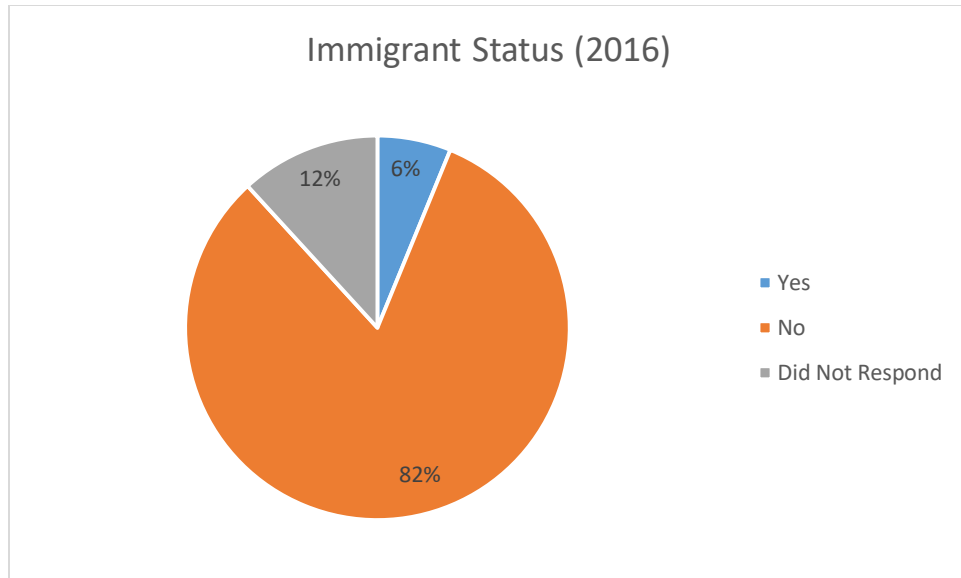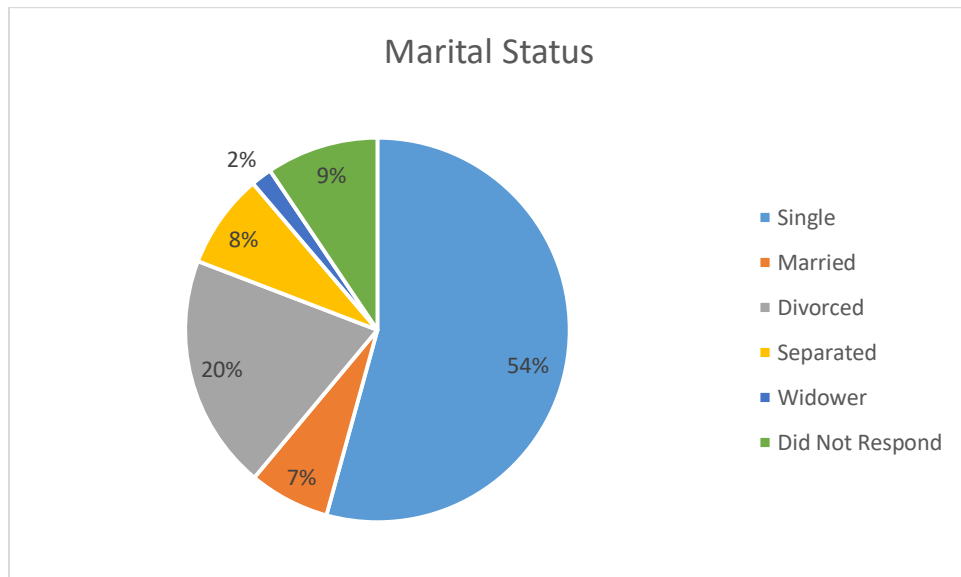**Figure 3.** The figure above displays the housing breakdown of CEF members based on their initial intake forms that are administered when individuals first decide to actively engage with

CEF, as well as monthly updates administered when members come into the office for a meeting (N= 339).

Figure 4. The figure above displays the current income status of CEF members based on their initial intake forms that are administer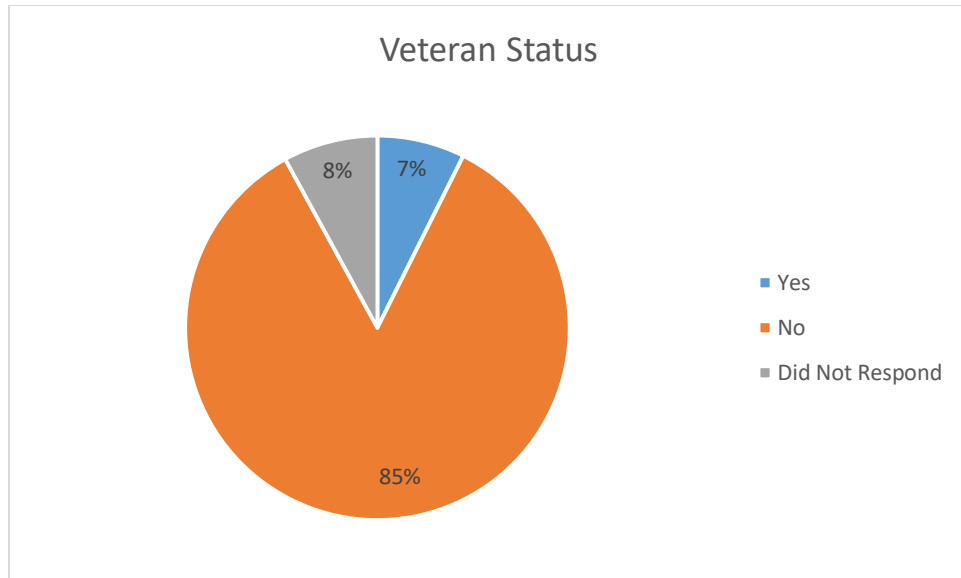ed when individuals first decide to actively engage with CEF, as well as monthly updates administered when members come into the office for a meeting (N= 339).
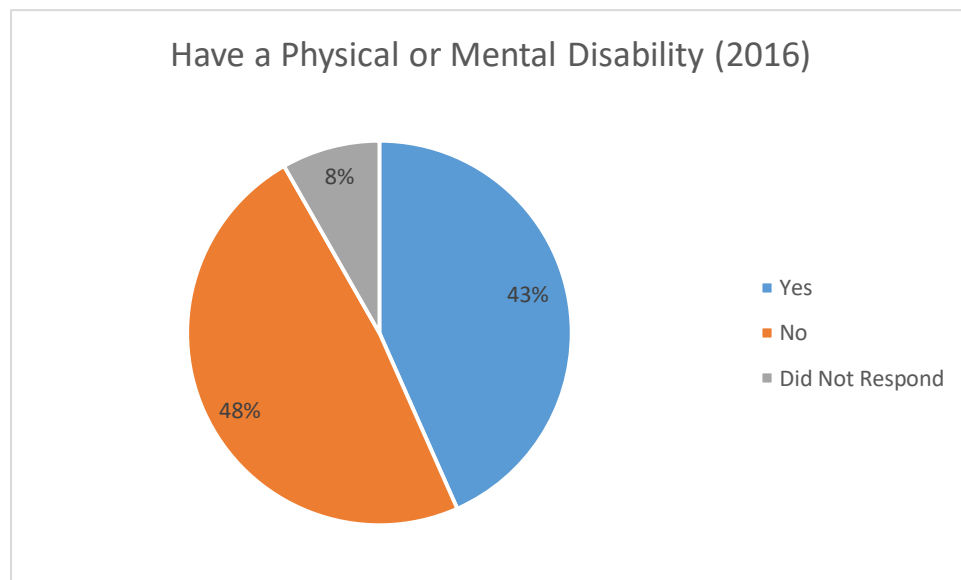
Figure 5. The figure above displays the proportions of CEF members that identified as having a disability, or not, on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Figure 6. The figure above displays the proportions of CEF members that identified as with Hispanic/Latino ethnicity, or not, on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

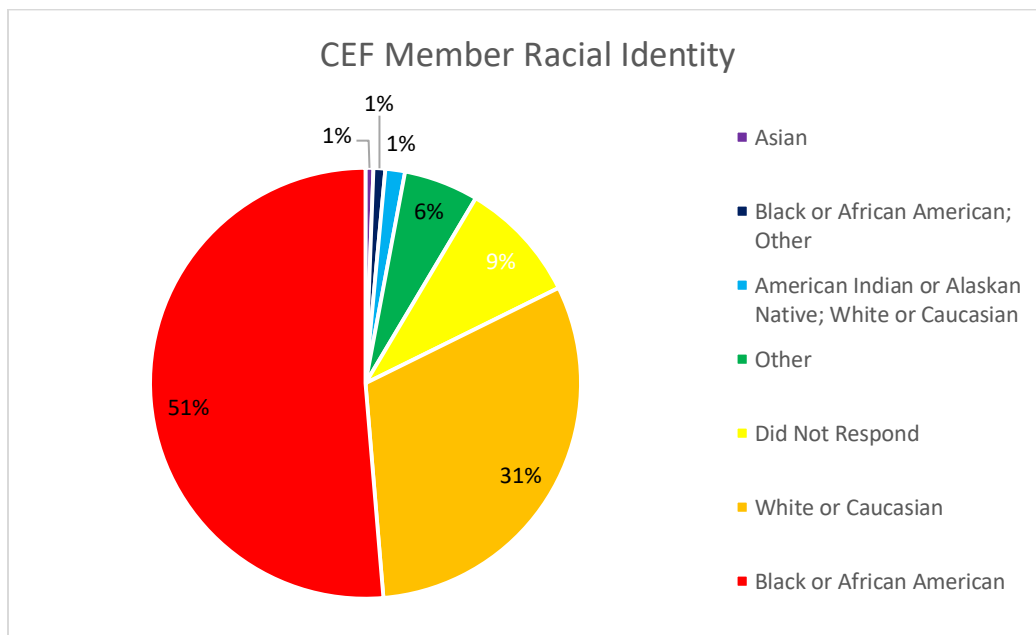**Figure 7.** The figure above displays the different proportions of education obtained by CEF members identified on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Figure 8. The figure above displays the different proportions of CEF members that identified as an immigrant (not born in the US) on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Figure 9. The figure above displays the marital status of CEF member on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Figure 10. The figure above displays the veteran status of CEF member on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Figure 11. The figure above displays the racial identity distribution of CEF member on their initial intake forms that are administered when individuals first decide to actively engage with CEF (N= 339).

Methodology Materials

This section contains the literature, scripts, and interview schedule utilized during this research project.

Interview Schedule

1. What does the word "health" mean to you? What does "good health" mean?
2. How often do you think about your personal health?
3. When you do think about it, what comes to mind?
4. Where does your personal health rank in relation to getting a job, finding housing, or any of your other primary goals or concerns?
5. What parts of your general, personal health are most important to you? Why?
    a. Ex. weight, exercise, diet, cholesterol, etc.
6. How would you rate your health on average?
7. How often do you feel sick?
8. Have you ever brought up health or healthcare in a CEF meeting?
9. Do you have any illnesses or disabilities that affect your daily life or require you to purchase medications or other forms of treatment?
    a. Physical, Mental, Acute, Chronic
        i. Ex. Diabetes, chronic pain from previous injury, depression, addiction, etc.
        ii. How do you obtain your medication?
10. When was the last time you saw a healthcare professional?
    a. What were your feelings regarding this visit and its outcome?
    b. What are your general feelings or outlook regarding healthcare?
        i. (Ex. Is it helpful to you? Do you feel you receive adequate help and care if/when you go?)
11. How accessible do you perceive healthcare resources are for you?
    a. How easy is it for you to go to the doctor?
    b. What are some of the factors that limit/inhibit your healthcare access?
12. Do you have a general strategy for accessing healthcare services?
13. What is the most common illness or sickness that you feel you experience?
    a. Others around you experience?
14. What is your general criteria to decide if you need seek out medical attention?
15. Where do you go when you get sick or need medical attention (both emergency and general medical needs)?
16. What constitutes an emergency? What determines a regular/non-emergency visit?
    a. How do you know when something is an emergency that needs to be addressed ASAP vs. can wait a few days?
17. Who do you reach out to for health and medical advice (if not a medical professional)?
    a. Ex. friend, relative, doctor, etc.
18. What are your thoughts on the medical/healthcare system?
    a. Related to quality of care, access, cost, treatment, etc.?
19. What are your thought on a "Right to Healthcare?"

Healthcare Access Survey

<u>Study Description</u>: The purpose of this research study is to understand how members of CEF think about their personal health and the health of those around them. This study also seeks to find out the extent CEF members use and access healthcare resources as well as how they perceive their access to healthcare. Your responsibility as a participant is to answer the following questions as thoroughly and truthfully as you can, based on your own personal experiences and opinions. All responses are confidential and will in no way be connected back to a specific individual.

<u>General Health Questions</u>

In the section below, please **<u>Check</u>** or **<u>Fill-in</u>** a response to each question with the best answer that matches your personal experiences and opinions.

1. Do you have any illness or disabilities that affect your daily life?

⬭	Yes
⬭	No
⬭	Prefer not to say

2. Does this illness or disability require you to purchase medications or other forms of treatment?

⬭	Yes
⬭	No
⬭	N/A
⬭	Prefer not to say

3. How often do you think about your personal health? (Best estimate)

⬭	Daily
⬭	Weekly
⬭	Monthly
⬭	Rarely
⬭	Prefer not to say
⬭	Other:

4. List your personal goals and then rank them from most important (1) to least important (5) by clicking and dragging the text boxes. (Ex. Finding a job, housing, savings, etc.) (If you prefer not to say, please list "Prefer not to say" or N/A in the spaces provided))
   Goal 1:
   Goal 2:
   Goal 3:
   Goal 4:
   Goal 5:

5. How accessible do you think healthcare services are for you? (How easy is it for you to see a doctor or get medical treatment?)

(3 = neutral)

Very Inaccessible (Difficult)	1	2	3	4	5	Very Accessible (Easy)
	◯	◯	◯	◯	◯	

6. What are the reasons why you choose to see a doctor or other healthcare professional? What are the reasons you choose not to? Please list any and all reasons that you can think of.

7. When was the last time you saw a healthcare professional (doctor, nurse, dentist, etc.) for any sickness, emergency, or health issue?

◯	A week
◯	Two weeks
◯	Less than a month
◯	More than a month
◯	Less than six months
◯	Less than a year
◯	Over a year
◯	Over two years
◯	Prefer not to say
◯	Other:

8. What were your feelings regarding your last visit to a healthcare facility?

(3 = neutral)

Very Unsatisfied	1	2	3	4	5	Very Satisfied
	◯	◯	◯	◯	◯	

9. Do you feel you receive adequate help and care if/when you see a healthcare professional?

◯	Yes
◯	No
◯	Prefer not to say
◯	Other:

10. What parts of your health are most important to you? (Ex. Diet, exercise, hygiene, etc.)

(List as many as you wish)

11. What is the most common illness or sickness that you feel you or others around you experience? (Describe it the best you can if you do not know the name)

(List as many as you wish)

12. How would you rate your feelings towards your personal health on average?

(5 = neutral)

Unhappy   1   2   3   4   5   6   7   8   9   10   Happy

13. How often do you feel or become sick?

◯	Every few days
◯	Every few weeks
◯	Every few months
◯	Prefer not to say
◯	Other:

14. Where do you go when you get sick or need medical attention? (Including emergency and general medical needs) (List as many as you want)

15. Who do you most often go to for health advice? (**Check all that apply**)

◯	Parent
◯	Sibling
◯	Other Relative
◯	Friend
◯	Prefer not to say
◯	Other:

16. Have you ever made an appointment with CEF specifically related to health or healthcare?

◯	Yes
◯	No
◯	Prefer not to say

17. If you answered "Yes" to the above question, what was the health issue that brought up this conversation or meeting? (List your response in the space provided)

◯   Prefer not to say

18. Have you ever taken a health education class? (Ex. High School of Community Health Class)

◯	Yes
◯	No
◯	Prefer not to say

19. In general, would you say your health is:

◯	Poor
◯	Fair

⬭	Good
⬭	Very Good
⬭	Excellent

20. Compared to one year ago, how would you rate your health in general now?

⬭	Much worse now than one year ago
⬭	Somewhat worse now than one year ago
⬭	About the same
⬭	Somewhat better than one year ago
⬭	Much better now than on year ago

21. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your **physical health**?

	Yes	No
Cut down the amount of time you spent on work or other activities	⬭	⬭
Accomplished less than you would like	⬭	⬭
Were limited in the kind of work or other activities	⬭	⬭
Had difficulty performing the work or other activities (for example, it took extra effort)	⬭	⬭

22. Within the past two weeks, how often have you felt anxious or stressed?

⬭	Hardly ever
⬭	A few times
⬭	About half the time
⬭	Most of the time
⬭	All the time

23. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your **emotional health** (such as feeling depressed or anxious?

	Yes	No
Cut down the amount of time you spent on work or other activities	⬭	⬭
Accomplished less than you would like	⬭	⬭
Were limited in the kind of work or other activities	⬭	⬭
Had difficulty performing the work or other activities (for example, it took extra effort)	⬭	⬭

24. During the past 4 weeks, to what extent has your physical or emotional health interfered with your normal social activities with family, friends, neighbors, or groups?

⬭	Not at all
⬭	Slightly
⬭	Moderately

⭕	Quite a bit
⭕	Extremely

25. How TRUE or FALSE is each of the following statements for you?

	Definitely False	Mostly False	Neither True Nor False	Mostly True	Definitely True
I seem to get sick a little easier than other people	⭕	⭕	⭕	⭕	⭕
I am as healthy as anybody I know	⭕	⭕	⭕	⭕	⭕
I expect my health to get worse	⭕	⭕	⭕	⭕	⭕
My health is excellent	⭕	⭕	⭕	⭕	⭕

26. Describe the symptoms of a sickness, illness, or injury that you consider an emergency or that you think requires that you seek out emergency medical services? (Describe and/or list your responses in the space below. Be as specific or as general as you wish) (Ex. I think a fever above a certain number is an emergency. I think a cut of ___ size is an emergency)

General Demographic Questions

In this section, please provide any demographic information that you wish to include. You are not required to answer any of the following questions unless you choose to do so. However, all responses are confidential and will in no way ever be connected directly back to you.

1. What is your gender identity?

⭕	Yes
⭕	No
⭕	Other:
⭕	Prefer not to say

2. What is your age?

⭕	0-18 years old
⭕	19-30 years old
⭕	31-40 years old
⭕	41-50 years old
⭕	51-60 years old
⭕	60+ years old

3. What is your racial, ethnic, or national identity?

4. What is your highest level of education?

⬭	Up to High School
⬭	Some High School
⬭	High School Diploma
⬭	GED
⬭	Some college or undergraduate program
⬭	Associate's Degree
⬭	Bachelor's Degree
⬭	Master's Degree
⬭	Degree higher than Master's Degree
⬭	Prefer not to say
⬭	Other:

5. How long have you been working with CEF?

⬭	Less than 3 months
⬭	Less than 6 months
⬭	Less than a year
⬭	1-2 years
⬭	3-5 years
⬭	6-7 years

6. What is your current housing situation?

⬭	Local Community Shelter
⬭	Transitional Living
⬭	Renting
⬭	With a Friend or Relative
⬭	Live outside/On the street
⬭	Other:

<center>**FOCUS GROUP SCRIPT**[23]</center>

<center>**Jonathan Wall, PI**</center>

As people are arriving to the focus group, I will obtain informed consent from each, and note their names. Once people arrive, we will start the introduction.

Introduction:

"Good morning/afternoon/evening and welcome. Thank you for taking the time to join us in our discussion of health and healthcare resources. My name is Taylor Wall and I am a student at UNC-CH. I am conducting a study about health and healthcare resources because I am interested in people's challenges, perceptions and behaviors regarding their health and available healthcare resources. Following this, I wanted to facilitate a group discussion focused on these topics. There are no right or wrong answers. I expect that you will have differing points of view. Please feel free to share your point of view even if it differs from what others in the group have said – everything you have to say is relevant! I want to understand your experiences and opinions about your personal health, the health of those around you whom you interact with, as well as those regarding healthcare resources in this community."

"We are recording the session because we don't want to miss any of your comments. [We will be the only ones to listen to this recording, and it will be destroyed after the data analysis.] Before we begin, let me suggest some things that will make our discussion more productive. Please speak up so that everyone may understand you. Only one person should talk at a time; so we should not interrupt each other. Please feel free however to respond to what other people have said, but please help us to foster a comfortable and respectful atmosphere of sharing. We'll be on first name basis, and in our later reports there will not be any names attached to comments. Your comments are confidential."

"If you want to follow up on something that someone has said, or agree/disagree or give an example, feel free to do that. Remember there are no wrong answers, only potentially differing points of view. Don't feel like you have to respond to me directly the entire time. Feel free to have a conversation with each other in the room about these questions. My job as moderator is to simply guide the discussion. I am here to ask questions, listen, and make sure everyone has a chance to share. I am interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance to speak. We just want to make sure that we hear from all of you. We will be done by _____."

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[23] This focus group script adapted, with permission, from a study performed by Dr. Mark Sorensen, UNC Chapel Hill Anthropology Department Associate Professor.

Opening questions:

1. I would like to establish some group discussion "ground rules" to help make sure the discussion provides a safe and comfortable space. What are some ground rules you think we should all follow?

2. I would like to start out by learning more about all of you. Could we please go around the room and each of you give a brief introduction of who you are? This could be anything you wish to share such as how it is you came to live in the Chapel Hill community, what brought you to this class, or anything you wish to share.

*Main questions***:**

1. HEALTH:

What does the term "health" mean to you? What are its components? In the past 10 years, has the health of residents here changed, and if so, how? Who in the community are the most healthy, how do you know, and why?

2. HEALTH RISKS: When was the last time you were sick or hurt and could not work? What happened? Who helped you or who did you go to for help? How common is it for people here to not have enough food to eat or money to buy basic supplies? What are the various risks to households here socially, economically, and in terms of health? What are the most common illnesses people have? How severe are these risks and how common? What do you do to prevent them? What do you do to cope with them once they have occurred?

3. MAPPING ACTIVITY: Next, I would like for us to work together on a "community mapping" activity. Essentially, we are going to use these markers, poster board, and labels to construct a rough map of the Chapel Hill area. Please fill in locations people commonly use, gather, and hang out, as well as important streets and landmarks. This does not have to be to scale or perfect. Think of it like drawing a general visual map for someone that is asking for directions around Chapel Hill. Where are the local healthcare facilities like doctor's offices, hospitals, etc.? [These maps will be used in the final study report as a visual image that will be analyzed]

4. FUTURE: What do you think the future holds for members of the Chapel Hill community in terms of health, community living, household economics?

In conclusion:

Of all the health issues that we discussed, which is the most important to you? Is there anything that we should have talked about but didn't? What did you like the most about this discussion?

The following is an excerpt from one of the focus group discussions which went along a tangent related to "alternative medicine" and experiences with home and folk remedies. I have included this in the Appendix because, although it was not directly related to the thesis topic, it is an interesting dialogue which could be used in future research related to interactions and experiences of "alternative medicine," among other focus areas.

D: *"Well, back in the day, when I was growing up, you know you have the older people who will tell you, if you got a cold, you take some honey, then you put the, whatever, whiskey? (N: White liquor) And they would give it to the kids, just a little bit too, and it seemed to help, I didn't go to the doctor. And honey really works, that why I tell...and she recounts her experience looking up diabetes and lemon benefits. Sometimes, just your family can tell you things and help you get better (Age 52, African American, female, apartment rental)."*

N: *"Go back further and further and further. (He talks about elderly advice and use of roots and natural medical herbs found in the woods.) Sassafras tea (Age 72, African American, male, homeless)!"*

D: *(She describes how to make it since she grew up on it) And also, my daddy, I don't know, he'd boil some leaves for us, when we was teenagers, and the water turned green, you put a little sugar in it, and he said it was only for...he didn't give the boys any, only for girls. You know, a bunch of stuff, I know you're right about that."*

N: *"I don't have no grudges against doctors today. They go to school, they paid a lot of money to go to school. BUT, they don't really know what's going on. Old folks, the ones before me, I'm 72 years old, the one before me, and the one before that, my grandparents, they know what's going on. They could find all kinds of stuff out of the woods and make you, and heal your body with."*

D: *"Yes, there are things in the woods, but people just don't use it."*

N: *(He recounts an accident as a child. His grandmother got some sugar, spider webs, and milk, and mixed it up, put it on, and it stopped the bleeding)*

D: *"Oh! You know what, about the itching? It's a flavoring, but it's a pure almond extract, it stops itching. Yes, it works because I've tried it."*

M: *"And what do you think about the Glaxo…They were the great researchers in the war, with the herbs and the plants and converting into medications at a very high price. So originally, in the early years, the herbs that they are talking about, were what made the medications. The brand name medications came from the plants, the herbs. So it's the same process, they make, and the researchers, the investigators, in the great laboratories we have here (Age 59, Latina, female, apartment rental)."*

D: *"Native Americans were already here and knew all about the..."*

M: *"The Native Americans, they find so many, like in Latin America...and like in Europe, they have so many great things to take for medication. Thanks God for providing Earth rich in medication and natural...(overlapping agreement). Thank you God for we are in the paradise!"*

N: *(Goes on to describe other things white liquor is good for) "Rock candy and white liquor will knock the cold right out of you..."*