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Health Care Experiences of the Uninsured at the Dawn of the 21st Century

Sylvia Jalil-Gutierrez

University of Connecticut, sylvia.jalil-gutierrez@uconn.edu

Sylvia Jalil-Gutierrez

gutierrezs@ccsu.edu

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Health Care Experiences of the Uninsured at the Dawn of the 21st Century

Sylvia Jalil-Gutierrez, Ph.D.

University of Connecticut, 2016

Using the framework of critical medical anthropology “Health Care Experiences of the Uninsured at the Dawn of the 21st Century” investigates how those lacking health insurance in a U.S. mid-sized northeastern city strive to meet their health care needs. Fieldwork was based on in-depth semi-structured interviews, participant observation, and demographic data of patients who sought care at a non-government, non-profit primary care mobile health clinic, between November 2012 and July 2013.

In addition to exploration of health care seeking strategies, I investigated how migration issues played an important role in the health and health care experiences of participants since 80% were born in another country. These participants exhibited symptoms of migration trauma to various degrees. Their narratives described their anxiety, stress, and frustration as they struggled to meet family and financial obligations and the impacts these had on their health and well-being. Participants also explained how they utilized their support networks to overcome the financial and health care challenges they faced and described their views about the differences between right and deservingness in health care. This work highlights how individuals from this particularly vulnerable population experience the political economic forces that are behind the social origins of disease, and how migration also impacts health. It also sheds light on shortcomings of current biomedical system ideology, policies and practices and highlights participants’ sufferer experiences, and their medical

pluralism practices.

The lessons learned should be useful to medical anthropologists, health care advocates, health practitioners and policy makers responsible for the design, development and implementation of health care strategies best suited to the needs of precarious populations.

Health Care Experiences of the Uninsured at the Dawn of the 21st Century

Sylvia Jalil-Gutierrez

B.S.N., Boston College, 1975

C.S.S., Harvard University Extension, 1987

M.B.A., Rensselaer Polytechnic Institute, 1991

M.A., University of Connecticut, 1991

A Dissertation

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University of Connecticut

2016

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Sylvia Jalil-Gutierrez

2016

APPROVAL PAGE

Doctor of Philosophy Dissertation

Health Care Experiences of the Uninsured at the Dawn of the 21st Century

Presented by
Sylvia Jalil-Gutierrez, B.S.N., M.B.A., M.A.

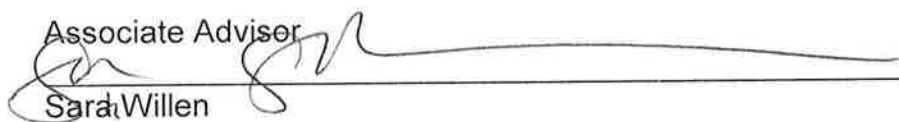
Major Advisor

Merrill Singer



Associate Advisor

Sara Willen



Associate Advisor

Karen Breda



University of Connecticut
2016

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Dedication

I dedicate this dissertation to my father who taught me from a very young age that the greatest crime against humanity is poverty. He always believed that this planet and this country are rich enough to provide healthy, uncontaminated food, clean water, a healthy environment, adequate shelter, a good education, and of course, quality health care.

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List of Acronyms

ACA - The Patient Protection and Affordable Care Act

ACO – Accountable Care Organization

CCD - Confraternity of Christian Doctrine, aka Catechism

CNA – Certified Nursing Assistant

COBRA - Consolidated Omnibus Budget Reconciliation Act

CPAP – Continuous Positive Airway Pressure

ECHN – Eastern Connecticut Health Network

EHR – Electronic Health Record

FQHC – Federally Qualified Health Centers

IFI – International Financial Institution

IMF –International Monetary Fund

JNC - Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure

NGO – Non-government Organization

PAP – Patient Assistant Programs

SAP – Structural Adjustment Policy

SNAP – Supplemental Nutritional Assistance Program

UDHR – Universal Declaration of Human Rights

WB –World Bank

WTO – World Trade Organization

CHAPTER ONE: INTRODUCTION

In this introductory chapter I lay out the groundwork for this dissertation, beginning with the goal of this research and why I undertook this research, followed by a discussion of the health insurance system in the United States, including the Patient Protection and Affordable Care Act and health care systems in select other countries. I then discuss health disparity, health inequality and health inequity including anthropological perspectives on inequality and health. Finally, I provide a brief synopsis of the methodology employed and end with an outline of the dissertation format.

Research Goals

The goal of this research is to contribute to our understanding of socially contextualized illness behavior and experience, an issue of concern within medical anthropology, but also with implications for public health and public health policy. Illness behaviors and experience do not occur in a vacuum. Rather, they exist within specific social, cultural, and political-economic contexts. The goal of this research then is to understand illness behaviors and experience within the context of the current U.S. health policy climate. Furthermore, the research is designed to understand the experiences of the uninsured who attend a mobile clinic. Free clinics have been an important resource for underserved communities. As such, this study also seeks to understand how a free standing mobile health clinic fits into the overall strategies of the uninsured to meet their health care needs.

Thus, the research questions addressed are:

- 1) What are the experiences, mechanisms, strategies and processes by which underserved populations (specifically the uninsured) in the greater Hartford area

attempt to meet their health care needs through mobile health clinics?

- a) How do they utilize the clinic's services, i.e. what kinds of health issues bring them to the clinic?
- b) Are they able to adhere to treatment regimens provided by mobile clinic doctors? If not, why not?
- c) What other types of health services (non-mobile clinic) do they use and for what reasons?

2) How do patient help-seeking strategies reflect broader factors in the political economy of health care in the U.S. and the treatment of subordinate populations with reference to health care access?

- a) How do various stakeholders (defined as patients, clinicians, and board members) think about who deserves health care and why?

Genesis of the Research

For over 25 years I was educated, licensed and worked as a registered nurse in community health center settings. During that time I often witnessed the hardship experienced by those individuals who have no health insurance or who are underinsured in meeting their health care needs. During this period of time in health policy circles, I often saw how healthcare professionals talked about how people must take personal responsibility for their own health. This argument is ideologically connected to what is often referred to as the culture of poverty, an argument in which the poor are largely blamed for their dire economic circumstances because they are believed to lack middle class values. As stated by Herbert Gans (1995:1): "The labeling of the poor as moral inferiors...blames them falsely for the ills of American society and economy, reinforces their [mis]treatment, increases their misery, and further discourages their moving out of poverty". The supposition that poor and marginalized groups are responsible for their impoverished circumstance because they are lazy, ignorant, lack motivation, and do not take responsibility for their health care are all part

of a larger culture of poverty argument. For example, former Republican Congressman Paul Ryan asserted during his run for the vice presidency “We have got this tailspin of culture, in our inner cities in particular, of men not working and just generations of men not even thinking about working or learning to value the culture of work, so there is a real culture problem here that has to be dealt with” (Clawson 2014).

Yet, as Carol Stack (1974:23) notes, “many of the features alleged to characterize the culture of poverty—unemployment, low wages, crowded living quarters—are simply definitions of poverty, not a distinct “culture””. Racist ideologies, and discriminatory practices also contribute to poverty’s persistence. As indicated in Table 1, African Americans and Latinos suffer greater poverty rates than whites.

Table 1
Poverty Rate and Ethnicity¹

Ethnicity	Poverty Rate
African American	27%
Latino	24%
White	10%

Anthropologists have adopted the concept of structural violence from peace studies to label the ways that dominant social institutions operate to maintain inequality in society. Victim blaming is seen as an ideological component of structural violence. My experience working with marginalized groups differed from those that would place them in the *culture of poverty* category and puts *culture of poverty* arguments in dispute. Their poverty and lack of health insurance did not, in fact, reflect the causal explanations of being lazy, ignorant, or unmotivated. Most of the people I came to know

¹ Data obtained from Kaiser Family Foundation (Kaiser Family Foundation 2013)

worked two to three jobs in low-wage, part-time employment. Yet, they experienced economic hardship and did not qualify for employer based health insurance, nor if they did, could they afford the premiums. Indeed, almost 46,000,000 Americans between the ages of 18 and 64 did not have health insurance in the United States in 2012 (U.S.Census Bureau 2012d). However, with the implementation of the Patient Protection and Affordable Care Act (ACA) in 2010, the number of uninsured decreased by approximately 10,000,000 (Martinez and Cohen 2014). As shall be discussed later, the ACA did not resolve all the problems regarding health care access.

My motivation for conducting this case study of a mobile health clinic was to learn about the health care experiences of uninsured persons living in greater Hartford, Connecticut. This is important because the Hartford situation, albeit local, is a microcosm of a larger situation both at the national level and even at the global level. The situation in greater Hartford is not isolated when looking at the global context. It is a representative case of a larger situation and points to broader national inequalities based on ethnicity and immigration status. My central thesis, therefore, is that economic hardship impacts health in very direct ways. I further argue that being an immigrant is a challenge to health and well-being, exacerbated by racism, language barriers, living conditions, and immigration status. Indeed, the global political economy has been a key factor in migration and migrants are a large proportion of the precariat and consists of millions of people the world over. They are the result of the neoliberal agenda. “The precariat lives with anxiety – chronic insecurity associated...with teetering on the edge...” (Standing 2014:34). As Standing (2014:302) notes “insecurity produces stress” and stress is a factor in ill health (Brunner and Marmot 2006; Thoits 2010). The

precarious state in which so many people find themselves brings into stark relief the structural inequalities responsible for the creation of the precariat and the health consequences of living in an ever increasing unequal world. Therefore, social programs and policies should focus on reducing inequality, including health inequality.

Furthermore, the health effects of immigration, i.e. immigration as a social determinant of health (Castañeda et al. 2015; Fleischman et al. 2015) need to be taken into consideration by policy makers and impels medical anthropologists and public health professionals to enter into the policy arena and support policies that will improve the health of immigrants. Clinics such as Malta House are still needed given there are those who still do not have health insurance. This is particularly the case for undocumented immigrants and lawful permanent resident immigrants who have lived in the U.S. for less than five years. Thus, these clinics need to be supported and policies implemented to support and expand their services.

Development of the U.S. Health Insurance System

In the early 20th century, fraternal orders contracted for health care services with physicians and hospitals, and hospitals also created their own prepaid insurance systems (Light 2004). However, beginning in the late 1920s, advances in medical technology, quality improvements in physician and hospital services, increasing income, and government policies favorable to insurance companies led to the growth and popularity of employer-based health insurance. With the rise of labor unions, these fringe benefits were seen as ways to keep wages under control. The first voluntary health insurance program was Blue Cross and Blue Shield. The Blue Cross hospital

coverage plan was created in Dallas, Texas in 1929 to fund hospital care for school teachers at Baylor University Hospital. This model spread to other states and led ultimately to the formation of the Blue Cross Association that operated independently of any hospital. Blue Shield was an insurance program to cover physician services. The first of these plans emerged in California in 1939. Physicians only accepted this system to prevent the creation of a national health insurance program (Almgren 2007b; Starr 1982; Thomasson 2002). The Blue Shield and Blue Cross plans became bargaining tools for labor as a package of benefits accorded to workers by employers. Thus began the dominance of the employer-based health insurance system (Almgren 2007b). Originally, Blue Cross and Blue Shield (or the Blues as they came to be called), which began working together in the late 1940s and merged in 1982, used a community-rating system. This system meant that insurance premiums were the same whether an individual was sick or healthy and the programs became financially successful. Seeing the success of Blue Cross and Blue Shield, for-profit insurance companies entered the health insurance market. However, these companies used an experience-rated system whereby premiums charged to individuals were based on their health status; healthy individuals paid lower premiums than sick or ill individuals. Thus, rates offered by for-profit insurance companies to healthy employee groups were lower than what Blue Cross and Blue Shield could offer (Light 2004; Thomasson 2002).

The creation of Health Maintenance Organizations (prepaid group practice plans) occurred as a result of the Health Maintenance Organization (HMO) Act passed by Congress in 1973 as a governmental attempt to curb the rising cost of health care (Almgren 2007b). The Act led to the popularity of managed care during the 1980s and

1990s (and is still practiced today). Managed care plans are regulated by managed competition through the rules and policies governing how the plans compete for subscribers. Employers offer employees different managed care plans from which to choose. Thus, employees' choices are limited to define health care networks through employer-sponsored health insurance products (Light 2004; Rheinhardt 2001).

The corporate control of the health care industry is what Light calls the “*managed-care-industrial-complex*” (2004:19) [italics in original]. Indeed, managed care plans accounted for 93% of all employer-based health insurance by 2006. In an effort to further reduce employer costs, employees are now expected to pay higher co-payment fees and higher deductibles within these managed care plans. Furthermore, health insurance companies have excluded those who are considered high risk (e.g., having pre-existing health conditions). Also, people who work in a small business (less than 50 employees) that does offer employer-based health insurance—many small businesses do not due to the prohibitive costs, or do not offer family coverage—have fewer health benefits than people who work in a large corporation and deductibles are higher (Almgren 2007a; EBRI 2009). The situation is worse if one is unemployed or has to pay for health insurance out of pocket. An individual health care plan can cost between \$200-\$300 per month with a deductible that can go as high as \$5,000 (Sered and Fernandopulle 2005b). This was the situation for many Americans who, as a result of the Great Recession of 2008, lost their jobs and with that, their employer sponsored health insurance.

The Patient Protection and Affordable Care Act

In March 2010 the United States Congress, and President Obama, signed the Patient Protection and Affordable Care Act. According to Jennifer Tolbert (2015), of the Kaiser Family Foundation, key provisions of the Act are:

- Insurers cannot deny coverage because someone has a pre-existing health condition.
- Renewal of health insurance is guaranteed.
- Insurers cannot increase premiums based on health status.²
- No patient cost-sharing requirements for preventive health services. That is, no co-payments, deductibles, or co-insurance are required for preventive health services. These services include well-women visits, all FDA approved contraceptives, screening and counseling for sexually transmitted diseases, breastfeeding support and supplies, and domestic violence screening.³
- Young adults may remain on their parent's health insurance until age 26.
- Health insurers must spend at least 80%-85% of premiums on health care claims and quality improvement.
- The maximum an individual or family is required to pay out of pocket per year is \$6,600 and \$13,200 respectively. For individuals with incomes 100-200% of the Federal Poverty Level (FPL) the annual out-of-pocket limit is \$2,250 and for families, \$4,500. For those with incomes 200-250% of FPL the limit is \$5,200 per individual and \$10,400 per family.⁴
- Since Jan. 1, 2014, people are required to have health insurance, with exceptions.⁵ A penalty will be levied on individuals if they do not have health coverage (\$95 for one person or up to \$285 for a family) or 1% of income, whichever is greater.⁶

² Insurers can charge older adults more than younger adults but not more than three times what younger adults are charged. Insurers can charge those who use tobacco 1.5 times more than what they charge for those who do not use tobacco (Tolbert 2015).

³ Religious organizations, such as churches and religious affiliated hospitals or universities, and closely held for-profit companies with strong religious objections are exempt from paying for contraceptive coverage. In these cases these entities must send a form to Health and Human Services or their insurance company stating their objection to covering contraceptives. The insurance company itself would then provide coverage without any cost sharing on the part of the insured (Tolbert 2015).

⁴ These limits apply to the 2015 calendar year.

⁵ Exceptions include undocumented immigrants, documented immigrants who have been in the United States less than five years, those whose coverage is not affordable (costs more than 8% of household income), for religious objections, members of Indian tribes, those with income below the tax filing threshold, and those who have short gaps in coverage of less than three consecutive months. Individuals can also claim hardship exemptions, including those with incomes below 138% FPL who live in states that did not adopt the Medicaid expansion.

⁶ The penalty increases to the greater of \$325 (up to \$975 for a family) or 2% of income in 2015 and \$695 (up to \$2,085 for a family) or 2.5% of income in 2016.

- Beginning in 2015 businesses with 100 or more employees must offer health coverage to at least 70% of full-time equivalent employees⁷, and their dependents up to age 26 but not spouses, or face a penalty of \$2,000 per employee minus up to 80 employees. This mandate goes into effect in 2016 for businesses with 50-99 full-time equivalent employees. For both types of businesses employers must offer insurance that pays for at least 60% of covered health care expenses, and the individual employee share of the premium must not exceed 9.5% of family income. Employers with less than 50 employees are exempt from this mandate.⁸
- Premium tax credits and cost-sharing reductions are available through Health Insurance Marketplaces (Exchanges) to make coverage more affordable for qualifying individuals. Premium tax credits are available only to U.S. citizens and legally residing immigrants⁹ who have income between 100% and 400% FPL and who do not have access to affordable coverage through an employer or public coverage (Medicaid, CHIP, or Medicare). Married consumers must file taxes jointly in order to qualify.¹⁰

Despite passage of the ACA, “health insurance coverage remains fragmented, with numerous private and public sources as well as wide gaps in coverage rates across the U.S. population” (Mossialos 2015:153). Other countries provide to all citizens and legal residents health insurance for physician services and hospital care through public funds, mainly taxes and have more control over health expenditures. Private health insurance is available to pay for health services not covered by the state, e.g. private hospital care or to avoid waiting for elective surgery (Mossialos et al. 2015).¹¹

⁷ For the purposes of the Affordable Care Act, full-time is 30 hours or more per week.

⁸ For more detail regarding employer requirements for businesses with 50 or more employees, see U.S. Small Business Administration (n.d.).

⁹ To receive Medicaid or Medicare one must have lived in the United States legally for at least five years.

¹⁰ The rule has a flaw, known as the ‘Family Glitch’. Family members are not eligible for exchange subsidies if the employee could get employer-sponsored coverage *just for him or herself*, for less than 9.5% (9.56% for 2015) of the household’s income (Kennedy 2013; Norris 2015). Senator AL Franken (2015) has introduced a bill to close this loophole.

¹¹ Singapore, Switzerland and The Netherlands differ from other countries’ health systems reported by Mossialos et al. (2015). Also, those who are undocumented are excluded from publicly financed health insurance except for emergency care or in the case of accidents. The Netherlands is the exception to this exclusion (Mossialos 2015:93).

The Patient Protection and Affordable Care Act in Connecticut

In 2009, the Connecticut state legislature voted on a health reform bill. The Connecticut bill, known as Sustinet, originally included a public option, and a strong, semi-independent board without political interference (Bordonaro 2011; Sustinet Health Partnership Board of Directors 2011). When the Sustinet bill passed in June 2011, it was in name only as there was no public option, and the semi-independent board would serve only in an advisory capacity (Buck and Sturvedant 2011; Pelto 2011). Rather than Sustinet, the Connecticut Legislature passed Senate Bill 921, Public Act No. 11-53, “An Act to establish a State Health Insurance Exchange” (2011), and HB 5013, “An Act concerning the Board Members of the Connecticut Health Insurance Exchange.” These laws allowed the State of Connecticut to create a health insurance exchange as a result of passage of the Affordable Care Act. Health insurance exchanges are “marketplaces where qualified individuals and small businesses can “shop” for private health insurance coverage” (Fernandez and Mach 2013:8).

In Connecticut the Health Insurance Exchange is known as “Access Health CT (<https://www.accesshealthct.com/AHCT/LandingPageCTHIX>). It is only one of 13 states (plus the District of Columbia) that established a state run health insurance exchange. State run health insurance exchanges are those where the state is responsible for all functions of running the health insurance exchange and the health insurance exchange is established and maintained by the state (Kaiser Family Foundation 2015b). Connecticut is also one of 28 states (plus the District of Columbia) that expanded Medicaid under the Affordable Care Act (Kaiser Family Foundation 2015b). Thus, While Connecticut enrolled slightly over 256,000 residents through the state’s health

insurance exchange, almost 80% qualified for the state's Medicaid. Moreover, a little over half of the Connecticut residents enrolled were uninsured. Yet, there are still 147,166 uninsured Connecticut residents (Pazniokas 2014).¹²

The Poor and Uninsured

The U.S. health care system was such that access to care was “*linked to employment creating a caste system of the chronically ill*” and those employed part-time (Sered and Fernandopulle 2005a:15, italics in original). To this I would add the *unemployed*. The ACA, however, is meant to mitigate this situation. How successful the ACA will be over the long term is yet to be determined.

Of those under age 65 who were below the poverty threshold in 2010, 29.5% were uninsured and 32.3% were near poverty (Cohen et al. 2011). In 2013, most uninsured came from the lower economic strata and yet had at least one family member who worked full-time (see Table 2).

Most working uninsured are employed in service sector jobs or in small businesses (Angel et al. 2006; Sered and Fernandopulle 2005a) and tend to be disproportionately represented within specific ethnic groups, as shown in Table 3).

Moreover, it is estimated that 59% of non-elderly adult undocumented immigrants

¹² Eligibility for Medicaid in Connecticut is 201% of the Federal Poverty Level (FPL) for parents of dependent children and 138% of FPL for single adults (Kaiser Family Foundation 2015a). Furthermore, Connecticut provides Medicaid and CHIP (Children's Health Insurance Program) to legally residing pregnant women and children, regardless of how long they have lived in the country, i.e., the five year legal residency prerequisite is not required (Pew Charitable Trusts 2014). Otherwise, to be eligible for Medicaid one must meet the five year legal residency requirement. However, the five year legal residency requirement is not necessary to qualify for other cost sharing or premium subsidies (access health CT 2014). As of Jan. 2015, 382,012 Connecticut residents received Medicaid coverage through the Connecticut Health Insurance Exchange, 81% of total enrollees (access health CT 2015).

are without health insurance (Passel and Cohn 2009).

Table 2
Economic Characteristics of Uninsured¹³

% of households with at least one full-time working member	60%
% uninsured with annual household income below \$19,530 (for a family of three)	27%
% uninsured with annual household income between \$19,530 and \$38,864 (for a family of three)	31%

Table 3
Uninsured by Ethnicity¹⁴

Latino	Black, non-Hispanic	Asian/Native Hawaiian or Pacific Islander	White, non-Hispanic	Other
25.6%	17.3%	6%	11.7%	3%

Health Disparity, Health Inequality, and Health Inequity

Health disparity and health inequalities are empirical concepts used to describe unevenness in health care whereby disadvantaged social groups (e.g., low income groups, racial/ethnic and other minorities) experience worse health or greater health risks than more advantaged social groups (Adler and Stewart 2010; Braveman 2006; Braveman 2014; Centers for Disease Control and Prevention 2013; Diez Roux 2012). Carter-Pokras and Baquet (2002) note that health disparity was a term used in the United States whereas health inequality and health inequity are terms more commonly used outside the United States.

¹³ Data obtained from the Kaiser Commission on Medicaid and the Uninsured (Kaiser Commission on Medicaid and the Uninsured 2014).

¹⁴ Ibid.

Kawachi et al. (2002:647-648), however, argue that health inequality is a descriptive term that does not infer moral judgment whereas health inequity refers to health inequalities that are unfair. Thus, in this reading health inequity connotes a moral value. The most widely cited definition of health inequity comes from Margaret Whitehead (1991:219):

The term "inequity" has a moral and ethical dimension. It refers to differences, which are unnecessary and avoidable but, in addition, are also considered unfair and unjust. So, in order to describe a certain situation as inequitable, the cause has to be examined and judged to be unfair in the context of what is going on in the rest of society...there is some ambiguity about the term [health inequality] as some use it to convey a sense of unfairness while others use it to mean unequal in a purely mathematical sense.

Yet, as Harper et al. (2010) note, neither 'health disparities' nor 'health inequalities' are value free terms. Many disparities and inequalities in health underlie social unfairness and inequity. In this sense, health equity is the principle undergirding a dedication to reducing, and eliminating, health disparities (Braveman 2014). In the United States, there is much evidence disparities are strongly correlated with advantaged or disadvantaged positions in the structure of social relations. Most disparities and inequalities in the United States are unnecessary and avoidable, i.e., they are health inequities. Indeed Healthy People 2020 (U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion (2010) defines health disparity as

a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Here again one can substitute the term 'health inequality' for 'health disparity'. Others, however, differentiate between biological differences in illnesses based on gender and age and health inequality based on social causes of avoidable health differences (Barr 2008; Singer and Baer 2012). Thus, used in this way, health inequality infers a sense of unfairness and injustice, i.e. inequity, while 'health disparity' only describes health differences that do not result from injustice or unfairness. For the purpose of this dissertation I will use the term health inequality, as used by Barr (2008) and Singer and Baer (2012) since many of the health issues of concern are the products of injustice and unfairness in society.

Anthropological Perspectives on Inequality and Health

Anthropological studies of inequality and health have examined, 'on the ground', the ways in which political, economic, social, and historical forces have affected the health of vulnerable populations. For example, Farmer and Bertrand undertook to track the chain of command in the death of a patient who was a patient tortured to death in Haiti. They found that the death was carried out, or ordered, by those in the Haitian armed forces who were trained and funded by the U.S. military. They wrote (2000:88) "Thus, this 'sudden increase in village-level mortality' was not to be understood without a systemic analysis that included the recognition and analysis of international economic and political ties that were and remain not independent of the health status of the poor."

Nancy Scheper-Hughes' (2004) and Lawrence Cohen's (1999) ethnographic research into organ trafficking has documented numerous cases of organ harvesting from the global poor living in the Third World to wealthy recipients, particularly those

living in First World, such that these international exchanges “involve and implicate the United States and Western Europe” (Scheper-Hughes 2002:59).

Other anthropologists have documented the ways in which economic inequality affect women’s reproductive health (Castro 2004; Inhorn 2003; Inhorn and Birenbaum-Carmeli 2008; Janes and Chuluundorj 2004); the impact legal and illegal substances have had on poor communities and communities of color (Singer 2008; Singer et al. 1992; Stebbins 1991); health policies’ effects on health inequality (Becker 2007; Castro and Singer 2004; Maskovsky 2000; Rylko-Bauer and Farmer 2002); health inequality among immigrants (Castañeda 2012; Chavez 1986; 2012; Fassin 2004; 2011; Holmes 2012; Larchanché 2012; Marrow 2012); and how racism impacts the health of people of color in the United States (Dressler 1993; Dressler et al. 2005; Good et al. 2003; Gravlee 2009; Gravlee et al. 2005; Hunt et al. 2013; Singer 1992). While this brief overview of anthropology’s role in understanding health inequalities is not exhaustive it does highlight some of the important areas where anthropology has made significant contributions to the field.

Racial ideology has been an important historical characteristic of health inequality in the United States and anthropology has had a long and complex history with the concept of race. As Armelagos and Goodman (1998:371) note, “The concept of race has been a core concept in anthropology for a long time...” They describe anthropology’s conceptualization of race as going through various understandings, from that of racial categories as immutable due to non-adaptive genetic traits linked to a specific racial group to the idea of different species of humans evolving in different regions of the world. Anthropologists and other scholars of the 19th and early 20th

centuries adhered to a form of scientific racism, i.e. looking for traits that could be measured and quantified, that resulted in those with white skin tending to be located on top of the hierarchy and darker skinned peoples on the bottom. Anthropologists were at the forefront in constructing race as a valid biological category (Gravlee and Sweet 2008). Franz Boas, however, challenged the notion of racial immutability when in 1911 he demonstrated that environment played a key role in human development. He also criticized the idea that one's race had anything to do with one's character (Armelagos and Goodman 1998). Because of Boas' work and that of other anthropologists who followed his lead, as well as the work of scholars in related disciplines, it has long been established that race is a social construction that has no biological basis (Byrd and Clayton 2003; Delgado and Stefancic 2012; Gravlee and Sweet 2008; Harrison 1995; Krieger 2000; Smedley et al. 2003). Thus, in anthropology today, the concept has largely been dropped as having any scientific validity as a biological status. Yet, as Krieger (2000) argues, although 'race' has no meaning biologically, it is nonetheless a significant social category in which the social reality of living in a racist society is embodied.

Methodology

This dissertation is based on an ethnographic case study of a primary care mobile health clinic located in Hartford, CT, which serves the needs of the uninsured. The primary data were collected from the perspective of patients, staff members, and board members. My entrée into this clinic was through a chance conversation with the medical director at the time who took an interest in my desire to conduct ethnographic

research among the uninsured.

While studies have been conducted on mobile clinics, they have focused mostly on patient provider communications (Carmack 2010; Davenport 2000; Deardorff 2009), treatment of specific illnesses, or the provision of specific types of care (Derose et al. 2002; Edgerley et al. 2007; Ellen et al. 2003; Hugo et al. 2002; Liebman et al. 2002; Martins N. et al. 2008; Pistella et al. 1999; Zalos and Trinh 2001). Holistic critical medical anthropological research that uses ethnography to address health seeking and health experience among the excluded poor who seek services from primary care mobile clinics is lacking.

This dissertation is the product of fieldwork conducted between November 2012 and July 2013 at four sites of a mobile health clinic in Hartford, CT that serves the uninsured. A limitation of the study is that, as a case study, there is no comparison to other organizations or populations that do not utilize the mobile health clinic. The study's strength is the rich, in-depth account of the thought and experiences of those who use this mobile clinic for their health care.

Format of the Dissertation

Chapter two details the research setting and methodology. I begin with a description of free standing clinics. I then trace the creation of the mobile health clinic and its organizational structure, and situate the local organization in the context of the larger global organization of which it is a part. This is followed by a detailed description of the research setting and methodology. Finally I present a brief history of the city of Hartford.

Chapter three addresses theoretical considerations. I begin with a discussion of critical medical anthropology, followed by health and human rights. Finally, I discuss migration theories, which relate directly to the population under study.

In chapter four, I introduce some of the participants in their own words by summarizing the results of the ethnographic study. Topics to be discussed include health issues and challenges, right to health care, funding of health care, work experiences, and in the case of immigrants their reason for coming here, and in particular cases, how they got here.

In chapter five, I discuss some of the key themes represented in participant interviews. Chapter six concludes with a summary of the study, study contributions, and reflections about the future.

Chapter Two: Setting and Research Methodology

Introduction

This chapter provides a detailed discussion of the research setting and methodology. I first present an overview of free standing clinics, followed by a discussion of The Order of Malta, the organization of which Malta House of Care, is a part. Here I provide a history of the Order of Malta, followed by a discussion of the Order of Malta in the United States and membership requirements and the Order of Malta today. I then present an overview of the organizational structure of Malta House of Care Foundation and Malta House of Care, Inc.

The research setting, Malta House of Care in Hartford, CT is then discussed in detail including the process a patient must go through to be seen by the Malta House clinical staff. I then detail the research methodology, limitations of the study, and ethical issues. I end with a brief discussion of the city of Hartford, where my research took place, and conclusion.

Free Standing Clinics

Free health clinics, critical safety net provider institutions in the United States, are nonprofit, privately funded organizations, staffed almost exclusively by volunteers. They offer an array of health services to economically disadvantaged, predominately uninsured individuals at little or no charge (Darnell 2010; Isaacs and Jellinek 2007; Nadkarni and Philbrick 2003; NAFC n.d.; NAFC 2011). According to Bridgeman (2010), 83% of free clinic patients are uninsured, unlike the clients of other safety net providers, such as Federally Qualified Health Clinics (FQHCs), where there is a mix of insured and

uninsured patients. Currently there are approximately 1,200 free health clinics nationwide and eight free health clinics operating in Connecticut with 14 delivery sites (NAFC n.d.; Potteiger and Munson 2011). Mobile health clinics are free health clinics based on a vehicle that visits specific locations around the city. Malta House of Care in Hartford, CT is one of those free mobile health clinics.

The Order of Malta

History of the Order of Malta

The Order of Saint John of Jerusalem, later known as the Order of Malta, was founded in Jerusalem in the 11th century by a group of merchants while Jerusalem was under Muslim control. They built a hospital to care for poor and sick Christian pilgrims travelling to the city. During the military campaign of 1099, Crusaders took control of Jerusalem and the hospital provided medical care to the Crusaders (Breycha-Vauthier and Potulicki 1954:554-556; Horsler and Andrews 2011; McHugh 1996a). The order's mission during the Crusades was not just to care for the sick, but also to defend militarily the Christian pilgrims, the lands won by the Crusades, and the Catholic Church. It became, therefore, a religious military order of the Catholic Church and during this time, its members took the vows of chastity, poverty, and obedience.

Furthermore, to be a member of the Order one had to come from the nobility (McHugh 1996a). The knights settled on the Island of Rhodes, from the early 14th century to the 16th century. When they were driven out of Rhodes by Suleiman the Magnificent, Roman Emperor Charles V allowed them to move to Malta. Indeed, the Order of Malta's full name is The Sovereign Military Hospitaller Order of Saint John of

Rhodes and of Malta. Finally, the Order made its headquarters in Rome, where it is today.

The Order of Malta in the United States

As mentioned previously Malta House of Care is an organization within the Order of Malta. In the United States there are three branches of the Order of Malta: The Federal Association, headquartered in Washington, D.C., the American Association, with its headquarters in New York City, and the Western Association, with headquarters in San Francisco (McHugh 1996b:10-11).¹⁵ Even though many members of the American Association live in southern Connecticut, the Malta House of Care is part of the Federal Association. The Federal Association has a grants committee and for the past three years Malta House of Care has written and received grant funding for diabetes treatment.

Interestingly, to become a member of the Order of Malta in the United States today a person must: be sponsored by a current knight or dame; “be an active and practicing Catholic in good standing; and pay an initiation fee, known as a “Passage Fee” of \$4,000 (U.S.) of which 2,000 Euros (about \$2,240 U.S.) are “sent to the Order in Rome to support international programs of the Order. For those under 35 years old the Passage Fee is \$2,500 (U.S.); the annual dues are \$1,200 (U.S.); and “members are requested and expected to contribute to the Order’s Annual Appeal” (Federal Association of the Order of Malta 2013:2). Donations to the Annual Appeal can range from \$25 to \$25,000. Thus, most of the Knights and Dames of The Order of Malta are

¹⁵ Information also obtained through board members interviews 2013.

wealthy Catholic professionals, heads of business, physicians, attorneys, etc.

The Order of Malta Today

Today the Order of Malta is made up of Knights and Dames, i.e. men and women, who are willing and able to pay the passage fee and annual dues. The Order of Malta has a government, an administration, and diplomats. The Grand Master is the Head of the Order of Malta, a lifelong position, elected by representatives of the Order worldwide. He also holds the rank of Cardinal within the Catholic Church. While it is no longer involved in military endeavors, the Order continues its mission of caring for the sick and poor, globally. Though not a nation-state, it does have limited sovereignty and observer status at the United Nations and issues passports to its diplomats for diplomatic purposes, has its own stamps and coinage, and has diplomatic relations with over 100 countries (Cox 2010; Horsler and Andrews 2011). It is one of the oldest international organizations in the world and predecessor of the International Red Cross. Currently there are 47 national associations (Breycha-Vauthier and Potulicki 1954; Horsler and Andrews 2011).

Malta House of Care Foundation, Inc. and Malta House of Care, Inc.

Malta House of Care, a non-profit 501c3 organization, has two separate boards of directors: the Malta House of Care, Inc. Board of Directors; and the Malta House of Care Foundation, Inc. Board of Directors. The Malta House of Care board is larger than the foundation board. As one of the board members commented

the Foundation Board is concerned about governance and fundraising because without adequate funds we cannot sustain the Malta House. But the board of the Malta House of Care is concerned about governance also and concerned about following the rules of the department of health for free clinics.

Therefore, the Malta House of Care board is concerned with clinic issues, such as making sure clinic best practices are being adhered to, making sure all staff and volunteers are properly credentialed, and other issues related to the functioning of the clinic. There is also an executive committee within the Malta House of Care, made up of four board members that, as one of the board members explains deals with “the nitty-gritty things” of the clinic. However, there are foundation board members who also sit on the Malta House of Care board to facilitate communication between the two boards.

The Setting: Malta House of Care

In the beginning¹⁶

In 2004, a group of concerned citizens, members of the Order of Malta came together to discuss the feasibility of starting a free mobile health clinic for the medically medically uninsured in Hartford, Connecticut. Two years after the initial planning meeting, in August 2006, the Malta House of Care Health Clinic (see Figure 1) opened its doors at Saint Peter Church in the predominately Latino South Green neighborhood, bordering the south-east corner of downtown Hartford and Sheldon Charter Oak neighborhood. A little over a year later, in 2007, a second mobile site was added, Sacred Heart Church, located in the northern sector of downtown Hartford on the border of the Clay Arsenal neighborhood, a predominantly Black/West Indian community. About a year after that, a third church site was added in the Barry Square/South End neighborhoods at Saint Augustine Church, which is in a predominantly Italian enclave

¹⁶ The following information was provided by two Malta House of Care, Inc. board members whom I interviewed in 2013.

that has seen an influx of Latinos and Bosnians in the last two decades. The final site to



Figure 1
The Malta House of Care Van

be added was Saint Joseph Cathedral in Hartford's Asylum Hill neighborhood.¹⁷ Thus, it took three to four years before all four Hartford sites were in operation (see Figure 2).

The Order of Malta in Connecticut did not offer any health care services prior to 2006.

¹⁷ Based on participant-observation I found that patients tended to go to the mobile clinic site closest to where they lived. For example, the Saint Peter Church site had the most predominately Latino patient population followed by the Saint Augustine site. The Sacred Heart site was predominately Black/West Indian and Saint Joseph Cathedral, because it was open late to accommodate those who worked during the day, had the most heterogeneous population.

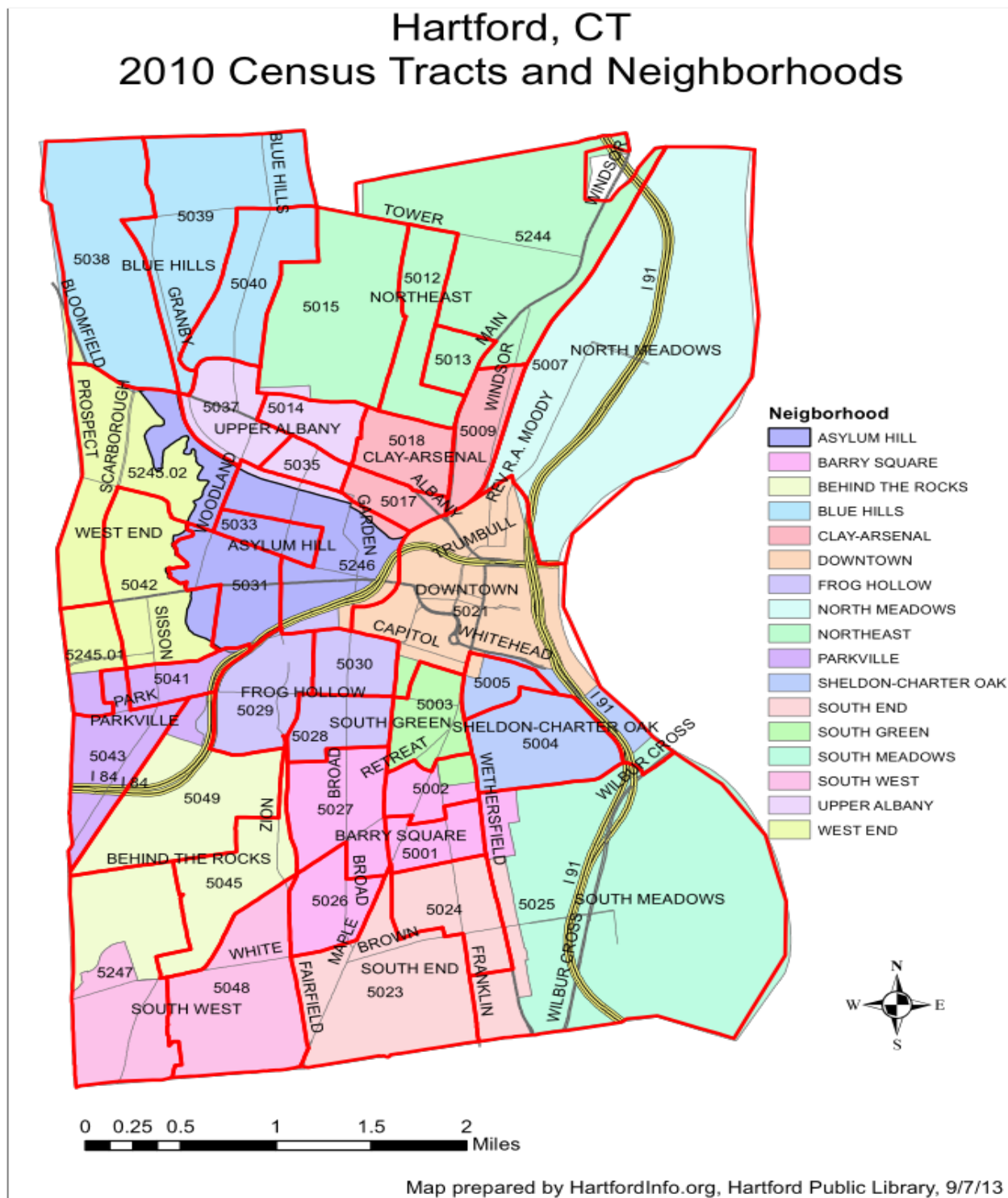


Figure 2

From 2006, when Malta House first opened its doors, to 2015 the organization “has provided over 35,000 patient visits...[with] 2,000 individuals identifying Malta House of Care as their only medical home (Malta House of Care 2014). There were only

two physicians and two to three nurses when the clinic opened. By 2012, each site regularly had four physicians and four nurses.

As a Roman Catholic organization, Malta House of Care has long had a close relationship with the Roman Catholic Archdiocese of Hartford and the Roman Catholic churches and parishes in the area. Board members thought Catholic churches would be appropriate sites for the van to park because the churches chosen have safe parking lots and parish halls which could be used as a protected place to register patients and as a waiting area. The clinic sites at Sacred Heart, Saint Peter's and Saint Augustine are open 1PM to 5 PM, Mondays, Wednesdays, and Thursdays, respectively, whereas the clinic at Saint Joseph Cathedral is open on Tuesdays from 4 PM to 7 PM to accommodate people who work during the day.¹⁸ Patient registration begins one hour before clinic service starts and closes one hour before the end of the clinic day.

In addition to medical staff and volunteers, three medical assistants worked at the Hartford sites. Their role included interpretation as all three were bilingual (English/Spanish).

Malta House of Care receives funding from the Roman Catholic Archdiocese of Hartford, the Order of Malta, private granting/philanthropic organizations, and individual donations. It does not receive any government funding.

Originally only the mobile health van itself was licensed to provide medical services and medical consultation. This meant that patients coming in for lab results, or

¹⁸ Due to construction of a minor-league baseball stadium in the Clay Arsenal neighborhood (Carlesso 2015), the Monday site for the mobile health clinic has been moved to St. Rose Church on Church Street in East Hartford. Also, the hours of operation changed to 12-4PM, Mondays, Wednesdays and Thursdays, and from 2-6PM Tuesdays (Malta House of Care 2014). However, during my fieldwork Malta House was still using the Sacred Heart Church and the hours of operation were 1-5PM and 4-7PM on Tuesdays.

results of other diagnostic tests had to wait and be seen on the van. Even vital signs (blood pressure, pulse, temperature, respiration) had to be taken on the van. In 2008, to improve the flow of patients in the clinic, Malta House applied for, and received, a site license for all four sites from the State of Connecticut Department of Public Health. The site license allowed clinic personnel to take blood pressures, vital signs, give lab and diagnostic lab results in the parish hall waiting areas where privacy screens are put up, away from where patients sit, to enhance confidentiality. Only patients who need to be examined by a professional must be seen in the van. Those who come to check their blood pressure or for lab results can be seen in the waiting area. This has improved the patient flow at the mobile clinic.

The Malta House of Care mobile clinic originally was meant as an alternative to the emergency room, e.g., people going to the ER for sore throats and illnesses of that nature. For example, a patient would come in complaining of a sore throat and their blood pressure was elevated. The patient would return two weeks later for a follow-up visit and the blood pressure was still elevated. It became clear to the clinic staff that the patient needed medication for high blood pressure and therefore, continuous follow-up care. The mobile clinic, then, became a “medical home” for the uninsured, where people are treated, and followed up for chronic illnesses such as high blood pressure and diabetes. Table 4 lists the percent of patient participants with chronic illnesses. If patients required specialized care, the mobile van physicians, would try to obtain that care through their personal contacts.

“You Need to Register

When a patient first arrives to the Mobile Clinic site he or she is directed to the

church hall, converted now to a waiting room. Thus, when a patient enters the hall he/she asks who the last person was who entered the room and sits next to that person as patients are seen on a first come, first serve basis.¹⁹

Table 4
Percent of Patient Participants with Chronic Illnesses (n=29)

Diabetes	27.6%
Pre-diabetes	10.3%
High Cholesterol	31%
High Blood Pressure	48.3%
Hypothyroidism	13.8%
Osteoporosis	7%
Arthritis	17%
Asthma	7%
Mental Health (Stress, Anxiety, Depression)	41.4%
Other	20.7%

The van driver, who was also the clinic security guard, made sure the van arrived at the church parking lot, usually a half-hour to fifteen minutes, before registration began, so that when the medical assistants arrived they could immediately begin registering patients. When the medical assistants arrived they sat at the registration table and one of them called the first patient to the registration table. The other medical assistant called the next patient and so forth until all patients had been registered. The patient was given a demographic form to complete. Once the patient completed the form, he/she would return to the registration table and the assistant would create a medical chart that included the demographic form and a general description of the reason for the visit. The demographic information was also entered into the computer. When the patient saw the nurse and physician, or the nurse

¹⁹ The only deviation from this is on Thursdays at Saint Augustine Church as there is a gastroenterologist who only sees patients requiring his specialized expertise. Patients see him by appointment and therefore just come to clinic at the scheduled appointment time.

practitioner, he/she would enter more detailed medical information into the computer.

If this was not the patient's first visit he/she was just asked to verify the spelling of his/her name and the demographic information. The medical assistant would have a progress note—a chart made out—for that day, again, with just a general description of why they came to the clinic. If a patient only spoke Spanish the medical assistant asked about any allergies and placed that information in the computer. If the patient was English speaking, the nurses were the ones that asked those questions. The medical assistants would also make sure the patient brought all his/her medication bottles to the clinic. Once registered, the patient sat down with the other patients in the waiting area. The medical assistants and nurses tried to separate the charts between those who needed to be seen in the van and those who did not.

Patients would then be seen by the nurse who took the patient's vital signs and as mentioned above, obtained more detailed information about why the patient was at the clinic. The chart was returned to the registration table. Though the charts were divided between those patients who only needed a consult and those who needed to be examined; the volunteers looked over the chart to make sure the patient was directed to the appropriate location. The staff then called the patient and escorted him/her to the proper health professional. Once the patient saw the physician, or nurse practitioner, he/she left the clinic. If the patient needed diagnostic tests, the medical assistants assisted the patient and instructed him/her about what needed to be done before exiting the clinic.

Methodology

This dissertation is the product of fieldwork carried out in Hartford, Connecticut from November 2012 through July 2013. The primary locus of the fieldwork was in and around the Malta House of Care mobile health van. This research study was approved by the University of Connecticut Institutional Review Board.

I used traditional ethnographic methods, including participant observation and semi-structured ethnographic interviews at each of the four case study sites. I conducted semi-structured interviews with twenty-nine patients, three clinic staff, and two clinic board members. Each interview lasted between one and two hours.

Figure 3 shows a comparison between the ethnic compositions of the patient population of Malta House and that of my sample.

As indicated below, my sample matches almost exactly the ethnicity of Malta House patients. While 92% of all Latinos living in Hartford are Puerto Rican, my sample included only two (6.9%) Puerto Rican patient participants. I attribute this to Puerto Ricans having automatic U.S. citizenship and thus being able to more easily obtain employment or government assistance, such as Medicaid. Of the eleven Blacks interviewed, eight (72.7%) were born in Jamaica. One (9.1%) was from Africa and two (18.2%) were African American. Indeed, like so many Caribbeans, due to the shortage of labor during WWI, Jamaicans came to Hartford to work the tobacco farms in the area. Often, these farms were owned by the same owners of the same farms they worked on in Jamaica. They then brought their families and settled in Hartford, making present day Hartford one of the largest Jamaican communities outside of Jamaica (Bauer 2013:157; Johnson 1995).

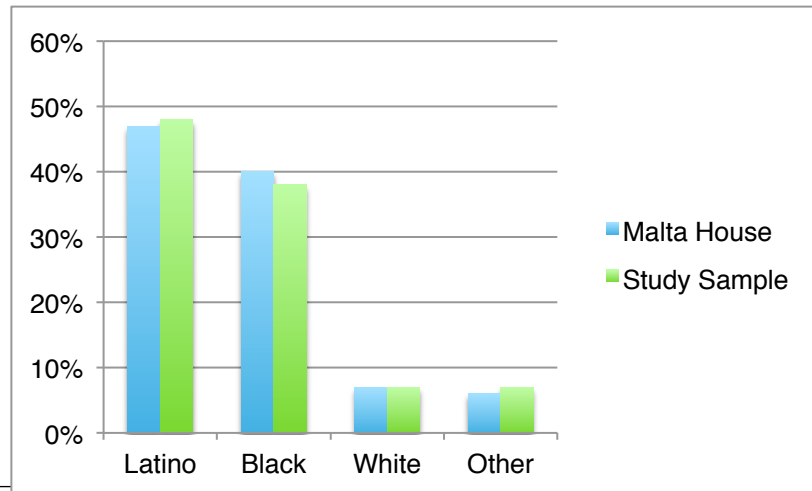


Figure 3
Ethnic Comparison between Malta House Patients and Study

Of the patients interviewed, 27.5% (8 of the 29) were undocumented, and all but one of the undocumented were Latino. Over two-thirds of the patient participants, 65.5% (19), were unemployed at the time of interview and 20.7% (6) worked part-time. One interviewee (3.4%) was self-employed and three (10.3%) worked full-time but either could not afford the health insurance or their place of employment did not offer health insurance. Of the 29 interviewed, 75.9% (22) had an annual household income of less than \$25,000; 17.2% (5) had annual household incomes of \$25,000 or more (see Table 5). Finally, according to staff approximately 70% of Malta House patients lived in the city of Hartford. In my sample 66% (17) of participants lived in Hartford.

Table 5
Income Distribution of Malta House Patient Participants (N= 29)

< \$10,000	41.4%
\$10,000-\$24,999	34.5%
\$25,000-\$39,999	17.2%
\$40,000-\$49,999	3.4%
Did not know household income	3.4%

Participant Interviews²⁰

The interviews elicited patients' narratives concerning strategies they used and the challenges they faced in attempting to meet their health care needs and explanations about how the mobile clinic fit into this process. I also asked patients about their work history, what they thought about health and human rights, knowledge of the Affordable Care Act, and demographic information, including date of birth, family structure, place of birth, education level, and household income (see Appendix One). I did not offer any framing to these questions, as I wanted to ascertain their own conceptualizations of these issues.

To recruit patients for the study, I introduced myself to each patient in the church hall waiting to be seen by the Malta House of Care nurse or physician, explained my research and gave each a letter with my contact information. A few patients called me to set up an interview but most who agreed to be interviewed set up the interview prior to leaving the church. Most of the patient interviews were conducted in the patient's home and some were conducted in a private spot in the church hall. To participate in the study patients had to be at least 18 years old, have a chronic illness, and be uninsured for at least three months at time of interview. As I came to know the staff through participant observation and explained my research, I would ask if they would agree to an interview.

²⁰ Based on participant observation it was clear to me that patients tended to go to the same site and were predominantly Latino and Black. Patients who went to the Saint Peter Church site in downtown Hartford were predominantly Latinos, followed by Blacks. The Saint Augustine site saw more Euro-American patients than the other three sites, but there were also a large number of Latinos and Blacks. Sacred Heart Church in the Clay Arsenal/North End neighborhood was predominantly Black, in particular persons of West Indian descent. Finally, Saint Joseph Cathedral saw about as many Latinos as Blacks, but was also a mix because this is the only site that is open late. In chatting with the staff and boardmembers, they also believed this was the case and thought that proximity to their home was the main reason. That is, patients went to the clinic site closest and most convenient to where they lived.

Three staff agreed to be interviewed. These interviews shed light about the main health perspectives on the health care system (see Appendix Two). Through staff members I was able to recruit and interview two board members to understand the historical framework of how and why the mobile van began. Furthermore, I explored the van's mission and future from the board member's perspective (see Appendix Three).

A written consent form was given, read and signed by each participant prior to the interview. No one who agreed to be interviewed refused to sign the consent form. All material was written in English and Spanish and interviews were conducted in English or Spanish for those who were Spanish speaking. I conducted and transcribed the interview, as I am fluent in Spanish and English. I obtained permission from the participants to digitally record the interviews. Nearly all participants agreed to have the interview recorded. In the cases where the participant did not want the interview recorded I took extensive notes during the interview. Field notes and interviews were analyzed to identify patterns and themes to describe the meaning and experiences of being uninsured.

Limitations of the Study

Though I attempted to recruit patients from all four sites, most of the participants who agreed to be interviewed came from Saint Peter Church and Saint Augustine Church. Interestingly, more patients tended to go to the Saint Peter Church and Saint Augustine Church sites than the other two sites. This may have been due to volume (more patients seemed to have attended the Saint Peter and Saint Augustine sites than the other two sites).

Ethical Issues

There were times when the lines between researcher and participant were blurred. I would be asked to translate for the nurses in the waiting area and once I was asked to translate for the medical director, also in the waiting area, as the medical assistants were occupied with other patients or otherwise not available. Since being part of the medical interview was not part of my research I was hesitant but in the end helped the nurses and the medical director out by translating for them. I justified my decision reasoning that the patients may have to wait longer than they already have or may not get seen because no one was available to translate for them. However, in this dissertation, I did not use any of the information I learned while translating.

The City of Hartford Past and Present

During the colonial period Hartford and its surroundings were dominated by an Agrarian economy. By the early 19th century, however, Hartford was already a non-agrarian economy establishing banks and large insurance companies (Chen and Shemo 2013; Walsh 2013). A strong manufacturing base developed in Hartford in the mid-19th century, requiring manufacturing labor in machine tools and gun manufacturing, the latter a result of Colt Firearms (Chen and Shemo 2013). As Andrew Walsh (2013:27) notes:

“[d]uring the 1850s and 1860s, Colt Firearms proved to be a critical incubator for industrial talent, with Colt workers spinning off into separate enterprises, especially in machine tools, creating companies like Pratt...for many decades.”

Industrialization in Hartford and the region was hampered by lack of labor. Massive migration from Europe, particularly from Ireland in the mid-1800s brought

much needed labor to Hartford and the region. At the end of the 19th century, Hartford became an important industrial driving force, developing large manufacturing corporations, and was one of the wealthiest regions in the country.

It was precisely at this time that Hartford, which was comprised of 87 square miles, was redrawn and split into what is now West Hartford, East Hartford, and Manchester. Hartford was reduced to its present almost 18 square miles. The large manufacturing corporations required even more labor. Migration, particularly from Eastern and Southern Europe filled this void. However, when new immigration laws were established in 1924 and 1925, Hartford had to search for labor elsewhere. It was at this time that African Americans from the U.S. South migrated to the area, with later migration coming from the Caribbean. Manufacturing continued to be an important economic force in Hartford during WWII and Hartford's population peaked during this time (Walsh 2013).

The post WWII era saw massive 'white flight' to the suburbs, a consequence of interstate highway construction, the GI Bill, and Federal Housing policies, which severely constrained people of color from moving to these same areas (Adelman 2003; Lee 2008; Walsh 2013). By the 1970s, Hartford was about half white (Walsh 2013:35) and by 2012 the city was 17. 2% white, 34.1% Black or African American, and 43.3% Latino, with 40% of the Latinos being Puerto Rican, 2.6% Mexican, and 6.6% South or Central American (U.S. Census Bureau 2012a). Thus, post-WWII economic prosperity and prejudicial government policies directed resources to segregated white suburbs, while once prosperous cities, like Hartford, fell into decline (Bauer 2013; Lee 2008). reduced to 10,000 with most of those disappearing by the 1990s (Walsh 2013).

While the insurance companies fared better in Hartford, at least until the financial crisis of 2008, there were few employment opportunities for Hartford residents who did not have the educational qualifications needed to procure work in this industry.

Furthermore, by the first decade of the 21st century many insurance companies moved their operations to suburban Hartford communities (Chen and Shemo 2013:210-215).

This made it difficult for Hartford residents who did not have access to an automobile to travel to these communities (Rojas and Wray 2013:243-244).

Indeed, in 2012, 43% worked very few hours or were unemployed (see Table 6). Furthermore, Hartford's current unemployment rate is 12.4%, higher than any other town or city in Connecticut (Connecticut Department of Labor 2014) and the employment situation is directly connected to poverty (see Table 7). My sample had a higher poverty level most likely due to a higher percentage who were unemployed (see Table 8).

Furthermore, 21.7% of Hartford households have annual incomes below \$10,000, and 25% of households have an annual income of between \$10,000 and \$25,000. The median annual household income in Hartford is \$27,753 (U.S. Census Bureau 2012b). The structural factors described above have led to Hartford becoming one of the poorest cities in the country since the 1970s (Bauer 2013; Walsh 2013). Yet, Greater Hartford is one of the wealthiest regions in the country (Bacon 2013; Chen and Shemo 2013; Walsh 2013).²¹

²¹ I use The Federal Office of Management and Budget Metropolitan Statistical Area (MSA) as defined in hartfordinfo.org to refer to Greater Hartford. See hartfordinfo.org (2012) for a map of Hartford's MSA.

Table 6
Employment Characteristics of Hartford Residents, Ages 16-64

Full-time or near full-time	41.0%
Part-time (less than 35 hours per week)	16.1%
One to fourteen hours per week	4.1%
Unemployed	38.9%

(Source: U.S. Census Bureau 2012c)

Table 7
Employment Characteristics of Interviewees²²

Full-time or near full-time	10.3%
Part-time (less than 35 hours per week)	17.2%
Unemployed	65.5%
Other ²³	6.8%

Table 8
Annual Household Income of Hartford Residents

Less than \$10,000	17.4%
\$10,000-\$24,999	30.3%
\$25,000-\$34,999	12.6%
\$35,000-\$49,999	12.1%

(U.S. Census Bureau 2013)

Conclusion

Malta House of Care came into existence to fill a need. Specifically, it serves the uninsured, including those who are undocumented, in meeting at least some of their health care needs. The mobile van set up sites in four different locations to try to

²² Numbers do not add up to 100 due to rounding

²³ One interviewee was self-employed and one worked two part-time jobs that equaled more than 35 hours per week.

cover as much of the area as possible.²⁴ Most of the participants interviewed were struggling financially and most lived in the city of Hartford, one of the poorest cities in the country. The mobile van set up sites in four different locations to try to cover as much of the area as possible.²⁴ Hartford's past and present is reflected in participants' narratives: stories of underemployment and unemployment, and of doing without. Their stories, which will be detailed in chapter four, will demonstrate the struggles and challenges they face particularly as it affects their health and well-being.

²⁴ Malta House of Care does not offer specialty care. The only exception is a gastroenterologist who volunteers at Malta House and only sees patients who have gastroenterological issues.

Chapter Three: Theoretical Frameworks

Introduction

Since the Industrial Revolution health professionals, social scientists and activists have been concerned about health and healthcare. Eric Wolf, for example, was one of the first anthropologists to take into account the historical context within which the economic relationship between the core and peripheral areas of the world came into view. With increases in the flow of people both internally (rural to city) and externally, particularly over the last three decades, social scientists have turned their attention to migration. Indeed, 80% of the patients I interviewed were born outside the United States.

This review of the literature, therefore, provides a framework that undergirds the research for understanding the main concepts underlying the ways in which Malta House patients made sense of their health care experiences. The chapter is divided into three sections: critical medical anthropology; human rights and deservingness, particularly as it pertains to health care; and migration theories. Within critical medical anthropology, structural violence, liberation theology and critical race theory are discussed. The chapter concludes with a discussion of key migration theories: neoclassical economics and new economic labor migration; world systems theory and migration; migration systems and networks; and the migration industry.

Critical Medical Anthropology

Critical medical anthropology (CMA) has its roots in the works of Karl Marx, Friedrich Engels, the Frankfurt School, and Rudolph Virchow, a German physician of

the mid-nineteenth century, and the founder of the German Anthropological Association, who is known as the “father of social medicine” for his work linking illness and disease to material deprivation (Baer et al. 2003b:37; Singer and Baer 2007:15; Waitzkin 1981). Virchow asserted that disease was a result of social organization, that is, it was socially produced (Scambler 2012).

In 1847 a typhus epidemic struck in Upper Silesia, a poor area of East Prussia. Virchow was convinced, based on his observations of the disease and the living conditions of the poor there that hunger and crowded housing were key factors in the spread of the disease (Scambler 2012). He also blamed the medical profession for their unwillingness to care for the poor because they could not pay for their care (Waitzkin 1981:84-85).

Critical medical anthropology (CMA) acknowledges and incorporates political economy in its analysis of health, health care, and health behavior (Singer 2004; Waitzkin 2000). It brings to light the ways in which political and economic forces construct health, disease, illness experience, health care access, and the quality of health care (Baer et al. 2003b; Morsy 1995; Singer and Baer 1995). As Wermuth (2003:21) states

[p]olitical economy embraces considerations of global and economic forces, the state, government, social classes, public administration, policy making, and the distribution of resources between and among populations...Political economy adds the dimension of power as institutionalized and wielded by a variety of social groups, organizations, and agencies. These institutional arrangements affect individuals' lives.

CMA research focuses on how people experience illness and links those experiences to larger systemic forces within society, e.g., the health care system, class divisions, and the political structure (Baer et al. 1986; Morsy 1979; Singer 1990). This

approach works on “the belief that social inequality and power are primary determinants of health and health care” (Baer et al. 2003a:3). As Merrill Singer (2004:26) wrote “...within CMA health is defined as access to and control over the basic material and non-material resources that sustain and promote life at a high level of satisfaction.” Kim et al. (2000a), for example, highlight how global inequality affects the health of the most vulnerable.

CMA has also been influenced by world system theory. Incorporating the world system perspective, critical medical anthropology is a theoretical framework useful to understanding the social origins of health, medicine, illness and disease, in a global, systemic context.

World System Theory posits that since the 16th century Europe and the Americas were already a world economic system that over time extended to cover the entire globe marked by the endless accumulation of capital, i.e. the world economy is a capitalist world economy. Nation states are tied together by this economic system with a specific division of labor in what Wallerstein (2004) calls core, semi-peripheral, and peripheral nation states. For example, while management headquarters may be in a core nation the actual production of the product is in peripheral or semi-peripheral nation states. The World System also involves a special relationship between the owners of production, capitalists and governments. Free trade, as Wallerstein (2004) notes, is not really free. The World Bank (WB), the International Monetary Fund (IMF), and the WTO (World Trade Organization) are predominately controlled by the core nation-states, i.e. the wealthy countries (Global Exchange 2011). These three organizations control the flow of goods, services, and capital as well as powerful, individual, nation-states. In

short, World Systems Theory is an analysis of the unequal relations of power among various regions of the world and the intersection and power play between economics and politics. One outcome of this power relationship is the economic and political paradigm of the late 20th and early 21st century, known as neoliberalism.

Neoliberalism is an ideology and policy that emphasizes the supremacy of a competition driven economy through privatization of all sorts of services, goods, and markets (Breda 2009:7; Coburn 2000; Esposito 2011; Farmer 2003b:5; Harvey 2006a:2; Navarro 2007).

Neoliberalism has not only made the poor poorer and the rich richer, but it has also pushed more people into poverty, such that the gap between rich and poor is greater today than it has been in decades (Harvey 2006b). Therefore, regarding issues related to health, Ray Elling states that biomedicine “must be seen in the context of the capitalist world system” (quoted in Baer et al. 2003b:40).

Agribusinesses, food corporations, industrial corporations, drug corporations, and medical technology corporations, all impact health, especially, the health of the poor. Indeed many people living in the world’s urban areas live under conditions of poverty, marginalization, and discrimination. The U.S. urban population, for example, is made up mostly of poor Latinos, African-Americans, and immigrants (U.S. Census Bureau 2011), a condition, according to critical race theorists, shaped by history and economic and power relationships leading to racism, itself a cultural construction (Delgado and Stefancic 2012). Critical race theorists analyze how power differentials negatively impact people of color. This is similar to critical medical anthropology’s analysis of how unequal power relations, including unequal power based on gender, class, and race,

affect health and illness.

For example, according to Ilene Hyman (2009) racism, also a factor in Canada, impacts health through the body's physiological stress response (Gravlee 2009; Krieger 2000a:63-64; Krieger and Smith 2004). In Canadian urban centers minority groups are two to three times more likely to be poor than other Canadians. Moreover, studies have linked poor health to the daily stress of living in poverty (Coburn 2000; Lynam and Cowley 2007), which seems to trigger a neuro-endocrinologic response that over time can weaken the body's resistance (Isaacs and Schroeder 2004). In addition, population density, infectious diseases, environment, and unhealthy lifestyles are issues affecting urban populations across the globe (as well as having impacts on the immune system).

Health policy is another area in which critical medical anthropology has made a contribution. For example, Castro and Singer (2004), in their edited volume on health policy, bring together various scholars, over half of whom are anthropologists, to analyze the connection between political economy and health policy, and its impact at the local level, in various contexts and geographic locations. The studies in this volume point to the ways in which health care policies in various cultural settings lead to detrimental health outcomes particularly for the most vulnerable in various regions of the world.

CMA is applied as well to the examination of social suffering (Biehl and Moran-Thomas 2009; Green 1998; Kleinman et al. 1997; Quesada 1998; Scheper-Hughes 1996; Singer 2006; Singer et al. 1992; Tapias 2006; Victora 2011). "Social suffering results from what political, economic, and institutional power does to people and reciprocally, from how these forms of power themselves influence responses to social

problems” (Kleinman et al. 1997:ix). In other words, physical and emotional suffering are both linked to socioeconomic inequalities, racism, political oppression, and other forms of power. Indeed, it is the poor and marginalized who are negatively impacted in our modern and capitalist economies due to the unequal allocation of material, social, and symbolic capital (Benson et al. 2008; Farmer 2003b).

Melanie Rock (2003), incorporating social suffering in her analysis of diabetes and mental health among the Cree aboriginal people of Northern Quebec, Canada, asserts that the onslaught of AIDS and its overlapping connections with racist ideologies, poverty and marginalization have contributed to the centrality of social suffering within anthropology.²⁵ She further argues (2003:158) that social suffering and social determinants of health are connected.

In keeping with the tenets of social epidemiology, the social suffering research agenda views disease and death rates as indexing social structures. To the extent that anthropology and epidemiology knowingly express a moral code with global aspirations, an academic interest in social justice is served.

Critical medical anthropology’s analysis of social origins of illness (Baer et al. 2003a; Frankenberg 1980; Singer 2004a) intersects with social epidemiology and public health in their concern with social determinants of health. As Baer et al (2003b:53) point out

CMA seeks to understand the social origin of disease, all disease. It shares this concern with other critical social scientists and public health researchers. Like the latter, critical medical anthropologists endeavor to identify the political, economic, social structural, and environmental and environmental conditions in all societies that contribute to the etiology of disease.

²⁵ For an extended analysis of AIDS and social suffering see (Farmer 1992; Farmer and Kleinman 1989).

Interest in the social origins of illness, and conversely the social determinants of health are the non-biological factors that affect health, income, education, occupation, environment, and diet, to name a few and it is important to understand the real causes of these determinants, namely the social system (Link and Phelan 1995; Scambler 2012). The processes by which poverty causes illness include spread of pathogens due to unhealthy living conditions, fragile or non-existent social support networks, and weakened immunity and neurophysiological development due to malnutrition (Nguyen and Peschard 2003). Another factor in health status is the gradient in health, that is, the effects of hierarchy. In other words, the higher you are in the social hierarchy, the better your health status and vice versa. For example, two of the most famous studies conducted on this topic were the Whitehall Studies. These studies showed an inverse relationship in the prevalence of ischemic heart disease, a shortage of blood and oxygen to the heart, between those in the lowest and highest employment grades of British Civil Servants in London, England. Furthermore, in the twenty years between Whitehall Study I and Whitehall Study II there was a greater difference in the prevalence of ischemic heart disease in the second Whitehall Study than in the first (Marmot and Smith 1991; Marmot et al. 1978). Like CMA, the Whitehall studies point to the significance of unequal class relations in illness experiences. The Whitehall studies, of course, focused specifically on ischemic heart disease (see also Marmot 2004).

Class disparities also exist in the United States, and having access to good medical care is predicated upon having health insurance. According to the U.S. Census (U.S. Census Bureau 2010a), 12.7% of those born in the U.S. are uninsured, while 34.3% of all immigrants, documented and undocumented, are uninsured.

The relationship between class and health in the United States is striking. Galea et al. (2011) note that in the United States about 245,000 deaths in the year 2000 were associated with low education, 133,000 with poverty and 119,000 with income inequality.

Class disparities, however, do not draw the same kind of attention as racial/ethnic disparities. As Isaacs and Schroeder (2004:1137) state, “Americans like to believe that they live in a society with such potential for upward mobility that every citizen’s socioeconomic status is fluid.” Nonetheless the gap between the rich and poor within the United States has increased since the 1980s.

According to Domhoff (2013), a great majority of the U.S. population owns less than 5% of financial wealth, defined as total net worth minus the value of one’s house (see Figure 4).

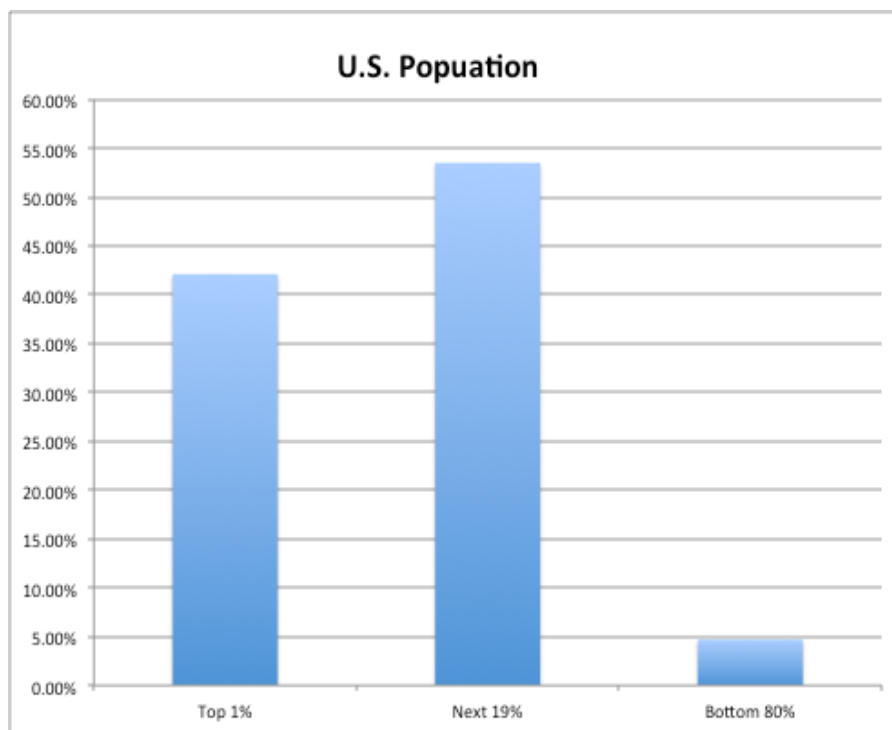


Figure 4
Financial Net Worth of U.S. Population

It is important to note that this has had an enormous impact on population health not just on the poor but the rich as well. In other words, those who live in countries where the distribution of wealth is more equal even the rich have better health outcomes than the rich who live in more unequal societies (Wilkinson and Pickett 2009).

This is evident in the European Union, the Nordic countries and in Eastern and Central Europe where the differences in life expectancy for men at age 15 in 1970 among the three regions were two years. By 1994 the differences increased to six years with life expectancy increasing in the Nordic countries and the European Union and remaining the same or worsening in Central and Eastern Europe (Marmot 1999). In Sweden and Iceland life expectancy for men is 78 years but in Russia it is 58 years (Marmot and Wilkinson 2006:1). When comparing per capita gross national income between the core and peripheral countries, Merrill Singer (2007:43) writes

In 1960, the difference between the richest 20 percent of the world's population and the poorest 20 percent was 30 to one, by 1990 it had reached 60 to one, and by 1997 was 74 to one, at which point the wealthiest 20 percent of the world's population was consuming 86 percent of the world's gross domestic product and the poorest 20 percent had access to only one percent.

Figure 5 is a snapshot of the gap between rich and poor for 1990 (light blue), 2000 (dark blue), and 2007 (darkest blue) (Ortiz and Cummins 2011). This global inequality is a reflection of opposing class interests, which influence government policies (Singer 2007), and is a factor in structural violence. Medical anthropologists working within the CMA framework have brought to light how structural violence affects people the world over (Bourgois 2003 and 2004; Farmer 1996, 2003a and 2004; Quesada et al. 2011; Scheper-Hughes 1992). Structural violence refers to violence driven systematically by economic conditions and political exclusion involving the social

machinery of oppression. Johan Galtung (1969:170-171), known as the father of peace studies, first coined the term structural violence in 1969, thus it is worth quoting him at length.

...individuals may be killed or mutilated, hit or hurt, in both senses of these words, and manipulated by means of stick or carrot strategies. ...But there may not be any person who directly harms another person in the structure. The violence is built into the structure and shows up as unequal power and consequently as unequal life and consequently as unequal life chances... *Resources* are unevenly distributed, as when income distributions are heavily skewed, literacy/education unevenly distributed, medical services existent in some districts and for some groups only, and so on. Above all, the *power to decide over the distribution of resources* is unevenly distributed. The situation is aggravated further if the persons low on income are also low in education, low on health, and low on power—as is frequently the case because these rank dimensions tend to be heavily correlated due to the way they are tied together in the social structure (*italics in original*).

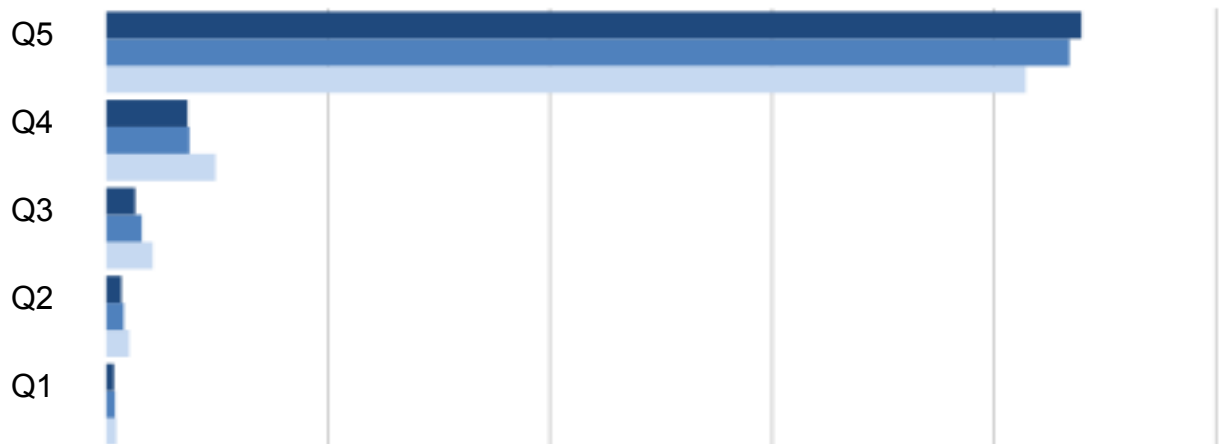


Figure 5
Global Income Distribution by Population Quintiles, 1990-2007 (or latest available) in 2000 U.S. Dollars

Source: Ortiz's and Cummins' calculations using World Bank (2011), UNU-WIDER (2008) and Eurostat (2011)

The systemic nature of the oppression gives it a sanctioned quality (Singer 2007), such as the structure of the health care system in the United States whereby undocumented immigrants are even excluded from the new health care law passed in

2010 (Artiga et al. 2009). Structural violence affects not only the poor, but also the uninsured, people of color, the sexually stigmatized, those who are or have been imprisoned, and those with drug and alcohol problems (Quesada et al. 2011). Philippe Bourgois (2003; 2004) examines structural violence in street drug culture in a New York City Puerto Rican neighborhood. Marginalization, discrimination, unemployment, and poverty are themes he examines in street drug dealers' pursuit of dignity and respect. Nancy Scheper-Hughes (1992) calls this "the violence of everyday life".

Violence is characteristically thought of as physical harm, and blame, or praise, placed on individual actors, what Paul Farmer (2004:308) calls "the erosion of social awareness" or "desocialization", or as Marx would have said, false consciousness. Structural violence, however, emphasizes societal, institutional, and structural dimensions of suffering, including the role of corporations, markets, and governments in furthering various kinds of harm in populations. Anthropologists have attempted to "resocialize" suffering created by structural violence by locating its origins in political-economic processes, social structures, and cultural ideologies (Benson 2008:590). Anthropologists have also brought attention to the relationship between physical violence and structural violence (Benson et al. 2008; Bourgois 2003; Heggenhougen 2009; Quesada 2009; Rylko-Bauer and Singer 2011; Singer and Hodge 2010; Susser 1998). Adrienne Pine (2010), for example, documents how state violence and neoliberalism are experienced by the poor and most vulnerable. Clarkin (2010) shows how malnutrition, including prenatal nutrition, during times of war have long lasting effects even after hostilities cease. As Rylko-Bauer and Singer note (2011) "the realities of war...[have] lasting degrading and negatives effects on human well-being."

Neoliberal structural adjustment policies have had an impact on structural violence, and have also been a focus of critical medical anthropology (Farmer 2000; Kim et al. 2000a; Paluzzi 2004). Structural adjustment policies (SAPs) refer to policies pressured onto developing countries by international financial institutions (IFIs) such as the IMF and the WB (which Kim now heads) to privatize public services and remove trade and investment barriers according to the neoliberal ideology that market efficiency will produce economic growth which will then reduce global poverty (Gershman and Irwin 2000; Pfeiffer and Chapman 2010). Armada and Muntaner (2004) analyze the impact SAPs have had on health reforms in Latin America. Towghi (2004), Chapman (2003) and Maupin (2008) examine SAP's influence on women's reproductive health. Kim et al. (2000b) highlight how SAPs not only affected the health of the poor in Peru, but also led to decreased wages and unemployment. Indeed, structural adjustment policies have been an important consequence of migration both within national borders, from rural areas to urban centers, and internationally as people search for work to improve not just their own individual economic situation, but also that of their families who are often left behind (Chavez 2013; Chomsky 2007; Holmes 2013).

Quesada et al. (2011) invoke the term "structural vulnerability" to expand the concept of structural violence to include not only political-economic factors, but also cultural factors and particular sources of physical and psychodynamic distress. These include social configurations supported by symbolic categories of worthiness, and the juncture of individual pathology and biography with marginalization. Thus vulnerability is produced by one's location in a hierarchical social order and in power relations and effects (Green 2011; Holmes 2011). Structural vulnerability has commonalities with

CMA in that both perspectives seek to interrogate the social and economic causes of people's marginalization and poverty. Structural vulnerability criticizes the concept of agency in that among the poor and marginalized decision-making and choices are limited, thereby limiting their agency (Quesada et al. 2011). By agency, I mean the decision-making power and choices an individual has at his/her disposal. The more power and wealth one has, the more decision-making power and choices, i.e. agency, one has available. Thus, structural forces constrain the choices that people can make. Critical medical anthropologists thus argue that experience and "agency" are "constructed and reconstructed in the action arena between socially constituted categories of meaning and the political-economic forces that shape the context [and texture] of daily life" (Baer et al. 2003b:44). In other words, they argue "people develop their own individual and collective understandings and responses to illness and to other threats to their well-being, but they do so in a world that is not of their own making, a world in which inequality of access to health care, the media, productive resources (e.g., land, water), and valued social statuses play a significant role in their daily options" (Singer and Baer 2012:38).

Regarding health care for example, in the United States, a poor, unemployed individual's choices regarding where and with whom to seek health care, are vastly different from those of a CEO of a major corporation. As anthropologist Thomas Leatherman (2005:53) notes,

A space of vulnerability...configures a specific set of conditions in which people live, and set constraints on how these conditions are perceived, how goals are prioritized, what sorts of actions and responses might seem appropriate, and which ones are possible.

This was evident in narratives of several participants in my study. For instance, Catarina,

like other participants, lost her job, and believed the stress she felt was a result of the loss of financial security, which affected her spending patterns *and* her health (see chapter four). She used to send remittances back to her family in Peru, but since she became unemployed, she was no longer able to do so.

A focus on structural violence has many commonalities with liberation theology (Berryman 1987; Farmer 2003b; Quesada et al. 2011), and CMA. Liberation theology, like CMA, is a critique of the economic structures that allow the few to amass enormous wealth while so many struggle to survive (Berryman 1987).

...poverty is not merely the lack of adequate financial resources. It entails a more profound kind of deprivation, a denial of full participation in the economic, social, and political life of society and an inability to influence decisions that affect one's life. It means being powerless in a way that assaults not only one's pocketbook but also one's fundamental human dignity..." (National Conference of Catholic Bishops 1986:43).

Liberation theology, or the 'preferential option for the poor', is a movement, a theory, and a philosophy that began within the Catholic Church in Latin America (Griffin and Block 2013; Gutiérrez 1973). Yet, one does not necessarily need to be Catholic, nor subscribe to any other religious belief to adhere to the key tenets of liberation theology. These key tenets are ecumenical (Farmer 2013). Furthermore, U.S. Catholic Bishops (National Conference of Catholic Bishops 1986) also argued that human rights must include not just civil and political rights but also economic rights. In addition, Paul Farmer (2013) argues that liberation theologians have underscored the shortcomings of the liberal human rights movements even those countries that have been signatories to human rights documents. The implication, therefore, is that despite countries signing onto human rights documents, they nonetheless, at the very least, turn a blind eye to human rights violations within their borders, and at worst, are perpetrators of human

rights violations.

In summary, liberation theology *and* CMA offer a critique of structural violence and structural vulnerability. In his 2014 Lenten message Pope Francis (who was an active opponent of liberation theory while in South America) now states:

Material destitution...affects those living in conditions opposed to human dignity: those who lack basic rights and needs such as food, water, hygiene, work and the opportunity to develop and grow culturally... Our efforts are also directed to ending violations of human dignity, discrimination and abuse in the world, for these are so often the cause of destitution. When power, luxury and money become idols, they take priority over the need for a fair distribution of wealth. Our consciences thus need to be converted to justice, equality, simplicity and sharing (2014:Our Witness).

Dr. M., for example, spoke about her religious consciousness and volunteering for Malta House as a form of commitment to social justice in caring for those who have nowhere else to go for primary health care.

Human rights and deservingness are discussed in the following section.

The Right to Health and Deservingness

Within anthropology, human rights has been a contentious issue since human rights were first codified in the United Nations Universal Declaration of Human Rights in 1948 (Goodale 2006; Messer 1993; Messer 1997; Nader 2006; Riles 2006). Historically anthropologists had misgivings about the declaration on the grounds that a universal framework did not reflect various cultural values, particularly non-Western cultural values (Brandt and Rozin 1997; Goodale 2006; Messer 1993; Messer 1997; Nader 2006). Nader contends that human rights is a form of “moral imperialism” (2006:6). Wilson and others argue, however, the human rights framework has expanded to include collectivist and indigenous rights (Messer 1993; Messer 1997; Wilson 2006;

Wilson 2006a).

Worker's rights of nineteenth century industrialization and socialist principles influenced human rights discourse (Ishay 2004; cf. Messer 1997; Nowak 2003). However, human rights did not become part of the general lexicon until 1948 with the passage of the Universal Declaration of Human Rights (UDHR) by the United Nations.

In contrast, taking into consideration the obstacles to realizing well-being (e.g. discrimination of all sorts, structural violence, and poverty, Singer (2004:26), using the critical medical anthropology perspective, defines health as "access to and control over the basic material and non-material resources that sustain and promote life at a high level of satisfaction." Thus, human rights, including the right to health, are applied dimensions of critical medical anthropology. Didier Fassin and Paul Farmer, both medical anthropologists and physicians, use critical medical anthropology to advocate for the right to health among the marginalized populations with whom they work while simultaneously work with them to meet their health care needs. Merrill Singer used critical medical anthropology in health praxis among the urban poor. As Baer et al (2003c:356) point out

...many critical medical anthropologists work as health activists for women's health collectives, free clinics, ethnic community health centers, environmental groups, AIDS patient advocacy efforts, antismoking pro-health groups, national health reform groups, and nongovernmental organizations (NGOs) in the Third World.

Human rights scholars and activists assert that social and economic rights cannot be separated from civil and political rights (Farmer 2003b; Gruskin et al. 2007:450; (Harvard Law School Human Rights Program and François-Xavier Bagnoud Center for Health and Human Rights Harvard School of Public Health 1993); Leary

1994; London 2008; Sen 2003). Indeed, without social and economic power it is difficult, if not impossible for people to exercise their civil and political rights. Farmer (2003b:16-17) asserts "...when we look at and listen to those whose rights are being trampled, we see...how the absence of social and economic power empties political rights of their substance." Furthermore, civil and political rights have had wider support than economic, social, and cultural rights. Moreover, countries that are signatories to human rights documents ignore, or worse, violate, human rights agreements (Farmer 2003b; Farmer and Gastineau 2002). The United States signed onto the U.N. International Covenant of Economic, Social, and Cultural Rights but never ratified it (United Nations Office of the High Commissioner for Human Rights 2014) and has been wary of recognizing economic, social and cultural rights as "rights" (Piccard 2010).

Structural adjustment policies, as part of the neoliberal project, have led to changes in health policy in many parts of the world (Castro and Singer 2004), thus denying many the right to health care. Yet in some cases, these neoliberal policies regarding health have been challenged. The Brazilian government, for example, eschewed the free-market, neoliberal approach in health care access and treatment for those with AIDS. As Abadía-Barrero and Brigeiro (2007:19) observe, "...people did not need to negotiate their health and right to live."

While the right to health seems to imply that institutions must guarantee one's good health, in human rights law this is not how the term is understood. As it is used in human rights law, it refers to the more detailed elements in international treaties (Leary 1994). Article 25(1) of the UDHR (1948) states:

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control (United Nations 1948).

While the Declaration specifies the right to medical care, it does not specify what health is, only that one has the right to living standards adequate for health and well-being. The Constitution of the World Health Organization (1946), however, does define health and acknowledges health as a fundamental right:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity... The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

Yet, as Wolff (2012:6) points out the right to medical care and the right to a certain level of health are not the same things. One can achieve “high levels of health” through sanitation, nutrition, safe working conditions, etc., which does not require medical care per se. Medical care expenditures may not may not lead to “decent population health” (Wolff 2012:6; See also Sen 2008).

Since then, other human rights documents offer yet more specificity of the human right to health. Article 12 of the International Covenant on Economic, Social, and Cultural Rights (1966), for example, includes language of governments’ obligation to improve environmental and industrial hygiene, reduce infant mortality and ensure the health development of the child, prevention of diseases and “[t]he creation of conditions which would assure to all medical service and medical attention in the event of sickness.” Thus, in the ICESR, the right to health includes the right to health care, at least when sickness occurs. Yet, as delineated in General Comment 14, Article 8 of the

(Committee on Economic, Social and Cultural Rights 2000), “[t]he right to health is not [the same] as a right to be *healthy*” (italics in original). Indeed, Article 11 asserts that a right to health is more than a right to medical care. It includes other factors, such as safe drinking water, adequate housing and nutrition a healthy environment. Besides this legal orientation to a right to health, other orientations include ethical approaches based on moral philosophy, symbolic approaches, policy-making approaches and what the right ot health means in the clinical arena (Willen 2011:308).

The ‘right to health’ has been controversial in the United States. While the concept of the ‘right to health care’ offers more specificity, this concept has also been controversial. One perspective is to view a right to health care as an issue of equality and justice using the language of human rights, while an opposing perspective is one in which a right to health care is coercive and imposes a redistribution of one’s resources (Leary 1994). Furthermore, who has a right to health care, i.e. who is deserving of the right to health care, has been a contentious issue in the United States, and elsewhere (Abadia Barrero et al. 2012; Abadía-Barrero and Oviedo 2009; Castañeda 2011; Willen 2011).

Discourses of citizenship and who is deserving of rights also impact health. The concept of deservedness has had a long history in the U.S. Indeed, since the 18th century relief for the poor has been decided by those with influence and power. They had the authority to determine who was deserving and not deserving of assistance. Ideas about who are the “deserving poor” dates back to late 16th century Europe and were shaped by the capitalist system and the need for low wage workers (Piven and Cloward 1993; Wagner 2005). Furthermore, in the U.S., deservedness has been

racialized (Katznelson 2005b; Neubeck and Cazenave 2001). For example, during the New Deal the Social Security Act excluded farm laborers, domestic workers and personal service workers, jobs held predominantly by people of color (Katznelson 2005a).

The welfare reform legislation of 1996 that significantly reduced public assistance to poor women was also racialized in that “[i]t particularly affected women of color because women of color are disproportionately poor” (Susser 2009:93). Furthermore, as Michael Katz (2010:519) argues, there is a distinction between “public assistance and social insurance”, both government assistance programs. Public assistance is for the ‘undeserving’ poor, e.g., poor single mothers while social insurance is for the ‘deserving’ poor, e.g. unemployment insurance. Finally, regarding inequality and class, Dorothy Roberts asserts that “corporate tax breaks...reveal that most welfare helps Americans who are not in fact poor” (1995:2612). The wealthy deserve government assistance, the poor do not, especially those deemed the ‘undeserving’ poor. Public policy rewards those at the top at the expense of those at the bottom. For example, in discussing U.S. welfare reform Singer argues “[It] helped create a workforce for [those] bottom-of-the-pay-scale jobs that nonetheless help corporations to reap bountiful benefits” (2007:44).

In California, for example, a heated topic in the early 1990s centered on whom had the right to use government social services and who did not. Undocumented immigrants can receive prenatal care and primary and high school education, but they cannot receive government assistance for health care (Zavella 2001:110).

Indeed, citizenship is about belonging, about who *deserves* to belong and who does not. Such configurations impact the most vulnerable among us, including the

poor and undocumented²⁶ (Briggs and Mantini-Briggs 2004; Chavez 2008; Fassin 2004; Horton 2004; Marrow 2012; Willen 2011; 2012b). As Chavez (2008) explains, meanings of citizen and non-citizen are made visible in who is included and who is not, who can claim membership in community and who cannot (See also Briggs and Mantini-Briggs 2004).

The political realities, and local politics, of community membership are exemplified in Marrow's study of public safety-net primary care providers who provide care to, among other populations, undocumented immigrants in San Francisco (Marrow 2012). San Francisco has established local government policies, Healthy San Francisco (HSF), to facilitate primary care health care access and services for undocumented immigrants in the city (Marrow 2012:847). Marrow (2012) notes four different discourses among providers regarding undocumented immigrants' deservingness of healthcare: 1) a human right—all people have a right to health care; 2) humanitarianism—providers have the ethical obligation to give care to everyone who needs it; 3) public health—providing care will decrease the population at large from contracting communicable diseases; and 4) social justice—that disadvantaged and underserved groups should be able to at least get basic care.²⁷

Marrow (2012) found that providers' trepidations about unauthorized immigrants were fiscal, not moral, though some providers and lower-level staff expressed views towards undocumented immigrants as less deserving of government sponsored health

²⁶ As previously mentioned, the Affordable Care Act excludes undocumented immigrants. Furthermore, 16 states have not adopted Medicaid expansion (Connecticut has adopted the expansion), and seven states are discussing expanding Medicaid (Kaiser Family Foundation 2014).

²⁷ While Marrow uses the term "unauthorized" for immigrants who do not have legal residency status, I use the more common term undocumented (see also (Chomsky 2014b) for an extended discussion of the term's meaning.

care citing limited public financial resources that should be reserved for citizens and 'legal' residents. However, even providers who expressed these views also believed giving care to undocumented immigrants was the proper thing to do ethically from a humanitarian and human rights point of view (Marrow 2012). Thus, Marrow contends that the local policy and cultural climate supports public safety-net providers' judgments of undocumented immigrants as morally deserving of care. Yet, issues remain. Although the cultural dimension of local health policy in San Francisco provides public funds to provide primary care, as Marrow (2012:851) notes:

...San Francisco's inclusive local policies, are modeled on and partially embedded within the more restrictive structure of federal and state Medicaid policy, which effectively deters some unauthorized immigrants from accessing care in HOC [Hospital Outpatient Clinic].

In addition, to qualify for Healthy San Francisco, residents must show proof of Medi-Cal denial (California's Medicaid system) and Medi-Cal requires proof of citizenship or legal immigration status. Therefore only a very few unauthorized immigrants are able to access the public safety net.

Unlike the public safety net in San Francisco, which is embedded within federal and state Medicaid policies, as mentioned above, the mobile clinic in Hartford has no such restrictions. It is an independent clinic, and does not receive any federal or state money. Through my interviews and participant observation I found that the clinic did not ask about legal status. Thus, those who were undocumented were less fearful about coming to the clinic than if those kinds of questions were asked.

In summary, critical medical anthropology connects 'on the ground' health experiences with the larger structural systems so as to make visible the ways in which these larger structural forces impact people's health. Undergirding CMA is an aspiration

for social justice in health care and health care access.

Because almost 80% of the patient participants were immigrants, the nature of immigration, who migrates and why, are important factors in the patients' stories, and in their overall health and well-being. Therefore, the next section will discuss some key theories of migration and how these theories relate to patients' migration trajectories.

Theories of Migration

After the Second World War, migration expanded involving all the world's regions with dramatic increases of migration from Asia, Africa, and Latin America, particularly since the 1960s (Castles and Miller 2009b:2; Massey et al. 1998b:2). Movement of peoples across the globe has been facilitated by advances in transportation and communication. Indeed "more immigrants entered the United States in the 1990s than during any other decade in its history" (Katz 2013:158).

Prior to WWII, European migration to North America reached a pinnacle between 1850 and 1914. Migration is not something new in the human experience, however. Since human beings have been on Earth they have been in motion.

This section briefly outlines some of the key theories related to migration: macroeconomic explanations; segmented labor market theory; world systems theory, migration systems and networks, and the migration industry. These theories are not mutually exclusive; rather, they are different, yet complementary aspects of the migration process.

Immigrant participant narratives provide a lens on immigration itself as a social determinant of health (Castañeda et al. 2015; Fleischman et al. 2015). The

narratives also reflect the global dynamic of flexible and reserve labor, transnational transnational communities and the burgeoning migration industry.

Migration, Neoclassical Economics, and New Economic Labor Migration

Rapid global integration, the movement of goods and capital, is giving rise to large-scale migration.

[W]ithin the sending nations there is a sharp imbalance between labour supply and demand; within receiving nations low birth rates and ageing populations produce a limited supply of workers while capital-intensive technologies yield a stratified demand producing plentiful opportunities for natives with skills and education, unemployment for those who lack schooling or special skills, and a segmented demand for immigrant workers (Massey et al. 1998b:7).

Thus, individuals decide to migrate because of lack of economic opportunities or low living standards in their home countries, and better economic opportunities and living standards in the country to which the individual migrates. They surmise that the costs and risks of migrating are worth the benefits (Borjas 1989; Castles and Miller 2009c:22; Chiswick 2008). Another decision-making strategy is one in which the decision to migrate is made by the family, household or community known as *new economic labor migration theory (NELM)*. In this way, resources are pooled together for an individual, or for individuals, to migrate with the expectation that he/she, or they, will send remittances back to the family, or household, or community (Massey et al 1998a:24).

The above explanations are often referred to as 'push-pull' factors of migration and are based on modernization theory (Rostow 1960). Migration is seen as an equilibrium process such that there will be a more equal balance between population pressure and resources (Brettell 2008b:119; Castles et al. 2014b:29). The decision to

migrate for work is exemplified by interviewees I discuss in chapter four.

Another labor focused migration theory is the segmented labor market theory. This theory posits that international migration is driven by the demand for both highly skilled and low skilled labor. This dual labor system is especially pronounced in large global urban centers such as New York, London, and Tokyo, among others (Sassen 2000). Low-skilled laborers are often temporary workers who can be dismissed at will and as Sager (2012:66) asserts, “[i]n many markets, immigrants compose a temporary, marginalized workforce kept in check by laws enforcing their precarious status.” Other factors in labor segmentation include ethnic/enclave entrepreneurs and ethnic enclaves (Chiswick and Miller 2008:28-34; Massey et al. 1998a; Portes and Bach 1985b; Waldinger et al. 1990; Zhou 2004). As Portes and Bach (1985a:203) observe, “[e]thnic enclaves are a distinctive economic formation, characterized by the spatial concentration of immigrants who organize a variety of enterprises to serve their own ethnic market and the general population.” Ethnic/enclave entrepreneurs are those who have businesses in neighborhoods where fellow immigrants from the same region or country reside (Garrido and Olmos 2009:200-201). Puerto Rican and West Indian businesses are local examples of ethnic enclaves.

One other type of ethnic entrepreneur is that of the ‘middleman minority’ defined as an ethnic entrepreneur who serves a mainly non-ethnic clientele. That is, the ethnic entrepreneur’s customers are predominantly not from the same ethnic group as the ethnic entrepreneur. Thus, in the United States “black and Hispanic communities provide a particularly important market for middleman minority groups, such as Koreans, Indians, Arabs and Chinese, who have adapted their business locations

to the residential concentrations of blacks and Hispanics” (Waldinger et al. 1990:121-122).

Indeed, the participants I interviewed, most of whom live in Hartford and as discussed in chapter two, are predominantly Latino or West Indian, are the very customers of the myriad of ethnic businesses that dot the Hartford landscape. Moreover, the majority of my participants are on the low end of the segmented labor market.

Ethnic enclaves are but one component of migration systems and networks, described in the section that follows.

World Systems Theory and Migration

World systems theory analyzes global connections and movements within a political and historical context, which has led to economic domination. As Sassen (2008) argues, the dual labor market can be explained using world systems theory. Core nations, through economic domination, extract resources, including labor resources from weak nations. Furthermore, high government debt is linked to cuts in programs for women and children, particularly education and health care (Sassen 2008:466). World systems theory focuses on “the macrolevel processes that shape and sustain population movements” (Brettell 2008b:119). Indeed, austerity measures, such as those required by the IMF and free trade agreements, lead to deeper poverty in the Global South such that migration to the Global North is an option employed by those affected by these measures. The transference of resources from the periphery to the core, including labor, leads to development of the wealthy nations at the expense of poor nations, i.e. their underdevelopment. World system and dependency theory illuminate

the unequal power relations between rich and poor nations. Sassen (2005:2) argues that free trade agreements are also a key factor in the migration of professional workers. She writes:

At the top there is the transnational market for high-level managerial and professional talent across economic sectors, from finance to engineering; this market is increasingly shaped by public and private regulations. At the bottom one finds an amalgamation of mostly informal flows, with the “global care chains” among the most visible ones. (Sassen 2008:457).

Indeed, women make up a vast majority of the “global care chains” (Sassen 2008). In my own study, 60% (9) of the female immigrants interviewed had worked as Certified Nursing Assistants (CNAs), home health aides, or engaged in domestic work, e.g. cleaning houses or child care.²⁸

Finally, when emigrants decide to migrate they usually move to areas where they have friends or relatives, i.e. where migrants from their community or region have already established networks, as discussed below.

Migration Systems and Networks

Other approaches have as their focus migration systems and networks. Migration networks are those networks developed by immigrants in the receiving country. These networks include religious organizations, ethnic associations, and professional networks. They foster the development of immigrant communities and overlaps with ethnic enclaves and ethnic entrepreneurs. In the Dallas-Fort Worth metropolitan area in the United States, for example, anthropologist Caroline Brettell (2008a:123) states that

²⁸ According to the U.N. Department of Economic and Social Affairs (2013), 51.1% of immigrants in the United States are women. In my study, 65 (15)% of immigrant patients interviewed were women. The difference may be attributed to: 1) Women tend to seek health care more than men do; and 2) Male immigrants may not have been comfortable being interviewed by a woman.

Asian Indian entrepreneurs who focus on the “ethnic consumer market...best illustrate the centrality of such businesses to the construction of community.” Current migration processes have also given rise to transnationalism, defined as maintaining social, political, economic, or religious participation and/or relationships across national borders (Castles and Miller 2009b:3; Glick Schiller 2003:105; Glick Schiller and Fouron 1999:344; Guest 2014:518). As anthropologist Glick Schiller (2003) argues, there are different ways in which migrants participate in transnational processes, from maintaining ties to the home community without engaging in political activities to full-fledged nation building processes. These processes are part and parcel of *migration systems*. Ten of my participants (43.5%) engaged in transnational processes, either through sending remittances, or maintaining contact with their home communities through video communication such as Skype or Facetime, and often both.

Migration systems theory proposes that migration between sending and receiving countries is historically linked resulting from colonization and “political influence” (Castles and Miller 2009c:27; Portes and Böröcz 1989; Portes and Rumbaut 2006:355). While the United States did not colonize Latin America per se, it did have strong ‘political influence’ in the region. This influence, and the close proximity of Latin America to the United States, accounts for the large Latino population here.

Migration systems encompass not just the historical linkages, but also the laws and structures that control and enable migration both in the sending and receiving countries (Hollifield 2004; 2008). Migration systems theory, as asserted by Castles et al. (2014b:43) “[also] looks at how migration is intrinsically linked to other forms of exchange, notable flows of goods, ideas, and money.”

The Migration Industry

The above explanations of factors influencing international migration point to what scholars have termed the 'migration industry' (Castles and Miller 2009a; Hernández-León 2008; Hernández-León 2013; Sørensen and Gammeltoft-Hansen 2013). Hernández-León (2008:154) defines the migration industry as "the ensemble of entrepreneurs, who motivated by the pursuit of financial gain, provide a variety of services facilitating human mobility across international borders." It is made up of individuals and services who are active in the migration process, including "moneylenders, recruiters, transportation providers, and document pushers" (Hernández-León 2008:155). Sørensen and Gammeltoft-Hansen (2013:6) add two other groups as actors in the migration industry: "control providers", e.g., private contractors who carry out forced deportations and/or operate detentions centers, and who are responsible for executing immigration checks; and advocates for immigrants, e.g., NGOs, faith-based organizations, those involved in social movements, and migrant networks. Indeed, the migration industry is a predictable outcome of the social networks, which are elements of the migration process (Castles and Miller 1998:97). The migration industry can be divided into three main groups: "facilitation, control and rescue" (Sørensen and Gammeltoft-Hansen 2013:6-7). While the migration industry is not a new phenomenon, what is new is how it impacts migration flows and the migration industry more so than at any other time in history (Sørensen and Gammeltoft-Hansen).

As a case in point, anthropologist Hans Lucht (2013) details the story of Ghanaian smugglers working in Niger who are paid by would be migrants attempting to cross into Europe, much like the smugglers used by Mexicans and Central Americans

as they attempt to come to 'El Norte' (the North), i.e. the United States (see Juana's story in chapter four). The outsourcing of border control into African territories, as a result of European pressure, as described by Lucht (2013), is similar to what is occurring between the United States and Mexico. The United States is pressuring Mexico to increase its control of the southern border, i.e. the border between Guatemala and Mexico (Archiblod 2014).

The attacks of September 11, 2001 (9/11), the economic crisis of 2008 and violence and conflicts in many regions of the world have led to fear and resentment of immigrants, and their criminalization. Immigrant criminalization has produced a growth in privately run immigrant detention centers over the past decade (ACLU and ACLU of Texas 2014; Fang 2013; Selway and Newkirk 2013), part of what Douglas and Sáenz (2013) refer to as the immigration industrial complex. Blaming the powerless is not a new phenomenon. When the economy worsens, and inequality rises, as has been the case in the United States for the past three decades, scapegoating is common. Now the scapegoats are immigrants, who are blamed for a plethora of the country's social ills (Douglas and Sáenz 2013:207).

The increase in immigration raids and fear of being incarcerated in Arizona led to one of the participants, Milagros, to move to Connecticut.

In summary, after WWII, migration increased at an unprecedented rate, particularly over the last three decades. While immigrants who come to the United States come from every region of the world, the sending regions have shifted from Europe in the 19th and early 20th centuries to Asia, Latin America and the Caribbean since the 1960s (Castles et al. 2014a; Massey et al. 1998c; Rumbaut 1994). For

example, according to the U.S. Census (2013a) 60.4% of the foreign born population in greater Hartford were from Asia, Central and South America, and the Caribbean. In my own sample 91% (21) of my patient participants were from Mexico, South America, or the West Indies. As you will see in chapter four, separation from family and community, the pressure of surviving in a new land along with the pressure to send remittances has had a negative impact on people's health and well-being. "Migrants are linked to non-migrants through social ties that carry reciprocal obligations for assistance based on shared understandings of kinship, friendship, and common community origin" (Massey et al.1998c:101).

Conclusion

In this chapter I have outlined some theoretical frameworks that are relevant to the narratives provided by my participants, as will be highlighted in the next chapter: critical medical anthropology and theories of migration.

Political economy and world systems theory incorporate the effect of global and economic forces and institutionalized power in people's lives.

Critical medical anthropology focuses on the political economy of health and investigates how social inequality and power affect health and well-being. CMA also incorporates critical race theory (Delgado and Stefancic 2012) and the concept of structural violence in its framework. Moreover, liberation theology brings in a religious dimension into the picture.

Migration is a global systemic issue as demonstrated in my research. The economic challenges people face have motivated some to seek better economic

opportunities than what is available in their own communities. Indeed, processes of migration globally often are the result of structural violence. Migration networks and systems are also relevant to my study. Most of my patient participants were immigrants and many came to the U.S. for economic reasons. As Massey et al. (1998c:67) argue, “[i]n no small way...the North American migration system is a political economy that reflects the interests of the superpower at its core.”

My participants also came to the Hartford area because they had either friends or relatives already here who could make their transition a bit easier. Others came for family reunification. Yet, as Leinaweaver (2010:81) states: “[T]he emphasis on... families...should not obscure the ways in which migration embodies and mediates cross-border inequalities.

As previously mentioned, 27.5% (8) of my participants were undocumented and in the United States this translates to denial of human rights, including the right to health care. As Cecilia Menjivar (2006:1007-1008; see also Coutin 2003) asserts:

...legal nonexistence is a state of subjugation that results in vulnerability to deportation, confinement to low- wage jobs, and the denial of basic human needs, such as access to decent housing, education, food, and health care.

Finally, what is common to all of these approaches are issues related to inequality, power, and social justice. Indeed, anthropologist, Jennifer Hirsch (2003:231) has called for a “liberation anthropology [which] like liberation theology, [and critical medical anthropology, involves] a commitment to social analysis that reveals the underlying causes of suffering and ill health, including the pathogenic role of social inequality.” Nancy Scheper-Hughes (1992) exemplifies this “liberation anthropology” in her analysis of child neglect and infant death in light of the political-economic realities of

poor mothers in Alto do Cruzeiro, a shanty town in Northeast Brazil. She asserts that anthropology can be used as a “tool...for human liberation” (Scheper-Hughes 1995).

Chapter Four: In Their Own Words

Introduction

In this chapter, I introduce some of the participants in their own words through which they express their perspectives and their life experiences. As mentioned in chapter one, this study set out to explore the experiences, mechanisms, strategies and processes by which underserved populations (specifically the uninsured) in the greater Hartford area attempt to meet their health care needs through mobile health clinics and how patient help-seeking strategies reflect broader factors in the political economy of health care in the U.S. and the treatment of subordinate populations with reference to health care access.

Participant voices support my argument that economic hardship impacts health in very direct ways. It also reinforces my argument that being an immigrant is a further challenge to health and well-being.

All the patient participants interviewed suffered from some sort of chronic illness, e.g. high blood pressure, diabetes, or arthritis. The oldest was 75 years old and the youngest, 35. The median age was 52. Ten patient participants were male and 19 were female. Twelve patient participants were born in Latin America, eight were born in Jamaica, one was born in Nepal, one was born in Ghana, and one was born in Guyana. Of those who were born in the United States, two were of Puerto Rican descent, two were African American and two were white.

I discuss, in detail, eight of the thirty-four participants interviewed.²⁹ Participants were selected who were best able to describe more richly their experiences and who

²⁹ Pseudonyms were used to protect participants' identity.

represent my key arguments. Other participant voices were included at appropriate points to reflect perspectives similar or contradictory to the interviewees discussed in detail.

Topics to be discussed include health issues and challenges, right to health care, funding of health care, and work experiences. While the focus of this study is on the health care experiences of the uninsured who seek services at a mobile health clinic, immigration as a contributing factor in participants' health also surfaced, as 23 of the 29 patient participants were immigrants.

For Spanish speaking participants, I quote them in English in the text with the original Spanish quote given in appendix four.

I also provide board member and staff perspectives of Malta House patients and the organization.

Specific structural pressures facing the patients I interviewed are under-employment and unemployment and lack of health insurance.³⁰ Two factors contributing to the employment situation among participants were the 2008 recession, and low paying wages. The transformation of the U.S. economy has led to a shift to a service oriented and flexible labor economy, leading to low wages in comparison to manufacturing jobs, and unemployment. This shift has been a key factor in the precarious circumstance people now face, including those I interviewed (Standing 2014; 2014a). Schrecker and Bambra (2015:45) assert that

“...the ways [jobs] are organized have changed considerably over the past few decades, with a decline in the number of standard full-time, permanent jobs, and a sharp increase in flexible or precarious employment: more and more people

³⁰ The ACA had not yet been implemented at time of study.

are working on either temporary contracts or no contracts, with limited or no employment...In this new economy, skills, working hours, contracts, conditions, pay and location are all more flexible and precarious.”

Patient Participant Voices

A common thread among participants was the expression of suffering and illness and how the biomedical category becomes translated from disease to illness to sickness. Another point that comes through in the interviews is the individuals' perceptions of the political economic situation that provides the context of their everyday experience.

Juana

Juana came to Malta House one day for her follow-up visit for her diabetes. I approached her to introduce myself and explained what I was doing. Juana agreed to be interviewed. The interview took place in the office of Saint Peter Church as Juana is a patient who came regularly to the Saint Peter clinic site. When Juana came to Hartford she would attend religious services at Saint Peter Church. The priest there mentioned to the congregation that the Malta House Mobile Clinic came to the church every Wednesday afternoon for those who did not have medical insurance and needed care. This is how she found out about Malta House. She had been coming to the clinic since 2006. At time of interview Juana was 55 years old, soon to be 56. She was from the state of Oaxaca in Mexico and an outgoing, pleasant person with a wonderful sense of humor. When she came to the United States in 2002, she planned to work picking asparagus in California but since she arrived in Arizona rather than in California (details of her journey will be described below) she decided to go to Maryland where she had a

cousin. In Maryland, she found a job working as a nanny but left because the father was taking illegal drugs. So she came to Hartford to stay with female relatives of a male cousin. When I interviewed Juana, she had type 2 diabetes³¹ for 16 years.³² Juana explained how she was diagnosed and how that impacted her life trajectory.

I worked in a bank...I worked in Mexico in a bank. I worked 17 years. Then they laid me off with severance pay because I did not have much education. I only finished secondary school and began working. Before just with junior high school you could work. But not now. Now they don't accept you. So they gave me my severance because they wanted someone with more education and I didn't have more education. And I was going to work for another bank and there they did many medical tests and I came out with diabetes. So they did not accept me because I had diabetes. And you know that in Mexico even if you are young—and I wasn't that young—I was over 40 years old, they did not accept me. They did not accept me to work. That's why I came here. I'm a single mom. I have a 26 year old daughter. I left my daughter when she was 16 years old. I came because I needed to give my daughter an education. She finished her education. She has a bachelor's degree in pedagogy.

In small rural Mexican towns, like the one Juana came from, access to higher education was difficult at best, and often young people only completed secondary school, 'la secundaria', which is equivalent to junior high school here. As the quote above indicates, when she applied for a job in another bank she was not hired because she was too old and was diagnosed as having diabetes. Indeed, age discrimination is quite common in Mexico.³³ Had Juana been able to get a job in a bank, she would not have left Mexico. As the quote shows, she needed income to support her daughter's education.

Like Juana, Lucha, a Peruvian woman, was also supporting her children:

³¹ In type 2 diabetes, patients produce insulin through the pancreas (where insulin is normally produced), but cells throughout the body do not respond normally to the insulin. A fasting blood sugar of 126 mg/dl or above is an indication of diabetes (WebMD 2014).

³² Medications and Diseases mentioned in this dissertation are also briefly described in Appendix Five.

³³ It is not uncommon in Mexico to find discrimination employment ads based on age (usually age 22 not older than 35), or gender, or both simultaneously (Hawley and Solach 2007).

...I still have two daughters that I am taking care of who don't live here. I have two daughters. I had three [children] but my son died not too long ago, at age 27...He was studying [in Peru] and graduated and worked six months and well, I still couldn't bring him here. So he came to visit me every once in a while and he died in an accident...So I have two daughters left. One in Buenos Aires is studying medicine, she has two years left, and the other one is in Bilbao doing a master's degree. So the situation there is very difficult because she does not have a job. In Spain there are no jobs. There are no jobs so I still have to help my daughter...the situation in Argentina is very bad also. So I am still helping my two daughters...So what I earn is not for me here. It's as if I have two houses...the economic reality is very hard.³⁴

The 2008 recession has had a deleterious effect on the global political economy. The unemployment rate in Argentina was 7.5% April to June 2014 (Turner 2015) and in Spain, 23.7% July to September 2014 (Roman 2015).

"Death don't come today, come tomorrow."

At Malta House, Juana was diagnosed with high blood pressure³⁵ and high cholesterol.³⁶ In early to 2011 she was diagnosed with hypothyroidism.³⁷ As she told it:

I was very bad with the thyroid. I got extremely thin that people thought I was going to die. I was skinny, skinny, skinny such that right then I said "death don't come today, come tomorrow. Here, here they detected it. When I was so skinny that they didn't know what I had and there is a doctor here who is very good. Thanks to that doctor I'm alive. They did an infinite number of tests. The doctor I am waiting for. She is my doctor. They did many tests...I am so far away from my country and the family...sometimes not even with money! It's that medicines here are so expensive. And they can't sell you the medicine without a physician's prescription. That's the problem."³⁸

³⁴ Many Peruvians who immigrate to Argentina are students (Durand and Breña 2010:21). Furthermore 77% of Peruvians surveyed in 2004 stated they had firm plans to emigrate and 86% of those were between the ages of 18 and 24 (de los Ríos and Rueda 2005:30; Takenaka and Pren 2010).

³⁵ High blood pressure (hypertension) is a common condition in which the force of the blood against artery walls is considered high by one's health professional (Mayo Clinic Staff 2015).

³⁶ Cholesterol is a type of fat (lipid) in the blood. If there is too much cholesterol it begins to build up in the arteries (blood vessels that carry blood away from the heart), causing a hardening of the arteries, atherosclerosis (WebMD 2014a).

³⁷ Hyperthyroidism occurs when the thyroid gland does not produce sufficient thyroid hormone (WebMD 2014b).

³⁸ As of 2010, controlled substances, such as antibiotics and narcotics, can no longer be sold over the counter. They can only be obtained with a physician's prescription (Ellingwood and Sanchez 2010).

Juana expressed deep gratitude for the clinic that, from her perspective, saved her life. Furthermore, the clinic attempts to have patients see the same physician for continuity of care.

Juana had been taking Levothyroxine³⁹, a thyroid medication since she was diagnosed. She had gained weight and her thyroid was under control. Juana also took oral medication for her high blood pressure and high cholesterol. She took insulin⁴⁰ for her diabetes. When I asked her how she obtained her medications, she replied:

I pay, I pay. I buy them. I buy [them]. For example that one costs me very little. It costs me for one month it costs—before, before I bought for one month six dollars, six dollars for each medication. But recently I've told them to give me for three months so that's a little bit—a little bit more—um, now they charge me like 24, 28, 20, like that more or less for three months.

She added that Malta House gave her the insulin and the test strips so she did not have to buy those. She stated:

What I cannot buy, and what is extremely expensive, is the insulin. They give it to me. They give me the insulin. I have never bought insulin. They give it to me because it would cost me like one hundred and fifty-eight dollars for Lantus⁴¹ and that's for one month.

Rather than the government subsidizing the cost of medication, the neoliberal free-market ideology compels those who struggle financially to rely on charity or go without medications.

Juana did not use any home remedies for her health problems, except when she had a cough. One day when I was chatting with her in the clinic she said that for a

³⁹ “Levothyroxine is used to treat an underactive thyroid (hypothyroidism). It replaces or provides more thyroid hormone, which is normally produced by the thyroid gland” (WebMD n.d.).

⁴⁰ “Insulin is a naturally-occurring hormone secreted by the pancreas. Insulin is required by the cells of the body in order for them to remove and use glucose from the blood. Cells use glucose to produce energy that they need to carry out their functions” (Ogbru et al. 2015).

⁴¹ Lantus® is a brand of insulin.

cough one should, before going to bed, take *yerba santa* (*holy herb*), an herb grown in hot climates, put in a liter of milk and boil it, take it off the stove, boil it again, take it off the stove, and boil it a third time then place a cinnamon stick in it and drink it while it is hot. Then, go to bed with VICK's Vap-O-Rub on the neck and chest. She said that the next morning the cough would be gone. Juana asserted this remedy was very effective for coughs and respiratory ailments.

Juana worked in local restaurants but the restaurants closed or she was laid off because there was not enough work. After that, she made ends meet by selling hats and scarves that she knitted and by doing seamstress work, such as hemming pants and dresses for friends and acquaintances. It was with this small income that she bought her medications and her food. She lived in a basement apartment and said her landlady was very understanding and if she could not make the rent on time she could pay it little by little.

Juana's landlady was from the Dominican Republic and I would chat with her at the clinic during participant observation as she also received her medical care from there. In our conversations, she would express sympathy for the poor and for those who are struggling. Her worldview, therefore, drove her to have compassion for those like Juana. Indeed, among the West Indians and Latinos I interviewed it was the social networks they had established that allowed them to survive, and to mitigate, at least somewhat, the inhospitable circumstances resulting from structural violence.

Like Juana, Carmen was undocumented and worked in the informal economy to cover living expenses:

I'm not working now. But I go—I'm preparing some tamales to sell to have for the week for my food and to put some money together to pay the rent...[Whispering]

I rent a room. I spoke with the owner. For example, right now I'm paying behind schedule. I am going to be behind in my rent because I'm supposed to pay on the first but now it's been many days.

Many people from Latin and Central America come to the United States without authorization because it is extremely difficult to obtain a visa. The Immigration and Naturalization Act of 1965 placed quotas for residence visas based on family reunification and labor force needs. Even those who can come legally for family reunification have been waiting years for a resident visa (azcentral.com 2013; Gonzalez 2013; National Visa Center 2013).⁴² Many who enter the U.S. legally by obtaining non-immigrant visas, become 'illegal' by overstaying their visa or violating the conditions of the visa. Furthermore, obtaining a non-immigrant visa is expensive and bureaucratic and there is no guarantee the visa will be approved (Chomsky 2014a). Therefore, many Latin Americans, particularly those from Mexico and Central America, contract a 'coyote'⁴³ to cross into the United States 'illegally'.

Juana and others hired a 'coyote' to take them across the border into the United States. The 'coyote' brought the group on the U.S.-Mexico border but on the Mexican side the 'coyote' told them they would need to walk for six hours.

"I came as a wetback."

I came as a wetback.⁴⁴ I came walking. I came ten years ago. I crossed the border. I came through Arizona. We came from my town to the Federal District, 12 hours traveling from Oaxaca to the Federal District. In the Federal District we took a plane to—um, what is the name of that town, that city. Oh, what's it

⁴² Spouses, minor children, and parents of U.S. citizens are exempt from the numerical quotas (National Visa Center 2013).

⁴³ A 'coyote' is a person whose occupation is smuggling people across the U.S.-Mexico border.

⁴⁴ It is important to note that I did not ask any participant their immigration status but some participants volunteered such information in the course of the interview.

called? It's not Guadalajara. Oh, I don't remember. I don't remember what it's called. Anyway. We arrived. And from there we took a van. We took a van that took us close to where the United States borders with Mexico. But I didn't feel it. Since the trip I took was at night. I didn't cross the ocean. I didn't cross the river. They say that you cross a river. But they made us go through Arizona.

Juana's journey became long and arduous. The coyote brought them just to the Mexican Arizona border where they had to walk across to slip into Arizona.

Then from there, there was a song, there's a song, I don't know what it's called. We arrived there. We waited on the plane in Hermosillo. Hermosillo, Sonora. We arrived by plane to Hermosillo, Sonora. Then from there they disembarked us like-because we were like 30 that came here. We used Coyotes. Then from there they told me we were going to walk for about six hours. Oh Miss! We walked more than six hours! I brought a suitcase and I threw everything out. I brought a bible with photos of my daughter. I brought a bag where I had medicines, since I'm a diabetic I brought medicines. In my suitcase I brought robes, I brought brand new pants, brand new! I brought brand new blouses. But I didn't know. I had on two pairs of pants, one a pair of jeans and the other a pair of work pants. And I wore a little jacket and a blouse because I didn't think it would be that cold.

"I suffered to come to this country."

Juana related her journey from her town to the United States and then from Mexico City to northern Mexico.

We left the Federal District, we left about, I don't know, around 8PM, something like that. By plane. By plane. And we arrived where I said, Hermosillo, Sonora. And from there with a van, or cars, I don't remember. I know that we traveled like that. Oh my God! I-I brought money. I tell you I brought my ID, I brought my license-my driver's license. I brought a little wallet that my sister-in-law gave me and I brought a bag with all the medicines. But since I could no longer walk, Miss. They told me six hours. In six hours I could do it. We left at 6 PM. The border patrol grabbed us at around-at around one in the afternoon. Without drinking any water, without eating. The border patrol grabbed me. I had new sneakers, brand new. The soles of my feet, little stones and sand got inside my shoes. It was night. It was very dark. You couldn't see anything. I walked among the cacti.

Juana had to walk through the Arizona desert guided by the 'coyotes'. She described the terrifying experience as the tears flowed from her eyes and also from mine.

If you saw how my legs were full of thorns and of prickly spines. I suffered to enter this country. I suffered. ...the soles of my feet, became—how can I say it—like they scalded. The meat looked red, red. I couldn't walk anymore. I told the young man that came by. Three coyotes went with those who could walk well who didn't have any problems and three people stayed with us. Three coyotes stayed with us, with those who could not walk. Oh, Miss! Me with my sneakers that my feet were bleeding. I didn't know anymore. I couldn't take it anymore! I couldn't take it anymore! They told me six hours. How could they make someone walk so long! And since a helicopter came—tra-tra-tra—and um, we hid among the cactus. I couldn't walk anymore. I told them "Just leave me here. Leave me here for the coyotes to eat me. And we hid inside all those plants with thorns. I didn't know what was there. Everything was dark, dark.

Juana narrated the conversation she had with her daughter before making the grueling journey in winter.

I came in January and it was cold—the end of January. I was in the hospital. They grabbed me in Arizona. They felt sorry for me. Because I gave them—I brought about one thousand dollars. No I brought about two thousand dollars or one thousand five hundred dollars—one thousand dollars—something like that. Because I—I was dumb because I didn't do my papers when I worked in the bank. When I saw that it was too much, that it was very, very hard I said to myself "No, it is best if I go to the United States. I'll go as a 'wetback'. Why? So that my daughter can study. Because if not, she will not make anything of her life." So I came. But I told her. You have to promise me. "Yes mom, I promise you." OK. I'm going to go but only so that you can study. Not for you to play the fool. So that you make something of yourself. "Of course, no, no." So that certainly was good, eh, because she responded [positively].

Juana recounted how she ended up in a hospital in Arizona.

So I arrived at the hospital, at the hospital and there they took care of me. But, look, I told them everything. I told them, look, I'm—I'm a diabetic. I had surgery...everything, everything I told them. When they saw how bad I was—I came with I don't know how high a blood sugar I had. And they gave me IV [intravenous]. I came extremely undernourished. But there, there, those from the—when the border patrol grabbed us, they put us all—they didn't put me in the back with all the rest. They didn't—I told them, look I'm so and so from so and so, I was born on such and such a date, here is my ID card, here is my pocketbook, here is the money that I bring... I bring \$1,500. I bring 800 Mexican Pesos. And what are you going to do? I told them I am going to work. I'm coming because I—I want to give my daughter an education. So then they told me—the ones who—who—who—the ones who grabbed me. The ones from the border patrol. "Well, you're in very bad shape." They carried me. They had to carry me because I couldn't walk anymore.

This experience of receiving care in Arizona is different from the care she received at the mobile clinic in Hartford in that in Hartford she was never asked about her immigration or income status.⁴⁵

“My feet were full of blood.”

Juana had to walk barefoot because she could not bear wearing shoes since her feet were in very poor condition. She related how the border agents caught her, yet she was permitted to stay in the United States for 25 days.

[The border agents said] “Miss you can’t walk anymore” “No” I told them. “My feet are already bleeding.” So then I took off my sneakers and I came with nothing so that my feet could ventilate, right? Because my feet were full of blood. Like that I went walking, like that. But still like that. But when they saw that I couldn’t anymore they put me in the—in the—in the same car where—where they had all the other people... They took everyone out of the car. They checked everyone. They took everyone’s fingerprints. Everyone’s. Not me. Because I was very ill. So they made—they made—how can I put it—they looked for the Mexican Consulate. I was in the hospital for three nights and two days. And they gave me a chance to stay—the ones from immigration—not the ones from the immigration. Yes the ones from immigration. They gave me 25 business days for me to be anywhere in the United States for me—for me to get healthy.

Like Juana, Milagros crossed the Mexican border into Arizona. She came in 1992 and worked in Arizona for ten years before coming to Hartford. She worked cleaning a nightclub, cleaning offices, and cleaning a restaurant. All these cleaning jobs were with the same owner. She would have three different cleaning jobs at the same time working for the same company, the same owner. Despite this Milagros believed her life was better here than in Mexico:

When I came here I was working in the Maquiladora in Mexico but I came here. It was much better because it was a change for the better. If it had been the same

⁴⁵ Juana was diagnosed with uterine fibroids and had a hysterectomy in Mexico, three years after giving birth.

or worse well we would go back to Mexico. But it was better. I always worked, I had my three jobs.

She worked like this for two or three years, then worked in a restaurant washing dishes, preparing food, whatever needed to be done, 12 hours a day, seven days a week. She assesses the situation in Arizona prior to moving to Hartford:

Things have changed a lot. Now it is very difficult there with the laws that are there with Joe Arpaio even more so. Now it's like being harassed. It's like a harassing situation there. Well when I was there John McCain was still there. Janet Napolitano, the head of Homeland Security, was governor there, those three, Joe Arpaio, John McCain, and that woman started complicating things. And it's been many years like that. Years before. But it was never like it is now. It wasn't that constant harassment.

Milagros contended this was not always the case for immigrants, particularly undocumented immigrants. She described her own personal experience of evading the Arizona immigration officials.

There were stores that were open 24 hours a day. I could travel to Las Vegas, to Los Angeles, wherever I wanted to. We could travel. We could get on a plane. It was different, very, very different...When I came here, one year before coming here there started to be many raids, raids, raids...In the restaurant [where I worked] there were many-various raids until I said to myself "no, well, if they get me, moreover my daughter, and I don't have any family here, where will she stay?" Even when I got to my job, it was a plaza with various stores with the restaurant. I saw the immigration officials where we parked in the front...and what I did was I went around and I came back.

Discriminatory practices in Mexican employment, low wages, and the inability find to jobs in Mexico, forced Juana and Milagros to risk crossing the U.S.-Mexico border.

"I don't have a right [to health care here] because I am not from here."

I was also interested in finding out what Juana knew about the ACA signed by President Obama in 2010 and her thoughts on health care as a human right. When I

asked Juana what she knew about the Affordable Care Act she stated she did not know much except that it excluded the undocumented. Juana believed this is at it should be. Thus, when I asked her who, in her opinion, had a right to health care in the United States, she responded:

The citizens—the citizens. Those who are citizens have a right. We, as undocumented, well we don't—me—I recognize that I don't have a right because I am not from here. But, look here they give you a lot. Much more than one expects. Because if I didn't find this center—this medical center—this Malta House for the poor—this is for people who don't have health insurance. And don't have—because one comes here because one does not have resources. Because otherwise, I would go to my [private] doctor and pay my doctor. But how much will it cost me? It's a lot of money. The little that one earns to send home to the family, one spends it on paying the doctor. And—and I am in agreement with, I am in agreement that the citizen has—has his/her insurance, has—has his/her benefits. We, thanks to charitable people—there are a lot of good people in this country that we come to this place and they take care of us.

Juana's response is unique in that of the eight participants who admitted they were undocumented, she was the only one who believed she did not have a right to health care in this country. It is possible that the existence of Malta House affected her ideas regarding a right to health care. Although I did not ask, I question whether she would have answered in a similar fashion if she did not have Malta House as a source of health care.

Celeste, a legal resident from the West Indies, had a similar point of view.

Citizens and legal residents, kids, senior citizens and indigent too [have a right to health care]...Practically everybody [deserves health care]. The rich and poor. Ok. Practically everybody because if you don't have your health you can't work. So practically everybody [deserves health care]. ... It's just that the rich can pay on their own. So they deserve health insurance too. They need to have the right too but they can afford it. But those who can't need to have the right to have access to it too because they, you know, can't afford it half the time. In that sense they deserve it even more than the rich. Because the rich, they practically don't get ill, you know. ... I don't want-I don't mean to sound this harsh but we have to look about we the legal ones and the citizen ones. Those who are here illegal they don't need to be here at all. [They] don't deserve health care... back in the

days like in the 80s and the 70s and the 60s it was fine having all these illegals coming over for a better life to escape their impoverished country and all that ugliness. But now that the economy is such as it is we don't have any more room for you. Sorry to say but we have to [look out [for] ourselves now. All the citizens, and you know, who are entitled to it then, you know.

Of the eleven documented, i.e. legal immigrants, only one other, Thomas from Nepal, had a similar sentiment. I asked him who in the U.S. had a right to health care. He responded: "Everyone who [sic] are legally living here." When I asked him who deserves to have health care he responded: "Everyone deserves, Ok? If we are talking after taking care by the government that [is a] different thing. In my opinion...who illegally entered, these people, ok, they don't deserve." I probed further and asked him if a right to health care and deserving health care are the same or different? He answered: "Well I think right, is uhh, every person, ok, every human being, all have the right. But deserving, I think that who are legally here deserve. Everyone has the right but not everyone deserves I think."

Based on his response, he sees deserving of health care as those who deserve to receive government assistance in paying for health care and only those who are citizens and legal residents are deserving of government assistance.

On the other hand, Elizabeth, a West Indian nurse who was working part-time, subscribed to a discourse of individual responsibility when I asked her who had a right to health care.

I don't know about right to health care because if you don't take care of yourself and you don't do what you're supposed to do I don't think you should have any right to anything... Say for instance someone who is an alcoholic and drinks and drinks and drinks himself and then has cirrhosis of the liver and then has kidney problems and ...[y]ou give them the kidney and then they go mess up another kidney... So that's, uh, in that case that's, uh, that's my problem with a right because you have a right you're not gonna take care of yourself and then access all these expensive resources because it's your right.

Yet, when I asked Elizabeth who deserved health care she replied:

Everybody deserves to-to-to receive health care... everybody deserves health care... some people would argue to say like I was sayin "Oh the drunks and whatever, they don't [deserve health care]" but I can't say that, you know, because it's a moral-it's an ethical issue for me whether they're illegal aliens, whether they're citizens or whatever they de-some people say "Oh they're illegal aliens. They don't deserve-deserve health care. They're here illegally" and all of that and they're here already. They deserve care. You better give them care or else they'll end up in the emergency room and in the hospital and there's no bill so everybody deserves care.

I asked Juana who deserved health care in the United States, and why.

Well, everyone deserves it. Everyone deserves health care. Because we are human beings. If a dog—if a dog—see how they are gone after here—a dog, a cat... How they are gone after by the firemen to save the animals. Now a person, a human being? Imagine!

When I asked her who should pay for health care in the United States she replied:

The two must pay [the companies and the government]...because, look, I'm saying, right? If it's the employer they have to have a—a set fee for the government so that their-their-their, um, employees may go to the Government health plan. I say it is the govern—that it has to be the two mutually, the government and the employer. Yes, because, because, the government also without the fees from the businesses is nothing. They have to contribute, they have to contribute, the two of them. The two of them must contribute.

Juana's story is one of resilience and survival. Yet her experiences connect to the violence created by governmental and social institutions, as outlined by the critical medical anthropology perspective. Yet her conviction that as an undocumented person she did not have a right to health care surprised me. However, she asserted everyone deserved health care. Her perspective was very much influenced by the fact that she was able to receive health care through Malta House.

Carol

"I really don't have the money. I really don't."

I interviewed Carol at her home. I met her at Saint Augustine Church. She had a lovely condominium on a quiet street in Manchester, CT. We sat in the living room that had a big screen T.V. and an entertainment center (CD player, tuner). Pictures of herself and her sister when they were younger (in their late teens or early twenties) were hanging on the wall. Carol, an African American woman born and raised in Connecticut, was 53 years old at time of interview. She was diagnosed with diabetes in 2010 at Malta House. At time of interview Carol was also suffering with pain in her right shoulder.

[Two years ago] I had a yeast infection and [Dr. X] had me go take a blood test... and that's when I found out that I was a diabetic...and that's the only thing that has been wrong with me. Um, I need to lose weight. If I don't, you know, I lose 50 pounds I wouldn't have to take the medication. Well now, what's going on with me now, is, um, I guess I have inflammation. I have inflammation in my right shoulder. They took an x-ray and that's when they found out, all they could see was inflammation so they referred me to a [sic] orthopedic and physical therapy but I didn't go see one. I didn't—I didn't go see them because I really don't have the money. I really don't.

Carol, also had difficulty paying for dental care. She narrated her experience:

...I have a regular dentist. But he does not do surgery. He referred me to this other man who charged all this money so they referred me to UCONN...I had an appointment with them...[I have to have surgery on my tooth and] for me to get my surgery or whatever that's \$232.00 right there. That's all included just to be seen and everything...I'm supposed to go get surgery...Well I'm trying to weigh my options. I'm trying to think if I should just pull it and get a false tooth, I mean a partial or something. I don't know.

Like Carol, other participants in my study also were diagnosed with diabetes.

Thirty-five percent (ten) of patients I interviewed had diabetes. When I asked Carol what she thought caused her diabetes she responded:

I used to be a vegan and then I stopped. And I started back eating meat...It was eating meat, the fat in the meat. But, you know, and my menopause too, you know, my menopause. I know there was one time I was going through that and I was just eating whatever I wanted to eat.

Ten percent (three) of interviewees were pre-diabetic.⁴⁶

Like Carol, Ana was a diabetic and hypertensive and believed her illnesses were caused by not eating the right foods: “Can’t afford it.” Ana relied on FoodShare⁴⁷ for her groceries.

“We need health care and it’s just not fair.”

I asked Carol who had a right to health care in the United States.

...the non-insured because they don’t have the money. They don’t have a job. They just don’t have the money and we need health care and um, it’s just not fair. Plus the state, I don’t know. They’re ridiculous um, dealin with this...when I went to [a health clinic]. They did the calculation to see if I qualify for the state or whatever and I didn’t. I think the people called it a spend-down or something. I don’t know. I didn’t have enough bills or something. I don’t know.

Likewise, Liz, a young Latina woman, stated:

I think anybody who just needs it [has a right to health care]. Anybody who can’t attain it by working or otherwise...like there’s people that just can’t help themselves. ...Everyone deserves to receive health care.

Gloria had a similar perspective. She believed a right to health care was for those who worked with the exception of those who were extremely poor. She explained:

All those who work, right, and also cooperate [have a right to health care] so that now, and over time, then, they can be taken care of because if not, how? For example, the people who work they give, a certain amount is taken out of their paychecks, isn’t that so, and they even help. But also there are people who are very, very poor and don’t have but should also be helped, right?...like the animals

⁴⁶ Prediabetes, aka borderline diabetes, is when one’s fasting blood sugar is between 100 and 125mg/dl (WebMD 2014c).

⁴⁷ Foodshare is a non-profit organization that works with local programs to feed the hungry in Hartford and Tolland counties, Connecticut (Foodshare.org 2014).

I see on television. [T]hey give a lot of help to those animals so if they help an animal how are they not going to help a person? We all deserve but there are different categories, right? There are people who have their own resources and with their own resources can get seen. But there are people who work who should be able to get seen because they are already taking it out of their paychecks, so they are helping. So that's the way they are cooperating so that they can look after their health later or at the present moment.

I asked Carol who deserved health care in the U.S. and she replied "everybody."

I mean, because even when I was working, all my life I've been working, I've been paying for it, and I had it. And um, now that I don't, you know, have a permanent job I can't get health care and it's been hard and I just thank God for Malta Care. It's a beautiful thing because I don't have the money. Well, we deserve it and [have] the right to have it. Yeah, I believe every American has a right to have it. They shouldn't be home sick and can't go to the doctor. Everybody should have a right to health care.

For Carol deserving health care and right to health care were conceptually the same thing. Indeed, when I asked Carol if there was anyone who did not deserve to receive health care as a right in the United States she replied: "No". Furthermore, she argued the wealthy should pay for health care.

Who should pay for it. You know what. The people that make six digits. The people that make—the wealthy, the people that make all this money, you know. Cause I even try to help people and with my poor self, I have. I'm a giving person and sometimes, you know, I ask God, why have you made me this way? You know? It's like I'm always tryin to help somebody but when it turns around for somebody to help me, you know, they're not around. But it's right to give.

Carol went on to say that employees paid for their health insurance in employer based plans, and children could obtain state sponsored insurance through HUSKY, and the elderly through Medicare. "So everybody is all set except the young adults and the uninsured." In fact, I asked her if she knew about the ACA and she said she did because "I watch CNN and all that stuff" and hoped to enroll when it became available.

I'll just be glad when we can get this insurance. It bothers me because I can't, you know, I can't do nothing about my shoulder. I mean it bothers me because I can't do my hair like I use to. Now, I mean, this arm can, before I couldn't even,

you know, go over really that much but it's—it's, it's—not like I used to because I used to be an athlete and I decorate and you know, I do a lot of things and I can't use my arm like I used to.

However she also admitted she preferred to get a job that had health benefits. “I also want to get a full-time job too, so, you know. Because if anything ever happens, if I ever have to go to the emergency room, so, you never know.”

This was Lucha's concern also. She feared that as she got older she would encounter serious health problems:

...because of age I think things present themselves. Health problems manifest themselves, right? And I worry about what lies ahead...The pressure of age brings on different things...Suppose I need surgical intervention that here costs a world of money. I ask myself “what kind of debt will I be in?” ...I say to myself “the bill that”—I—I—I will get sick from another problem (laughter).

Sam, a white male patient participant, also had similar concerns:

I have...thoughts about [an] emergency, um, because if one does come up I can't—I—I don't have a way to afford it. I still have the issue of having the emergency and I'm gonna have to have that addressed or taken care of...if I had some serious, real serious health issues I—I—there would be an impact on this period of my life.

Like so many of the participants in my study, Carol was uninsured as a result of job loss. Carol had worked as a CNA since 2010. She was a high school grad and had several certificates. At time of interview she worked for a home health agency. Before that she worked as a receptionist at a small manufacturing company for five years, and prior to that she was a receptionist/secretary/admin tech. The jobs she held were lost because the positions were eliminated. Regarding the CNA position Carol admitted:

I was a receptionist. I got laid off. My job was eliminated in August of 2009. So that's why I went to school to be a CNA. Now I wanna go back to my old field because I hate this field Sylvia. The medical field, I mean everybody tryin to be a CNA but you can't get no full time job. I had-just had a client and you can't-she's

in a hospital. Now I have no job. It's like she's in the hospital I have nobody, you know, it's like this is crazy. I have a mortgage to pay. This is-I don't know. It's real. Everybody-that's what they're tryin to be, a CNA. But I don't like it. It's been three years now. It's nothing but per-diem, you know. That's why you can't get into a convalescent home and that's where I want to be because home care, you know, your patient either goes into the hospital or they die, you know. And plus it's not enough money, you know.

In fact Carol's annual household income, when I interviewed her, was under \$10,000. Carol was especially concerned because she was still paying the mortgage on her condominium and was unemployed.

"God. Just having a relationship with Him and reading His Word"

Carol had to deal with a personal tragic event in her life. "I lost my son in November 2011]. It was a very sad day. The 24th homicide he got shot. Very sad day. Very sad, sad, sad, sad, sad, sad day."

Her son was killed when he was defending his cousin who Carol said "was bad news". I asked her what has helped her through this period in her life. "God. Just having a relationship with Him and reading His Word, and um, and it's the faith."

Lucha also relied on her faith to help her deal with tragedy. She explained she came to the United States on a tourist Visa but it expired⁴⁸ when she received news that her son died in an accident. Therefore, as she stated "I could not go home to bury my son." She feared that if she returned to Peru, she would not be permitted to come back to the United States. She stated the priests in the church where she worked as a

⁴⁸ Immigrating to Europe, Canada or the U.S. from Peru on a tourist Visa was quite common. In fact, between 1990 and 2005, 93.5% of Peruvians who emigrated did so on a tourist Visa (Organización Internacional para las Migraciones 2006:58). In Lucha's case, she became a permanent resident when she married a South American who became a U.S. citizen and then applied for her to become a permanent resident. The application was approved and in 2012 Lucha became a permanent resident. She plans to apply for U.S citizenship when she is eligible to do so, in 2015.

cleaning lady helped her get through this difficult time.

The priests have helped me a lot. Talking with them. I have a priest I am very fond of and who understands me and they all have lived through this tragedy with me because I couldn't—couldn't go home to bury my son. I had to stay here. So it was a Sunday. So only with the affection they have for me and I also have other very close friends, um, that I have been able to bear this, right? It was the priests' affection—decency—which for me was very important. I don't know what would have happened if it had been any other way. That is why I say this is my house.

Milagros, had surgery in her mouth about four years ago:

...when they did surgery on my mouth...that was in Saint Francis Hospital...but my church sent me there...my church paid for it. The church [The Church of Jesus Christ of Latter Day Saints] paid for it because they sent me there. I think there were church brothers who were doctors who worked there. Um, I don't know if they were dentists or something like that. I received the bill in the mail and they told me to bring it to them and they would pay it. It is a strong community that helps a lot for those who need it.

Ana, who was from Jamaica, asserted: "To tell you the truth I have good friends. I have good friends, people, friends and my church people encouraging. A whole [lot] of prayin, you know. A lot of prayin."

As the quotes above show, Carol, Milagros and Ana relied on their faith and their faith communities to deal with the challenges and tragedies in their lives.

Catarina

"I was always healthy but the stress of being unemployed affected my health."

I met Catarina at Saint Augustine Church and interviewed her in her home. Catarina was 50 years old, married and had a son 32 years old. She lived with her husband and son, had been here in the U.S. for 23 years, and had legal residency. She was from Lima, Peru. She finished high school in Peru and wished to continue studying but could not as she was unemployed and thus had no money. Her husband

worked at a Hartford bakery but his hours were reduced.⁴⁹ She was out applying for three different jobs the day I interviewed her. She was even willing to volunteer somewhere just to keep herself busy. She was working at a home health agency but left because she was only making between \$8.50 and \$9.50 an hour and the company was getting \$17.50 an hour. She explained:

They have uniforms, different uniforms, pants, or-you have to cook for them, bathe them, make them dinner, take them shopping, all that. How much do they pay? Eight dollars and fifty cents and nine dollars and fifty cents [if] you have to clean the house. There are no holidays. They don't pay holidays, they don't pay mileage rate... I was working for them and the government pays them \$17.50... They don't pay for your gas, they don't pay anything.

Also, according to Catarina, the agency had odd rules. For example when she and her client signed the form of how many hours she worked and what she did they could not go over the line where they were to sign and they had to use the exact same pen to sign the form. She found these rules illogical.

Catarina was concerned about the family's financial situation because they still had a \$700/month mortgage on the house they bought.

Catarina's parents were divorced and her 71 year old mother was in a nursing home and suffered from dementia. She sent her father back to Peru because she could not take care of both her parents.

⁴⁹ Massive Peruvian migration began in the 1980s with the implementation of neoliberal policies, structural adjustment (Massey and Capoferro 2006) rising unemployment, violence, and government repression (Berg 2010; Berg and Tamagno 2013; Durand and Breña 2010; Leinaweaver 2010). Violence and government repression were influenced by the rise of the Shining Path (Sendero Luminoso). For a detailed history of the Shining Path see Gorriti (1999).

"It must be the stress, the stress of being without work because I always worked."

In the fall of 2012 Catarina traveled to Peru and while there had a physical exam. It was then that she was diagnosed with hypothyroidism and pre-diabetes. She brought the results to Malta House and was being followed for these conditions. She took Metformin for pre-diabetes and Levothyroxine for hypothyroidism. I asked Catarina what she thought brought about her health problems. She responded:

Well, I was always healthy. For me, it must be the stress, the stress of being without work because I always worked. I think it's that because I never had any problems before.

Catarina's explanation implied that she believed if she had a job she would not have become ill. Indeed, she had lived in the U.S. for many years without being pre-diabetic or hypertensive. It was not until her employment situation changed that she suffered these maladies. This was also true of Celeste: "I have a family history [of high blood pressure] and of course the frickin economy and the stress and the whole nine yards and that."

"If I don't have health insurance, I'm a nobody. Without health insurance I'm worthless."

Catarina explained how being without health insurance affected her.

My dentist will not see me, my gynecologist will not see me if I don't have health insurance. They won't take me if I go like that, how do you say, as an uninsured person, no. The dentist, and I have been with that dentist for years, for years and he wouldn't take me and that's—I said to him "just to do a cleaning" and how do you say, um, "I will pay you. I don't take anyone without insurance." A man to whom I have given—I would go every year or every six months for him to clean my teeth. He wouldn't take me, nor the gynecologist, nor the dentist. So if I don't have health insurance I'm nobody. And if I apply to the state since I have a house I don't qualify. So I should have just been paying rent all this time. And this is

little, like rent. I pay \$700.00. This is a re—it's the same that any other person would be paying for rent. And as you see it's not a mansion. It's something small (laughs). So I do feel badly not having health insurance. I'm completely worthless for the doctors. Without health insurance I'm worthless. The two of them have made me feel the same way.

During this conversation, Catarina started to cry. She said that she even felt embarrassed about coming to Malta House.

I sometimes feel badly being at Malta House because I say, um, because there are people that—I see people that—the last time I saw three or four people who work. They have good jobs but with no health insurance. And I say “Wow. Leave it for people who don't work, who don't have money, who are in a bad way.” Because I tell you the truth. If I—I—I were working I wouldn't go to Malta House. Because that is for those who really need it. I saw—yesterday I saw a gentleman who had a security guard uniform. There are others who drive a school bus where they are paid \$20.00 an hour and they have Section VIII. Believe me I say...they all work but they don't have health insurance but they get money.

Catarina understood that Malta House was for people who did not have health insurance but thought that if people were working they could pay for their health care even if they had to pay a little at a time. She asserted “sometimes you can do a payment plan. I have done payment plans.”

Catarina also expresses shame about having to go to Malta House. “Honestly, I feel so embarrassed, sometimes, that's why sometimes I ask for pills for six months. Why? Because I am not going to go every three months.

Elizabeth, the West Indian nurse, also felt uncomfortable about going to Malta House, but for different reasons:

I, uh, did a search on the internet and I put in ‘free health care’ and go in and put ‘free health care for Hartford, Connecticut and then Malta House of Care came up and I said “Ok, you know what I am goin there.” I was, uh, I was concerned in the beggin about goin there because I'm thinkin, “Uhhhhhh, uhhhhhhhh, I'm gonna have to wait for a long time, what type of people are gonna be there I have to go sit beside.” So I was skeptical in the begging but then freeeeeeeeeee, free motivates people a lot. So I said “I don't care who I'm gonna sit beside, I don't care what-I don't care how long I'll have to wait, I'm gonna go...”

Here class issues and stereotypical notions of those in poverty (e.g., they are dirty, they smell) and uninsured were prevalent in Elizabeth's narrative. She imagined herself as someone who did not belong in the same category as those who attended Malta House. She had always worked as a registered nurse, made a good income, and had good benefits, including health insurance. Elizabeth's last job was with the State of Connecticut, but was laid off in 2012 so she had been uninsured for nine months.

Lucha also discussed her class status. In her interview with me, Lucha explained she had a Master's degree in auditing from a University in Peru and she and her husband had a successful business there. Her husband was having an affair so they divorced. Being distraught over the divorce she neglected her business and eventually lost it to her nephew. When she came to the United States, she worked in menial, low paying jobs. She was still in a menial job at the church but found it less stressful than other jobs she has had. Coming from a middle class professional background, having to work in menial jobs was a difficult transition for Lucha. Furthermore, she saw herself in a different class position from her Latino coworkers, and would try to find positions where she did not have to work with the 'masses'. She explains:

[S]adly, the people I have seen, we who came here—who end up staying—those of us who came—in my case, I came with a visa but it expired because I stayed here—we are a minority. The majority are the ones who came through Mexico, and—and so I'm very sorry to say, the large majority that come from there, their knowledge is minimal. And many who come from Central America don't even know how to read, they don't know how to sign their name, very little schooling. Many young people, many young people. I always tried to find a job that allowed me to get out of that mass where they put everyone.

"Before I didn't see any Gringos. Now I see Gringos."

Catarina went on to note that the economy was in such a state that she

observed, “Before I didn’t see any Gringos [at Malta House]. Now I see Gringos.”

For, Catarina a “gringo”, i.e. a white American, should have been able to afford health insurance, or be in a job that provided health insurance. Thus, her surprise at seeing “Gringos” at the clinic.

“They keep calling me and they keep sending me papers.”

Catarina also expressed anxiety about a medical bill from two or three years ago that she tried to pay off each month:

I have a bill that I have not paid but they want to charge me interest and I have been paying \$50, 50 and they keep sending me papers and they keep calling me and for \$1,000—\$1,050 I think it is. But they want to raise—they have increased it to \$2,000.00. And I tell them “I can pay you \$50.50 every month” but don’t charge me interest because I am not going to pay the interest. It’s not like a bill from a restaurant...It’s a medical exam...I tell you this depresses me because I’m used to—like I told you before I don’t have debts. I guarantee you that I don’t have debts. I’m up to date with the phone bill, up to date with the cable bill, up to date—what’s more I cut little bit of the cable and—and I’m watching, I’m cutting more because unfortunately I have to reduce expenses. But these people are calling me all the time. It drives me crazy.

Indeed, Catarina said she never experienced this before in her life.

...I didn’t know what it was to live from paycheck to paycheck. I never knew what it was like to live like that. Now I have to live watching if there is money to buy. Do I buy it, do I not buy it? I have to measure. And I was never accustomed to this...I never thought I would be in this situation. I don’t even want to call my country to—because before I would send, I would bring. Now I can’t even buy things, therefore I have to—I can’t—I can’t be, how do you say, I have to help myself. Nothing—nothing—nothing—nothing is guaranteed.

Discussing her predicament of being without health insurance Catarina critiqued the lack of information regarding the ACA.

...that thing with Obama. I have not—not—not heard any—listen, up to now I don’t know what is—what the benefits of the Obama plan are, what is Obama’s plan, what have they said, I don’t know. Believe me I would go to every house, I would knock on every door, because I would be a good communicator, and I would knock on every door and I say this is what Obama is offering this [plan]

would not suit you. But no one has explained it to me nor have they called me. That's what's missing. I tell you something, they lack explanation. Everyone asks "Do you know what the Obama plan is? I don't know. I don't understand, I don't know." Honestly, for me there is no information.

I asked Catarina who had a right to health care in the United States.

Everyone because all of us are human beings and none of us look for illness. Illness comes and when one least expects it. How do you say, if one had a magic wand that could get rid of all the illnesses how wonderful that would be. But no one wants to get sick. And I think everyone should-legal, illegal, citizen, non-citizen, rich, poor, we all should have medical care.

When I asked her who deserved health care in the United States she explained:

Everyone. Especially—I think, especially those who have worked here because there are people come here and get everything easily and-for example, I have a friend who has worked more than 17 years in the [State] Capitol and he has deportation orders and he has gotten sick. He has had two heart attacks, he has cancer, he has gotten five or six illnesses and he is to retire but what happens? Because he is not a resident⁵⁰ he is not entitled. And he deserves because he has worked for this country. He deserves to get health care. Why? Because he has worked hard here. He has cleaned the marble. He has cleaned the offices of all the congressmen.

Catarina continued:

Because there are people who—I know two girls that...they already gave them disability, and they speak perfect English, who could work as interpreters, bringing papers, in an office, or doing volunteer service, something to earn their medicine, but go from doctor to doctor and I don't think they are—that they are sick. They do it for the comfort, to be in their house, watching television, and not doing anything, and they receive their check and they go to the doctor like it's nothing. That's what I see.

Maria, a woman from South America, and Milagros had similar sentiments:

Maria:

If I am born here, I'll go and apply to the state. There are people I know here who don't have that medical assistance. That is the medical bureaucracy...I—I tell you...because we were walking to go to the Medical Center and there outside there is a church which is a shelter and people go and you see, overweight,

⁵⁰ I take this to mean he is undocumented.

conceited, full-bellied Americans and Puerto Ricans at three in the afternoon waiting for the shelter to open to go in and go to sleep. People who produce nothing who are from this country, they have their papers, they can-can take advantage of all the benefits and everything and no. For me those people do not deserve anything. But nonetheless they have more than what they deserve. Because I tell you—I tell you—with all the assistance they give, they harm the people.

Milagros:

...there are many people who don't work because they don't want to work. There are many people who ask for help just to ask to be taking drugs, to go to the casinos, to waste money...Or many people who have papers but who definitely like to live off the government. Those people they should really investigate and not give them any assistance. They should send them to go and work. The people who are working and want to get ahead, the people who are producing and who really want to get ahead are the ones who deserve. Those who don't want to get ahead and they are helping-those are the ones they help the most. But in general, the right-we all have a right [to health care]...[t]hose of us who live here. Regardless of whether we are here legally or not...Because it is a humanitarian reason.

Unlike Catarina, Maria, and Milagros, Lucha believed only those who worked had a right to health care, but everyone deserved health care:

The right comes after doing something. I'm always talking about productive people. We have a right always and when we contribute. Deserving, that's more complicated for me. Human beings deserve just for the fact that they are human beings. Everyone, white, black, yellow, rich, poor, everyone deserves. But the right is earned by doing something [i.e. being productive].

"...they have Dolce and Gabbana."

I asked Catarina if she thought there was anyone who did not deserve health care as a right in the United States.

I said everyone who is sick should—should have [health care]. But there are people who are not sick, who don't need it, who should...and they have [health insurance]. I know people who don't have anything [i.e. illness] and they have health insurance, and they get and get and I say, and they say that they investigate but they don't investigate anything because they have everything. My nails are done because a friend came and did them who is—who has stayed—since she has come from—from another state and has been practicing because

she knows—but it's not that I'm spending on nails because now I don't have enough to have my nails done. But there are people who have jewelry, have the best cell phones, the best cars, the best of everything and they receive government assistance and medical care. They have good eyeglasses. These are from Malta House. These glasses are from Malta House, that I got the eyeglasses from there also. But they have Dolce and Gabbana, brand names. They have like—I thought they worked, that they worked hard to get these things but no. It's just that the government gives them everything. They give them the blood sugar machine. I don't have the machine to test my blood sugar. They have—there's one I know who has three or four machines. And I have seen in the pharmacy those machines cost \$280.00, \$350.00, the cheapest at \$150.00 I cannot buy right now. I would love to but I can't buy it. What can I do?

Catarina, like other immigrants I have interviewed, believed there are people who took advantage of government assistance, who, in her view, were able to work. There was a feeling of resentment, anger, and injustice. As she mentioned, she thought it unfair that her friend who cleaned the floors and legislative offices in the state capitol, who became ill, could not get health care, and now faced deportation. It was ironic that he worked in the state capital, but it is possible that the state government outsources the cleaning services and that the company with whom the state contracts hires those who are undocumented. She conceptualized a right to health care as that to which everyone was entitled “because we are all human beings.” While she asserted everyone deserved health care, she qualified it by insisting that those who work were especially deserving of health care, regardless of citizenship status.

Catarina's case was particularly interesting because every job she had included health insurance benefits, but at the time of the interview she was being hounded by a collection agency for a medical bill, which she was paying off on a monthly basis. She was very worried about her financial situation and blamed President Obama: “Forgive me but what Obama has done is make me lose my job.” At the time, her annual household income was \$25,000. For Catarina President Obama had not done enough

to create jobs and this was Catarina's top priority. Indeed, like many immigrants, Catarina came to the U.S. because she could not find work in her home country. As she said "I came here to work, nothing more." Shortly after coming to the U.S., Catarina worked cleaning offices for one year. Then she worked in a dry-cleaners, then in another and finally in another. She worked at these three different dry-cleaning establishments for a total of 17 years. She lost her job with the dry-cleaners because many companies left the area and the company downsized so she was let go.

Like many Latin Americans, Catarina was one more victim of neoliberal policies that led to structural adjustment in Peru (Kim et al 2000b).

Finally, Catarina had medical needs which she could not afford, such as purchasing a glucometer to check her blood sugar at home. Indeed, doing without is a salient theme among the participants as expressed by Lillian, introduced below.

Lillian

I interviewed Lillian in the living room of her home. I met her at Saint Joseph Cathedral. She is a soft-spoken 62 year old Puerto Rican who lives with her 90 year old mother and her grandson. She recounted the story of her birth with a chuckle:

I was born in New York City. I was born on Broadway. Right in Manhattan at home. I was delivered by a police officer. And then I went to the hospital...my mother was walking with her sister in Central Park and she decided to go home instead of to the hospital. Geeeee! Interesting story, uh?

Lillian went to Puerto Rico when she was 15 years old. She lived with her aunt because her mother remained in New York. She finished high school in Puerto Rico, got married, got divorced and when she divorced she came back to the mainland and lived in New Jersey as her mother remarried and moved there. Lillian remarried but then

divorced and in the early 1980s she moved to Connecticut. A friend told her about Malta House and she started going there in the fall of 2011.

Lillian lived on a quiet street in her Cape Cod home, which she purchased in 2004. We sat on the large living room sofa. In front of the sofa was a coffee table. The room was also furnished with a sofa chair, TV set and a big picture over the mantelpiece of her son who died suddenly at the age of 28.

“[The COBRA]⁵¹ would go up to \$400 [a month] so I couldn’t afford it.”

Lillian was 62 years old and suffered from osteoarthritis in both hands, bone loss in her feet, and right knee pain. She worked for almost 30 years in various companies, mostly in human resources as a recruiting assistant. The last job she had with benefits ended in 2009 when she was let go. She explained:

I was diagnosed in 2006 with osteoarthritis in my hands and I have some bone loss in the feet. And in 2009, the beginning of 2009 I did suffer a fall. And I developed pain in the right knee. And this was when I was still working and I had gone to a knee specialist and they really didn’t find anything wrong but the pain never went away. They told me if the pain didn’t go away they would have to do an MRI or something but I-you know it wasn’t bothering me that much so I didn’t really-you know-pursue that and then I was downsized from the company that I worked for and I was paying out of pocket for the-um-COBRA. But at that time President Obama had said that they would pick up 65% of the cost and I would pick up the remainder so I did that for the 18 months cause that was the limit of the subsidy. After that it would go up to \$400 so I couldn’t afford it.

Lillian, like Carol, then attended Capital Community College for CNA training.

She noted:

⁵¹ The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a law passed in 1986 that allows workers and their families the right to choose to keep their employer’s group health plan for a certain period of time in the event of voluntary or involuntary job loss. The former employee, however, must pay the full cost of the premiums, including the share the employer used to pay, plus a small administrative fee (Employee Benefits Security Administration n.d.).

[I] graduated with an A and I couldn't get a job. The hospitals will not hire you unless you have at least about a year's experience. So I went to work for VNA doing home health care. And I did that for a year and then I just couldn't do it anymore. And I really wasn't making any money. And I, and I also tried to work the 24 hour week—at least you had to work—you had to work at least 24 hours a week to be eligible for medical benefits. Worked there a whole year was never eligible for the medical benefits because you're working per diem.

In the 1980s, when she was working and had health insurance, Lillian had surgery on her right hand for carpal tunnel syndrome. The surgery did not do anything to relieve the pain and the orthopedist found that what Lillian had was not carpal tunnel syndrome. Rather, what the orthopedist told Lillian was that she had cubital tunnel syndrome.⁵²

Although Lillian was told by the orthopedist in 2006 that she needed surgery in both hands for osteoarthritis, and the left hand was worse than the right, she told him to do the right hand because she was left-handed.⁵³ She described the surgery.

[the bone was practically eaten up from the osteoarthritis so the doctor removed the bone and took a tendon from my arm to make the connection...and then, after after that I—I was so afraid from so much pain that I went through in that surgery that I didn't go back and then he retired and I didn't have any more insurance.

“...if I had medical insurance I'd be able to do certain treatments or therapies or whatever.”

Lillian was also experiencing pain in her hip but could not afford certain therapies:

I mean I could probably be able if I had medical insurance I'd be able to do

⁵² “Cubital tunnel syndrome...is caused by increased pressure on the ulnar nerve..., in the area of the elbow commonly known as the “funny bone”” (WebMD 2014d).

⁵³ Osteoarthritis occurs when cartilage on the ends of your bones wears down over time (Mayo Clinic Staff 2014)

certain treatments or therapies or whatever. But, you know, since I don't. Like right now this pain um, in my hip, I had asked, um, a psychologist that I know—because I know my aunt one time had this problem and she went to a Chinese doctor that did acupuncture? And that seemed to help her so she told me about a place here in Hartford. I haven't checked it out yet but I know there's gotta be a cost associated with it. But, you know, I mean it's—having to live with this because you don't know when it's going to go away is very difficult...because, you know, physical therapy is not like you just go one time and that's it. You know they usually recommend that you go at least two or three times a week for X amount of weeks whatever.

“I never realized that your emotions played such a big part in how your body feels. You know?”

Lillian believed the osteoarthritis was a result of many years working in an office on computers all day. Lillian also had high cholesterol and had been recently diagnosed with high blood pressure at Malta House. In addition to pain medication for arthritis, Lillian was also taking medication for her high cholesterol and high blood pressure, as well as medication for anxiety and depression. She admitted that being without health insurance affected her emotionally.

Well, well it has made me feel, ahh you know, very depressed to see that now that I'm getting older and I don't have, you know, the insurance I used to have I can't, um, really feel 100% better, um, you know without having um, the medical issues taken care of because of cost. And I have to be grateful to Marta [sic] House of Care because at least they send me out for x-rays, they send me out for, um, mammogram, you know and things like that.

Lillian's knee pain was so severe that the physician at Malta House referred her to an orthopedic surgeon who was willing to perform knee replacement surgery free of charge through a program called Operation Walk (Foley 2011; Operation Walk USA 2014a).

...they put me on a knee replacement—possible knee replacement list and I believe it's with Project Walk. And I went to the surgeon and he said that the knee is out of place and that this whole side right here [points to right knee] is already eaten away so...this one also needs replacement [points to left knee].

But I didn't have it done...and they already scheduled me for surgery and everything.⁵⁴ But by the time I went to see him I said no. First of all I wasn't emotionally prepared for that? Cause that's major, major surgery. And as you can see I live with my mother and I have a fifteen year old grandson who was my deceased son's little boy. And so he lives with me and um, you know there's just no way that I can be held up like that and and plus they don't pay for the hospital. They only pay for-I mean the surgery is free.

However, the Operation Walk USA brochure stated,

Operation Walk USA provides all aspects of treatment—surgery, hospitalization, and pre- and post-operative care—at no cost to qualifying patients uninsured, underinsured, and cannot afford surgery on their own (2014b:2).

Operation Walk exists, as do other health related charity organizations, because, unlike other industrialized countries, the United States does not have a national health insurance system, except for Medicare for the elderly. The Affordable Care Act is not a national health plan per se in that individuals are required to buy insurance from third party administrators.

Due to Lillian's family responsibilities, and her concern that although knee surgery would be free, the other services involved, i.e. hospital stay, medications, anesthesia, and rehabilitation would not be, she did not have the knee surgery.

As mentioned above, being without health insurance affected her emotionally. However, she also attributed her deteriorating health to her son's unexpected death in March, 2006 at the age of 28.

[My son] was driving and his heart stopped. He was here, you know, a couple of hours before it happened. So that kind of-that was a major factor in my health going down. Because after that was when I developed the uhh, actually that's when I developed the cholesterol. Yeah, in 2006. And I developed vertigo. I was in and out of work a couple of times because of the vertigo. ...So it was difficult. ...So they ended up sending me to a cardiologist and then they-I went to the

⁵⁴ The organization is Operation Walk USA, not Project Walk, which is a for profit organization for those with spinal cord injury (Project Walk Paralysis Recovery Centers 2013).

cardiologist and he said “You know [Lillian], there’s nothing wrong with your heart. They did all kinds of tests my goodness. They had me on this treadmill and the stress test they call it. And at the end he says to me “[Lillian] the only thing that is wrong with you is that you have a broken heart. And I said well what do you mean? He says, “Well, you know certain emotions will cause your body to act out in certain ways. And all these things that you have, have been because of your emotional state.” And I never realized—even the high blood pressure—I never realized that your emotions played such a big part in how your body feels. You know?

Lillian credits Malta House with helping her deal with her health issues that she connects with her son’s death: “...Martha [sic] House of Care has helped me a lot um, to at least you know feel at least 50% better as far as, you know, because without them I mean I would really be worse off.”

“He had no heart disease. They said he had a healthy heart.”

Not only did Lillian’s son die unexpectedly but what disturbed her more was that no one could give her a cause of death, i.e. why her son’s heart just stopped.

He wasn’t sick. They couldn’t find anything wrong with him...he had no heart disease. They said he had a healthy heart. The autopsy they kept retesting and retesting until finally—and you know, I kept calling the medical examiner and they finally called me back and said “Listen, you know we had a big meeting with all the doctors and we don’t know what to tell you. We don’t know why he—why his heart stopped.” So they couldn’t find anything wrong with him. You know, and after a couple of years I remember I was taking my sister to UCONN...and...I went downstairs and they had a lot of flyers and I was reading through things and I found that um, there is a thing where there could be an electrical shortage of the heart and everything just stops. It has something to do with the arrhythmia. Not exactly—I can’t remember in detail but I says, “Oh, this is what happened.”

“Some care is better than no care.”

Being uninsured weighed heavily on Lillian. I asked her what knowledge she had, if any, of the ACA. She replied:

Only what, you know, what I’ve heard on the radio. When my son looked it up, You know. When other people have made comments in the family. I had a cousin in New Jersey tell me, “You know, Obamacare is not going to do your knee

replacement surgeries” and I said “Why?” And she says because I’m too old. And I said what do you mean? I’m only 62. So I don’t really know because I haven’t done the research.⁵⁵ I’m just hearing on the radio some things and you know apparently from what I understand there are some restrictions in that plan, I mean as far as-I think if you’re 70 you won’t be able to have certain surgeries done. I don’t know if that’s true or not because like I said I haven’t personally done the research...I would really like to you know, check it out and know if it’s, um... but I would think it’s better than not having any medical insurance at all... I mean at this point I will probably have to take it until I’m 65. I would have to get it because some care is better than no care.

I asked Lillian her thoughts on a human right to health. She answered:

Well, I think that every American citizen should have a right to health care. Um, you know whether they’re young or old, you know, everybody should have access to good health care. Whereas now, right now for example, we have the poor who don’t have anything [and] get free medical assistance. Ahhh, the people that are working they get subsidized medical because they have to, of course, pay a premium. And then you have the people that have lost their jobs who have to pay a mortgage, who can’t find another job. Um, maybe it’s because of their age. And then, you know having to, um, use up all of your resources to continue going on.

However, when I asked who deserved health care Lillian asserts, “Well, I think everybody should be entitled to health care.” I followed up by asking if there were people who do not deserve health care as a right in the U.S. and Lillian responded:

Well, like if you’re referring to people who are here illegally or something like that? I mean, I don’t know but I mean, nobody has control over getting sick. And I know that, I mean if I was in another country and I was sick I would want to have health care given to me.

Lillian’s responses suggested that she conceived of a right to health care as juridical in nature and deserving health care as a moral issue.

Being uninsured and losing her son so unexpectedly had taken a toll not just on Lillian’s physical health but her emotional health as well, to the point that she took

⁵⁵ Coverage of services, including specific surgical procedures are dependent on the individual insurance plan within the Connecticut Health Insurance Exchange.

medication for anxiety and depression that the Malta House physician has prescribed her. Other participants I interviewed or spoke with at the clinic also expressed suffering emotional problems, such as sadness, stress, or anxiety due to the precarious financial situation, they now found themselves in, again pointing to the social origins of illness, as in the case of the next participant.

Karen

Karen was a 62 year old Jamaican woman who never finished primary school. I met her at Sacred Heart Church and interviewed her in her two-floor apartment in an apartment complex east of the Connecticut River. She lived on the first floor and a young Jamaican woman, whom Karen called her daughter, but was not a blood relation, lived on the second floor. Karen was not working and was living with her daughter and her daughter lost her house so the two of them had to move to the apartment where they were living. Karen's rent was \$800/month. The room where we sat had a bed, and the kitchen was in the same room. The living room had been converted into a bedroom. Between the living room and the kitchen there was a washing machine and dryer. The kitchen was very small.

Karen had been going to Malta House since 2008, which she found out about through a friend. There, she was diagnosed with diabetes in late 2010, early 2011 for which she took glipizide.⁵⁶ She tested her blood sugar everyday. She also had high blood pressure, also diagnosed at Malta House about five years ago. She took on her own baby aspirin and a vitamin pill everyday. For her high blood pressure she took two

⁵⁶ Glipizide is used to treat high blood sugar levels caused by type 2 diabetes. It is an oral medication, that is, it is taken by mouth, unlike insulin, which can only be taken by injection (Mayo Clinic 2015).

medications that were prescribed by a physician at Malta House of Care. One was Lisinopril⁵⁷ and the other, Hydrochlorothiazide.⁵⁸ I asked Karen what she thought caused her health problems. She replied:

Worry. Right now worry has a lot to do with it because, you know, when-when you don't know where the money is coming from to pay bills and credit-I have two credit card bills and, you know, I think that's where it started. And then I used to help my daughter with her children and you know, kids. I said, "When I was in Jamaica I didn't have all these problems...Even right now I think I need a colonoscopy and I can't afford it because it is very expensive.

Here in Connecticut Karen had been working as a home health aide since 2005, but did not have health insurance. Karen was unemployed, a situation that caused her great anxiety. In Jamaica, on the other hand, Karen had extended family that helped her and often she had health insurance through work. She already had two daughters when her husband died. They were still small, one and three years old. She worked for a year after her husband died but then stayed home to take care of her children. Her mother and brother helped her during this time. She had two other children with another partner and all four children were grown; two of them were here and two in Jamaica. Karen married again in 2007 to a man she knew for a long time in Jamaica, but they no longer lived together. She visited him because they were still friends and he suffered a stroke.

From the late 1990s until about 2001 Karen would go back and forth between Jamaica and Florida. She had a friend and a brother who lived in Florida. She went back to Jamaica in 2001 when her mother died and then came back to Florida, and

⁵⁷ "Lisinopril is used...to treat high blood pressure (hypertension)...It works by blocking a substance in the body that causes the blood vessels to tighten. As a result, lisinopril relaxes the blood vessels" (Mayo Clinic 2015a).

⁵⁸ "Hydrochlorothiazide is used alone or together with other medicines to treat high blood pressure (hypertension)...It is a thiazide diuretic (water pill) used to help reduce the amount of water in the body by increasing the flow of urine" (Mayo Clinic 2015b).

finally in 2004 her daughters, who lived in Connecticut, told her to come here. Karen explained:⁵⁹

My daughters have been living in Connecticut but guess what, their [paternal] grandmother had adopted them so they couldn't file for me at that time. They couldn't do nothin to help me. I know that she adopted them but she said it wouldn't affect me. You know, that's where the lie comes in. Because I didn't know that I was really givin up my parental rights. So, you know, I didn't know. So, they couldn't help me. They were so frustrated and mad you know that they couldn't help me. And she went back to Jamaica and died down there.

Karen's legal status was unresolved, i.e., she was undocumented, and had not been back to Jamaica since moving to Connecticut, yet another stressful situation she had to deal with.

Karen's annual household income, at time of interview, was \$21,000. She admitted that being unemployed has influenced her health strategies

[b]ecause first thing to begin with sometimes you are sick and you don't have money to go to the doctor. You just have to try some home remedies and you can't go to the doctor.

Karen commented:

...I'm not tellin you no lies sometimes I drink some bush, cerasee seeds, sometimes I drink cerasee seeds, you know, a bush that grows in Jamaica, sometimes you bring up some cerasee seeds, some fever grass, you know, [that] type of stuff. Cerasee seed is really like a bush. It run on a vine. In Jamaica we use them as home remedies when you're sick...you drink it as a tea...It's bitter. You just boil them and drink them. It's good for bellyache and it's good for-my-my mother used it, not my mother, my grandmother and all of those people they drink it and I never seen anything wrong with them. I [also] use a lot of ginger and garlic...When we have cold we take honey and add a little rum to it [laughs].

"Most of it should come from the government."

Karen believed everyone had a right to health care and everyone deserved

⁵⁹ Karen's airfare to and from Jamaica was paid by her brother. Because she entered the U.S. by air I am assuming that she would come on a tourist visa and would return to Jamaica before the visa expired.

Health care. She explained: “[e]verybody should come together. That’s how I look at it. And we are all one. It doesn’t matter what color we are and what goes for one should go for all. That’s how I look at it.”

I asked her who should pay for health care in the U.S. and she responded:

Well, I think since we have been payin, um, Medicare and Medicaid and all those Social Security and all of those stuff, I think some of it—I don’t say we shouldn’t pay a part, you know, but I think most of it should come from the-the-the government.

Karen’s perspective is, essentially, how the ACA is structured. Many individuals, who are eligible to receive health insurance as a result of the ACA, pay a portion of the fee and the federal or state government pays the other portion. That is, the government subsidizes the cost of health insurance.

I asked Karen what had gotten her through this period of her life. She began to cry and said that God had gotten her through.

Well, I’m telling you the truth. I know God and whenever I have a problem I never feel that I can’t go to Him and talk to Him. I always depend on Him for anything that I want. Anything that I want. Because I know he’s the one who creates me. He’s my creator and if I am in need—you know when I look and I read my bible and it tells me about the sparrows that doesn’t work more than a farthing and how they never fall because he always take care of them. So how is it He’s gonna create me and let me suffer? No he doesn’t. He provides for me because I could remember once I wasn’t workin and things was so bad and I—I—I cried out to Him. I said ‘Lord, I don’t think you bring me this far to leave me so that I can’t—well I never used to pay rent, I was living with my daughter but, you know, sometimes you want something, you want to be independent and you don’t want to depend on them for everything.

Karen had a strong faith and also maintained that her church community had helped her when she was in financial difficulty.

And I cry out to him and it was about the Monday and the Wednesday this lady called me and she—she’s the director of a senior living facility and she called me and she said “I have a job for you. Can you come?” I said ‘Sure.’ And I packed my stuff and I went straight. And I said ‘Lord, who else could it be?’ Because you

see that I was down, I didn't have anything and I was tired of, you know, depending on my kids, and He made a way for me. So, I know Him, I know Him as a friend. I know Him as my maker and my creator. And that's what keeps me goin sometimes. And you know, when you have good friends at church you can call them and sometimes I will say 'You know, I have this bill comin up and the money is short and they say "How much do you want?" I say 'A hundred dollars.' "Come, I'll give it to you." Just like that. You know you have good church people. And I have been a Seventh Day Adventist...I have been a Seventh Day Adventist for years.

Similar to other participants' experiences, Karen has been able to tap into her faith community for assistance and support and was also grateful to Malta House but wished they had more services:

Sometimes I wish like Malta House could do more. I'm not saying that they're not doing enough. For instance, um, I-I'm having like problem with my denture. I used to go to UCONN and I can recall once because I wasn't working. They said they couldn't-I couldn't come. I said 'Couldn't you put me on a payment plan?' "No." I have to pay.

Yet, Karen is grateful for what Malta House *does* do:

I remember one time I was out of test strips for about six months because they wanted me to buy it and it was a hundred and somethin' dollars and I couldn't afford it so I stayed without it for three months and I said to them "I can't afford it...how am I gonna know whether my blood sugar is high or not?" They gave me another—they sent me back to [the] pharmacy to get it again. I went back to them told them when I went there it was 119 dollars and I couldn't afford it so I didn't have it...I don't know how they did it but when I went back I didn't have to pay for it.⁶⁰

Barbara, from the West Indies, had similar concerns:

I go to [another clinic] for dental. I need a lot of work that needs to be done and as I was tellin the doctor the reason I never really came is that I don't have the money to pay dental. It's so expensive. Most of the time they want money up front so I need a lot of work that needs to be done. I'm tryin to save the rest of the teeth I do have but at the same time as I said to him I have to come up with money to pay for it so now I have four teeth that needs to be pulled and he's talkin about doin a partial and he said that's 600 dollars and I said to him "I can't

⁶⁰ Karen did not have to pay for the test strips because Malta House covered the cost. As with Juana, if patients could not afford for their medications or diabetic supplies, Malta House covered the cost.

do that. I can't do that.

I asked Karen if she tried other dental clinics. She said someone told her the dental clinic in Harford wanted to look at your pay stub.

But somebody told me that sometime you have to take in your pay stub and sometime lookin at your pay stub even if you're getting \$1,000 a week it still cannot do because here I have to pay like \$840 every month for rent. Gas is different. Light is different. Your credit cards, you have-you have to eat, you know. So sometime lookin at your pay stub doesn't help. And I heard you have to take your pay stub in so...if—if I get like \$700 a week that can't even pay one month rent. I have to—to—to put it down and wait until—so sometime—I say it don't even matter. It don't even pays to go there because they're lookin on your little income and they don't know that you have a lot of bills to be paid. So, I don't know. The eye care is another one. Um, sometimes I don't know what happened. Sometimes my eyes would just be runnin, runnin wa—and then when—when the water, when you wipe like—it—it sticks like it's salt. I don't know what it is. I don't know. Sometimes it seem like the place is just blurry and I haven't gone to the eye doctor.

While Karen would like to find a job, she felt the government should pay for most of the health care since, in any case, “we have been payin...Medicare and Medicaid and all those Social Security and all of those stuff...”

The stress and anxiety of Karen's precarious situation, both financially and legally, greatly impacted her health. Charlie, on the other hand, introduced below, has multiple health issues for different reasons.

Charlie

“It's not a pill fix.”

Charlie, a 46 year old white bachelor I met at Saint Augustine Church, lived with his mother in a condo in a Hartford suburban community. He was a high school graduate who had lived in Connecticut most of his life. In fact, he attended five different Connecticut high schools. After high school Charlie hitchhiked across the country twice

and worked in a carnival in Iowa once. He returned to Connecticut and worked in various jobs, e.g. landscaping, painting, working in restaurants, and other odd jobs.

In the early 1990s Charlie worked for several alarm companies. He then worked in a friend's pawn shop selling his own merchandise out of that store, such as beepers and things like that, an arrangement he had with his friend. Charlie then sold his beeper business to his friend and started selling pre-paid cell phones in his friend's store. He did this for five or six years while also working in electronics. He left the pawn shop because his friend was not running the business very well. For two and ½ years (1999-2001) Charlie lived in Florida where he worked at different telemarketing jobs. He returned to Connecticut and started his own business installing surveillance systems for small businesses, e.g. gas stations. He also subcontracted for alarm companies. Charlie attributed his free spirit, or not wanting to be tied down to any one job to his moving around a lot in high school.

We sat in the living room where there was an entertainment center consisting of a CD player, TV set, and radio. Charlie seemed a very open, honest individual with an easygoing way about him. He had pain, stiffness, dizziness, and balance issues as a result of car and motorcycle accidents. He found out about Malta House because his mother knew one of the physicians who volunteered there.

I...have equilibrium problems from a motorcycle accident. It was from hitting my head. I wasn't wearing a helmet. Sometimes I walk a little funny. I've never fallen because of it but I can tell that someday it'll probably be an issue. When I'm older I think I'm gonna have a lot of issues with it unless it's cured and I don't think that's gonna be the case. It's been with me for ten years. The first couple of years it was really bad. Um, I was dizzy a lot. And I really don't get that dizzy all the time anymore but I—I lose my balance. That's a work in progress. They don't seem to want to address it very much. Any health care provider that I've talked to about it doesn't really want to address it because it's not a pill fix. And we've tried pills and it just—it just keeps getting worse...That's how I damaged my back too.

“...they let me go and I’m like how-how do you just let me go? I know somethin’s wrong!”

From the scene of the accident, Charlie was sent by ambulance to the emergency room and there

[t]hey did x-rays and kept lookin at it and they’d come in and ask me questions. And I’d tell em “Listen I’m tellin you there’s something wrong. Somethin happened there. I mean I’ve got more pain than I’ve ever felt before.” And they were givin me morphine. They were giving me some other pain killer first. I don’t know what they gave me but it didn’t do anything so they gave me more. It still isn’t doin anything. It might have taken a little edge off and they didn’t wanna keep giving me stuff and I’m like why. I’m in pain. What’s goin on. And it took so long. I was annoyed. It turns out they couldn’t—the x-ray wasn’t good enough to um, see the fractures. And so they let me go and I’m like how—how do you just let me go? I know somethin’s wrong! I know somethin’s happened here, you know. And I’ve been injured before so I can tell. You can tell when somethin’s really wrong. You can tell.

Charlie continued:

So I ended up, uh, goin the next day to a radiologist or something and they had me drink some fluid and put me on a CT scan⁶¹ or some kind of imaging machine, um, and then it was clear as day. You could see fractures all through.

Charlie seeking another opinion implies some form of plurality within the biomedical system. Charlie was fortunate that: he had the financial resources to seek another opinion; and that the trauma he suffered was recognized on the imaging, and finally legitimized by the biomedical system.

Because the accident was not his fault, he did not have to pay for any tests or treatments related to the accident. His last accident occurred November 2012 and when I interviewed Charlie he was receiving physical therapy, which was being paid for by the

⁶¹ "A computerized tomography (CT) scan combines a series of X-ray images taken from different angles and uses computer processing to create cross-sectional images, or slices, of the bones, blood vessels and soft tissues inside your body. CT scan images provide more detailed information than plain X-rays do" (Mayo Clinic Staff 2015a).

other person's insurance. However, he also went to a massage therapist, which he paid out of pocket. He explained:

I get massages every month I get sometimes more if I can afford to. It's expensive and right now I'm doin really good right now because I'm doin the physical therapy and the massages. I've never done both of those at the same time and boy does it make a difference! I think after this I'm probably going to go back to physical therapy every year or two for a short period cause it—wow! Wow! That helps. Physical therapy helps. I thought massages help. Physical therapy helps. I'll—I'll pay for it again even though—I'm tellin ya it's—it's—the—the massages...I go every four weeks, I pay the 60 dollars plus I tip her 20 bucks so it costs me 80 dollars to get a massage every month and it's a lot of money for a guy that doesn't have a lot but the-the benefit of it is extreme. It really, really makes a big difference.

Like Charlie, Sam, who is also white, and José and Gabriel, both Latino men, also sought alternative health care.

Sam:

I had a back injury and at work, I was at [an insurance company], and instead of wanting to go see an orthopedist, I wanted to see a chiropractor and they were up in arms about that. They didn't want to pay for it. At one point-and I-and I continued to see the chiropractor after the lower back problem was resolved and I told the chiropractor about these headaches...He was an old-he was an old-he was an older gentleman in New Britain and one day as I was getting ready to leave his office. I had one of these headaches come on. He put me in a side room, he took care of a couple more patients and when the headache subsided he brought me back in on the adjustment table and started to work on the upper vertebrae in what they call the ring...Haven't had a headache since...And I still see a chiropractor today and the reason I do is to keep all of that stuff in line.

José:

José sought acupuncture treatments. Indeed, Jose expressed distrust of the biomedical system. He had high blood pressure and took medication for it, though reluctantly. He believed that hard exercise where he sweats a lot, and acupuncture, would keep his blood pressure in check.

I have to force myself. I have to force myself...I like to be free, be independent, without any, without any pills, without any pills. But since I have to live in the

sense that I must eat and when I eat it's as if I have high blood pressure all over again. Until I do exercise that burns calories, a hard exercise, I will continue to be worried. Even now I'm worried because I like to exercise where I sweat a whole lot, and until I can find an exercise where I can do that—I exercise in the summer, even until November, December—I walk, I ride my bicycle, but I don't sweat. It's not hard exercise.

I was going to a Korean acupuncturist but he did not want to listen to anything I said and I didn't like that, but I want to find another acupuncturist that is not very expensive because my budget is limited.⁶²

Gabriel

Gabriel, was treated by a naturopathic physician in his home country. He was diagnosed with hypothyroidism.

When they [medical doctors] checked me they couldn't find anything but I was losing weight. I lost 30 kg. [66 lbs.] in a month a half and I was hospitalized for three months and almost a year and a half under ambulatory care. At one point I was taking 24 pills a day and then they had to empty my stomach and clean out everything. But finally they discovered what the problem was [hypothyroidism]. And luckily I was treated by a naturopathic doctor. He stabilized me and stopped all the pills and controlled me just with a strict diet and with exercise because I generally gain weight quickly because I like to eat.

Gabriel would come to Malta House every three to six months to check his thyroid and at the time of interview his thyroid tests were still within normal limits without having to take any medication.

In addition to massage therapy, Charlie used marijuana:

I smoke pot and I smoke pot every day and-and I wish I didn't have to. I do because my back is prominently my reason for smoking... it helps with everything but what it helps most with is the spasms. It relaxes my muscles so I don't get spasms, which means that I don't get pain. It's not like the marijuana is a pain killer but ultimately it does help the pain because it reduces the spasms and keeps me from getting really tight because I get really tight.

⁶² José asked me if I knew any low cost acupuncturists. I explained that a local hospital had acupuncture which at the time (2013) cost \$35 for 30 minutes and \$25 for the first visit. I gave José the phone number and he said he would call them. Since then the price has increased to \$45 and \$35 for the first visit. It is also interesting to note that a health facility where the biomedical system is dominant has incorporated alternative medicine. For a detailed discussion of this process see Baer (2004).

“Pot is perfect. It works great.”

Charlie tried muscle relaxants and other medications for back pain but he insisted they either did not work or they made him groggy where he wanted to sleep all day. As he put it:

Pot is perfect. It works great. Honestly I don't like the, um, you know, the breathing in smoke. I'd rather not do that. I'd rather take a pill, like a THC⁶³ pill. I know those are available in states where it's legal medically, um, it's not here yet and even for my problems I-on-on what's legal in Connecticut now I still wouldn't qualify-high restrictions...So, um, I smoke which is probably not helping my health, you know, smoking. I—I understand it doesn't really—I'm—I'm smokin maybe two joints a day so it's not, um it's-it's-it's not as much as like smokin cigarettes. I used to smoke cigarettes and my lungs are (Charlie breathed in deeply) are clear so I'm not too worried about the smoke but I still would prefer to take a pill and—I smell when I smoke and I have to go into a customer-if-if I'm havin a bad day I might smoke at lunchtime or something. And when I have customers to go to I don't want to smell so I worry about that. People have a horrible stigma of-of marijuana and I don't wanna come off like a hippy, druggy or something to my customers, you know, but, um—so it's a little conundrum but it's—wha—wha—whatever, I mean for me it works.

“It's not the expense of it.”

It's not the expense of it cause the Cyclobenzaprine⁶⁴ are expensive, um, and I'd have to take probably two or three of those a day so it would cost me more than marijuana to take those as well because I have no insurance that'll pay for those at all even if I get the scripts from Malta it's—it's—I still have to pay for those and that gets expensive. I still have em. I need to have em because there are times when I mean the pot isn't the answer all the time. Sometimes it's a bad day and—and this really happens mostly just in the winter if I'm workin hard and I'm stressed and um, then-then I'll get really tight and I'll have to take one or two-and-a couple of days—I'll try to do it on the weekend cause I'll sleep all through it. You know, whatever. I do what I can. Stretching is probably the most important thing. That—that matters more than smoking pot even. That—that's—stretching is the big thing for that, every day.

⁶³ Tetrahydrocannabinol (U.S. Dept. of Health and Human Services 2011) is the major psychoactive ingredient of cannabis, aka pot or marijuana.

⁶⁴ Cyclobenzaprine is a medication used to relax muscles. A common brand name is Flexeril, (Mayo Clinic 2015c).

In addition to smoking pot Charlie ate “things that contribute to health in general.” He took fish oil, bifidus, a probiotic used for digestion, which he took as a chewable tablet, “not every day but a lot”, and milk thistle seed, which he asserted that for him was a “miracle drug.” He ordered it online from California and used it as a liver tonic but said it was also good to clear nasal sinuses. He ground the seeds in a coffee grinder and mixed it with yogurt.

Despite biomedicine being the dominant medical system in the country, Charlie’s experience with other medical modalities, such as physical therapy, and massages, and mild thistle seed, exemplifies the plurality of medical systems that still do exist.

“The last couple of years have been really tough.”

Charlie was a self-employed, high school graduate, and said he did not mind paying for health care. For the past ten years or so, his business was installing surveillance systems for small enterprises, e.g. gas stations. He also subcontracted for alarm companies, but, at the time of interview, his business was not doing well.

I don’t mind paying. I really don’t mind paying for health insurance. It’s—I’m not a rich guy. I live at home with my mom, you know, and I’m—I’m doin this so I can keep my business going. I really hate to give it up after all the years I’ve put into it. The last couple of years have been really tough but if I can get through these I’ll be able to maintain being self-employed. Otherwise I’ll have to get a job or something. That’s tough. I won’t be making very good money probably at first because I don’t have any degrees. I have a lot of good skills but no degrees.

Charlie was able to pay for his health care, and that allowed him to keep his business going, but he was concerned he may not be able to be self-employed. Thus when I asked him if being without health insurance had changed the way he lived he replied:

Um, that’s hard to say. It could potentially because if—if—if I can’t keep my

business goin I'm gonna have to go get a job. Um, but I can keep my business going as long as I can afford my own health care. So, it hasn't but I'm tetering on the edge of that it may—it may change my entire life because I may have to go get a job to get insurance. Which I'm prob—I'm already there—since I've been 40 pretty much I've kind of been with that idea um, and I probably should go work somewhere and ultimately that's what I should be doing. That's what my mother wishes I would do, is get a job so I can have insurance because I'm getting older now and I'm gonna need more health care and um, it's gonna be hard to get.

Barbara and Elizabeth also expressed concerns about affordability regarding the Affordable Care Act.

Barbara:

But at the same time they have to understand is that I have 50 million bills coming in. Adding another one. They have to come up with something affordable. I work in the medical field. I should not even be paying that much...How can they expect people that can't afford to pay for it? I don't understand that.

Elizabeth:

...if it's affordable, like, if, uh, in case I have a job that doesn't have any insurance and if it's affordable and say if the insurance is gonna be 102 or so dollars per month that for me is affordable as opposed to 500 dollars a month.

Besides the health issues related to the accidents, before coming to Malta House in June 2012, Charlie was diagnosed with diabetes. In addition, he had high blood pressure, which he also had for a number of years, high cholesterol, and calcium deposits in his intestinal tract on his right side, also illnesses he had since before coming to Malta House. Charlie appreciated the services offered by Malta House, especially the fact that he could get the test strips needed to check his blood sugar at home: "I really needed to be testing more." He wished, however, he could have taken the diabetes classes but

[b]ecause I've never had insurance I've never taken the class. When you're diagnosed with diabetes your doctor will send you to this class. You go a few nights a week for a month or so and learn about carbs and stuff like that. I'd love to take the class but it's just not available for people that don't have insurance.

“Walmart did a revolutionary thing when they did those ten dollar meds.”

Charlie was able to pay for his other medications, pills he had to take for his diabetes, high blood pressure, and cholesterol, although at first it was difficult. While he did not use Walmart to obtain his medications he credited the store with bringing the prices down for many medications, including those he took.

At first, when I first got diagnosed with the diabetes they wanted me to take Metformin and Glyburide, it cost eighty dollars. It cost me eighty bucks a month to fill those prescriptions...and then Walmart, who—my mother's a hater and so many people I know are Walmart haters. But Walmart did a revolutionary thing when they did those ten dollar meds and it changed—and it has. It changed—it's changed the world. It really has. It's changed meds in this country like phenomenally because now everybody else is doing the same thing. And—and—I—I bless Walmart for—for doing that. It was a big move. It was a really colossal landmark as far as medication goes in my opinion and—and that made it a lot more affordable for me to take my meds. So-so it was hard at first for a year or so.

Charlie continued:

And I wasn't making a whole lot of money at the time I remember it was tough to come up with that 80 every month. I could do it but you know. And the doctor was really nice. He'd help me with uh, uh, he gave me um—he didn't rely on the Metformin and Glyburide, he didn't have samples, but he had samples for other stuff that I needed for stuff, you know. Which was great. The Cyclobenzaprine he'd give me samples for that, things like that, but it was—between the three of them—it was the blood pressure one too it was, um, it—it was getting expensive for a while. But now it's—it's awesome. All these programs are phenomenal. They make it affordable.

I asked Charlie what helped him during this period, particularly related to his health. He responded receiving help from Malta House, and his primary care physician, who retired, his supermarket, where he obtained his medications, and Walmart. His physician's retirement was the reason he sought out Malta House.

Malta has definitely helped me. I give them credit where it's due. They—they've definitely helped. What else has helped me? My doctor when he started to charge me, you know, 30 bucks instead of, you know, 60 or 80. Things like that. The [supermarket], Walmart. I give a lot of credit to Walmart. I never hear

anybody else sayin that about them. I really give them a lot of credit for doin what they did, changin so many meds, so many meds they did that with. And that was revolutionary when they did that.

Charlie normally went to a local supermarket where he could get his diabetic meds free of charge. He also took Lisinopril for his blood pressure, Cyclobenzaprine (Flexeril) for his back pain, and a cholesterol medication, but he did not know the name as the physician just prescribed it. He was taking a statin drug for his cholesterol about a year ago but was having side effects. “My legs stiffed. They got really, really stiff, like after takin it for two or three weeks.” Charlie explained it took about three months of not taking the medication for the stiffness to disappear.⁶⁵

“It’s hard for me to pay for the blood work.”

Charlie was also thankful he could get his blood work done in a timely manner. He expounded:

I can pay for my health care. It’s tough but you know, it’s hard for me to pay for the blood work. That’s expensive. Two hundred dollars every three months and that’s the bare minimum. Usually they want some other kind of test. That’s another couple of hundred...with all the testing that they’ve wanted me to do it’s been getting more expensive than I can handle. I probably can handle it but it really puts a cramp on things. Sometimes I get a good contract and I have a fair amount of money for a few months so—so—so I can do all that and—and—and I’ll try and catch up with what they want me to do but I put things off too easily cause, you know, money has—it’s hard and it’s easy to put your own health off or something so I end up doing that so, but Malta’s helped me a lot because it can—it puts me in a position where there’s a test that needs to get done, I can get it done right now and then its not six months later when I get it done and the doctor forgets even why we we’re doin it for. You know what I’m saying?

Elizabeth had a similar situation. She had an autoimmune disorder whereby

⁶⁵ Common statin drugs include atorvastatin (Lipitor), simvastatin (Zocor), lovastatin (Mevacor), pravastatin (Pravachol), rosuvastatin (Crestor)(Mayo Clinic Staff 2014a:1). According to WebMD (2014e) “Statin drugs work by blocking the action of the liver enzyme that is responsible for producing cholesterol.

she needed to have blood work done, but was not able to afford it.

...if you see how much-they charge some ridiculous amount of money for these labs, I don't know why because it doesn't need to be that expensive but it is the way it is but I just didn't wanna pay out of pocket for it so I figure I'm—I have the papers, I have the lab slips and all the labs I have to do but it will not get done until, uh, in thirty days when I'm eligible for my—for this insurance that I have for my new job.

The week I interviewed Elizabeth she had just started her new full-time job, which included health insurance.

“I can't do more than minimum payments.”

Charlie's annual income was between \$10,000 and \$25,000. However, he had debts totaling \$50,000. He explained:

...I have a lot of debt. I've refinanced stuff for the credit union. I make a payment to a big—I have one bigger payment now with the credit union and some tiny credit cards but—because, you know, rates are—credit card rates are outrageous... just wanted—I thought—I wasn't afraid of goin into debt my first several years of business because I knew that, um, you know, a lot of businesses don't thrive that well in the first several years. And I'm thinkin if I can make it through the first few years it's not a big deal because the next several years I'll be making the money and pay it back. And—and it is. I am payin it back but most months I can't do more than minimum payment so—but the minimum payments are steep. But I keep up with them, you know, so—but it's a struggle. It's—definitely—it's a struggle...A couple of weeks I can't make the payment on time so she'll help me and that helps me with my credit because, you know—so [my mother has] been instrumental in, you know, she helps me but she doesn't, like, give me money, you know, so—I—I think, like, everybody does with their parents if their parents are able. I feel sorry for the people that have loser parents that can't get any help from em.

“I'm gonna have to pay, you know, 20 dollars a month for those meds.”

Charlie had always been self-employed and never had health insurance. He tried many times to get health insurance but was never able to because of pre-existing conditions and those he could get were either not worth getting because the coverage

was so poor or much too expensive. He stated:

I spend a fraction of that paying for my own health care. So what the hell am I gonna pay for your insurance for that? I'm still gonna have to pay as much for my meds now, you know, because now my meds will be more expensive because I can't get em on some kind of program, you know, so it's like a big catch 22. You know, how—how is it that I can get—I can get diabetes meds for free from [the supermarket] but if I get insurance and I'm not eligible for that deal anymore or something then I'm—I'm gonna have to pay, you know, 20 dollars a month for those meds. It's so stupid I don't know why this industry has gotten so messed up. It really affects people like me you know, and—and—and it's retarded. I'm so for—I would've voted for Obama anyways but I voted for him especially because of the health care. I think that it's absurd that we don't have universal health care in this country.

This last comment led me to ask Charlie about his knowledge of the ACA, his opinion on health care as a human right in the U.S., and his opinion regarding who deserved health care as a right here in this country. Regarding his knowledge of the ACA Charlie declared:

It's—it's great, you know, and a lot of people um, hack it, you know, they say 'Oh it's horrible' and this and that and I'm like I don't know how they know. I don't know. I—I pay attention to the news. I'm—I'm—maybe not, you know, that well-scripted on—on the bill itself but it seems to me like nobody's even giving it a chance. I see people on Facebook saying Obamacare's a failure. I'm like it didn't even start! How do you say that! I don't—I don't know what people are thinking. I know so much more about politics and the news and everything than they do. And I'm like 'How do you think you know that?' So I don't know, just tons of propaganda out there, really, you know. In general, yeah, I think it's a spectacular idea. We're the only First World country that doesn't have universal health care of some type. Come on! Really!? We're the most advanced country on this planet, you know.

I followed-up by asking Charlie if he thought the ACA would affect him in any way. He answered:

It may very well add years to my life, you know, because it will help me keep in better health if I can get all the health care that I need. Now-now can I get that through Malta? Likely. You know, the testing and all that stuff and they're gonna help me do that type of stuff so considering Malta, maybe no. Maybe it's not gonna help but in general, the whole country? Absolutely because there's not Malta everywhere.

“In this day and age we can’t help everybody with health issues?”

Regarding who should have a right to health care in the U.S., Charlie responded:

Who shouldn’t? You know, why not? In this day and age we can’t help everybody with health issues? I understand maybe it’s a big expense but what’s more important, you know. You know, other things that are as important were taken care of like, like, police. You know, without police we’d have chaos and gangs running everything, you know. Um, paved roads, safe methods of travel, um, you know protection from other countries invading us and-and health care. Education, right? You know, um, and-and-and health care should be right in there with all those things if you ask me. It doesn’t make sense that it’s not.

Charlie wondered why Cuba could have universal health care and the U.S. could not.

The industry’s so overgrown within itself. Uh, things are so expensive. I mean if, um, compare us to Cuba. Cuba’s government does medical research. They—they provide medical treatment not only for Cubans but for anybody who happens to be there, you know, um, and-and-I think that’s a very natural thing that a government should do. I really do. It—you know. Even if you are not from that country. Maybe there’s restrictions. You can’t get an operation or—if I go to France and have a heart attack I should—I should be able to get medical treatment there, right? You know, I mean, without it costing me an outrageous amount of money. Um, same thing here, you know. We’re all citizens of this country. We all pay taxes. I’d rather pay more taxes and be able to walk into a hospital and not have to worry about coming up with 50 grand to pay for that visit.

In terms of who deserved health care in the U.S. Charlie asserted: Who doesn’t? Even if you’re not a taxpayer. Even if you’re not a citizen. I—I—I strongly believe that everybody should have medical treatment readily available.

I asked Charlie if there is anyone who doesn’t deserve health care as a right in the U.S. and he responded:

Not really. I—I, you know, and I should mention too I think, uh, um prisoners, in-in prison, should be eligible for the same health care as other people can get, um, and they’re not, they’re not. People wither away in prisons⁶⁶ and I know why

⁶⁶ While the U.S. Constitution guarantees those held in U.S. prisons a right to health, “In a national survey of the U.S. inmate population, “[m]ore than 800 000 inmates report having 1 or more chronic medical

the state does that, for two reasons: because they don't wanna pay for their health care, number two, they don't wanna pay for their extended time there. If they're lifers, why do you want them to live longer? They just cost us more money. Um, but, you know, as far as not deserving health care, I don't know. Maybe there are some people out there that don't...the two guys that did the home invasion in Cheshire [CT] several years ago. Maybe they're not deserving, you know what I'm sayin? Maybe this kid who shot up the school isn't deserving, you know, but—but in general I'm sayin yes I think most everybody, even people in—in prison, you know, deserve health care...Yes, to answer the question, everybody pretty much deserves it.

Andrew, a 1.5 generation West Indian, had a similar, though more nuanced response:⁶⁷

Health care as a right is a gray area. Not everyone may have a right to health care from a political standpoint. From a humanistic point we all have a right [to health care]. As long as a person is living in America they should be afforded health care. Look at migrant workers. They're doing a service for America and it would be unjust to exclude them from getting health care. They are contributing to this country. Everyone deserves [health care]. Even prisoners and those on death row get health care. If they get health care everyone else should also. Humanistically, we all deserve health care.

Charlie went on to say that the wealthy willingly pay for better care than what may be provided by the government and argued

that's their prerogative. You got money you wanna—of course, I would too. Who wouldn't? Nominal health care should be provided in a universal sense...People with lesser means can't afford heal-good health care access or fair health care access.

Charlie maintained that the government, the people collectively, should pay for health care:

condition[s], and their access to medical care appears to be poor, particularly in jails" (Wilper et al. 2009:669). However, prisoners' access to health care seems to be better in prison health programs affiliated with an academic institution, such as in Connecticut with UConn Health Center's Correctional Managed Health Care (UConn Health Center, n.d.). "Prison and jail health care, despite occasional pockets of inspiration, provided by programs affiliated with academic institutions, is an arena of endless ethical conflict in which health care providers must negotiate relentlessly with prison officials to provide necessary and decent care" (Dubler 2014).

⁶⁷ The 1.5 generation are those who were born in another country, but who came to the United States as children.

...it should be a government funded thing because of course the government can fund-fund it on a-on a much larger scale and can do much more per person per dollar. Well, us. Us. All of us collectively. It's not the government really but it's us collectively um, as a people...and should include mental health care. I also think that it absolutely should include mental health care which-which would help us overcome one of the big problems that we're having right now with what happened in Newtown, and the fear you know, in Aurora and all these things, these mental health people, you know, if they had access to—to mental health care by default just because they're here then these things probably would not have ever happened. That's our answer.

He continued:

All—it's all enwrapped in all that if you ask me. I think it's all relative. So it benefits us all...You know what I'm sayin? It's—it's ridiculous how everything's kind of like falling apart. I—I think yes it's very important. Not just my opinion that—that we should do that. I think it's essential... people are—uh, feel like lesser people, you don't feel like you matter which is another problem with these shootings and stuff, you know, they—they probably—they're—they're speaking out, they're lashing out because they feel like nobody cares probably, you know. I don't know that that's what the case is but I speculate that that's you know a contributor to it.

Charlie thought the U.S. was headed for a class war. He stated, “[w]e Americans are oppressed. We're oppressed by big business and big money.”

Charlie seemed to have good knowledge of the ACA as he insisted that he kept up with politics and the news. Charlie favored universal health care, such as what is available in Cuba and Canada. What was striking about Charlie was that although he was a small business owner his perspective pointed to a critique of the capitalist system. His critique could account for his more progressive stance on universal health care. Other participants have alluded to the gap between the “haves” and “have-nots” but not in such a direct way as Charlie did. Indeed, many scholars have written about the difference between the rich and the ‘rest of us’ (Edelman 2012; Kornbluth 2013; Krugman 2014; Piketty 2014; Stiglitz 2011).

In summary, the life experiences as described in these narratives emphasized

the mental and physical health impact the precarious economic, and in some cases, legal state endured by these participants. Yet their narratives also demonstrated the importance of community and family networks in easing these circumstances.

Among all the patient participants in this study, the primary reasons for being uninsured were unemployment resulting from job loss, immigration status, jobs that did not offer health insurance, or health insurance was unaffordable. Like Charlie, their experiences showed how their health experiences (micro-level) connected with the larger political-economic forces (macro-level), which is the strength of the critical medical anthropological perspective.

In addition to patient perspectives, I also interviewed board members and staff to understand if and how the changing health care landscape would affect the organization, and what they perceived the health care challenges within the community to be. Furthermore, it provided me with a strategic view of the organization and how those charged with accomplishing the organization's mission (providing primary health care to the uninsured) worked to accomplish the goal. As mentioned in chapter two, Malta House of Care is a non-profit (501c3), free standing clinic. It is not an FQHC.⁶⁸ While FQHCs do service undocumented individuals, unless they can show documentation of their income, they would be charged the full clinic fee. Despite Malta being a tax-exempt organization, unlike FQHCs, it cannot receive any government funding and must rely solely on private granting organizations and donations. However, Malta House can see undocumented immigrants without any penalty.

⁶⁸ FQHCs must provide comprehensive health services (U.S. Health Resources and Services Administration n.d.). Malta House only provides primary health care and therefore, would not even qualify as a Federally Qualified Health Center.

Board Member and Staff Voices⁶⁹

Julia

“You name it I’ve pretty much done it.”

I interviewed Julia, a member of the Malta House of Care, Inc. Board of Directors and a Surgical Clinical Reviewer at a local hospital. She became involved with Malta House in 2006 when one of the Board Members asked her if she could help them. She explained:

As things changed, my role just developed. You name it I’ve pretty much done it. I staffed the clinic, I’ve written some policies and procedures, helped get the EMR, electronic medical record going, at one point they asked me ‘Can you do the Tort Act.’ God, I don’t even know what a Tort Act is!

Julia did learn about the Tort Act, the federal law related to the licensure and credentialing of health care providers and was responsible for the protocols to ensure the health professionals who volunteered at Malta House were properly licensed and credentialed as specified in the Tort Act. She also did scheduling for Malta House when needed. She clarified:

So whatever needs to get done, kind of like utility. Yeah I think that’s a good word. Utility, whatever kind of needs to get done—now that things are settling down I will take a role of co-chair of the clinical advisory committee. I’ve been on that committee and with—when we had a volunteer coordinator and when she left I took over the schedule and the volunteers and said to...our chairman, “I work full-time. I go to school. I can’t do it all.

Julia became a member of the Malta House Board of Directors in 2009. She was concerned about providing good quality health care:

...we really need to make sure that we are delivering quality care. You know, um, reality is, as much as I personally would like to think it’s the same care as I’m getting with my physician, it’s not. You know, we don’t—we don’t have coverage

⁶⁹ Pseudonyms were also used for board and staff members.

for colonoscopies and I—my insurance pays for that. I got my tooth extracted my insurance paid for that I didn't have to go to the E.R. and stuff like that so I think will that change? Yeah, I think—I think as time changes and we get our networks together and our referrals I think we'll have that ability. But if you really need it and you're really having symptoms, you know, we'll get it for you. I think the mammograms we offer them just as much as somebody like you or I that has insurance and stuff like that.

Julia's observation draws attention to the way in which those who have private, employer-based health insurance receive better care than those who are uninsured, or receive Medicaid.⁷⁰

Julia was also responsible for obtaining coverage for the Board Members.

...the Tort Claims Act in 2010 extended coverage to board members so, you know, one of my responsibilities is "This is what we do. This is what I need for you to be able to submit to the Federal Tort Claims Act for coverage" in case the board was to get, um, named in a malpractice suit. They would—they would cover the board for that piece of it. It doesn't, you know the—the...Federal Tort Claims Act covers just malpractice so if somebody was to slip on the stairs it wouldn't cover something like that. It's strictly a malpractice so if somebody, knock on wood, we have not. We have not had any legal issues. If somebody were to sue and said "well the board didn't provide proper oversight for the medical issues that were going on in the clinic", then the board could be named in that malpractice suit.

Julia also believed that when the Malta House sites become all electronic there would be better information regarding health outcomes.

Well electronic, we've had a little bit of internet connection issues at the site. So we were supposed to be, um, improving our capacity with electronic medical record this [coming] week [third week of July, 2013] but we're gonna push that off until we make sure that our, um, the internet and stuff is good cause it's not only—we really have to have a very highly secure access with the type of information that's flowing from these lines. So that will come down. The same thing with diabetics. You look at their hemoglobin A1Cs⁷¹ over time that gives you

⁷⁰ A factor influencing health care delivery for Medicaid patients is physician reimbursement. Currently, it is fifty cents for every dollar of care administered to patients (Terzi 2015).

⁷¹ "The A1C test is a blood test that provides information about a person's average levels of blood glucose, also called blood sugar, over the past 3 months. The A1C test is sometimes called the hemoglobin A1c, HbA1c, or glycohemoglobin test...The A1C test result is reported as a percentage. The

an idea of their blood sugar control. How are we doing? I think we're OK. I think. I can't prove it. And you know, if you're not measuring it you don't really know. So this improvement in our electronic medical record will really help us to do that so if we find for instance that our diabetics, our hemoglobin A1Cs are high, is it a small population where we can take that and really concentrate on those 20 patients? Is it horrible that we really need to not only—you know we—re-educate our providers. We need to bring in somebody. Here's the latest guidelines for diabetes.

"I'm a firm believer that we can always be better."

Julia hoped that going electronic would position the organization to provide better health care for patients with high blood pressure and generally, as she explained:

The same thing with hypertension. There're [Joint National Committee] JNC seven guidelines, JNC eight guidelines⁷² that are best practice standard of care. Are our hypertensives being controlled? If not, how do we get them better controlled? And it's...re-educating the providers, the nurses, the patients themselves. Can we do something better with the patients? You know we would like to try to, um, historically, like I said the Federal Tort Claims Act was for the federally funded clinics. Then they extended it to the free clinics. So the electronic health record [EHR]⁷³ incentives have been to everybody that's getting Medicaid funding. Will they extend that? So we want to try to align ourselves with what other people are doing...So, you know, I think we provide good care, you know, and I bet—I—I—think it's probably excellent at points too but I'm a firm believer that we can always be better.

Julia was aware that patients have to wait a long time to be seen by the physician.

...our poor patients who wait a half hour or an hour.⁷⁴ How could we do better? We give great care, we really do but I'm always a firm believer that we can always be better. I believe in continuous process improvement. You can always,

higher the percentage, the higher a person's blood glucose levels have been. A normal A1C level is below 5.7 percent" (National Institute of Diabetes and Digestive and Kidney Diseases 2014).

⁷² Eighth Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure and Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (James et al. 2014; Joint National Committee on Prevention 2004).

⁷³ Electronic Health Record is a digital version of a person's medical record.

⁷⁴ In the U.S., it is not uncommon for people to wait to be seen, even when they have health insurance and have made appointments ahead of time.

always improve. So while we've come a long way there's still more to do.

I asked Julia what drew her to Malta House. She said that when her children were younger she volunteered teaching Catechism (CCD)⁷⁵ but that came to an end. She was looking for something else and thought Malta House would be good for her because by that time she was working on data bases and not performing hands on nursing, so she wanted to keep her hand in nursing practice and her involvement in Malta House just grew from there. In addition she said her mother was a good role model.

I think just the whole the—the concept of—of—just giving back to the community, you know. I, um, my mother was a very good role model for us. Always—she always volunteered whether it was teaching CCD or tutoring, [the town] had some very, very poor sections, and um, my mother would go to one of the area churches when they started tutoring sessions at night, she was a teacher and would tutor kids. So it was always there, you know. I don't live in Hartford but I work here and I believe the—the problems, the health issues in Hartford are all of ours. You know, I don't live here. I work here. It affects us all.

Speaking of health issues I asked Julia what she thought were the unmet health needs in the community.

Well I think some of the preventive, like the colonoscopies, some of the preventive health care measures that are not covered. You don't see [a lot of money and grants] with colonoscopies and colo-rectal screening. We can get some of that prostate screening] for men through the men's health institute. You know I think we mirror the city of Hartford. Asthma's⁷⁶ a huge problem and the inhalers are \$250.00 a pop. The same thing with diabetes. You know, Hartford has no grocery store⁷⁷. You know, how do we—I think diet is—is a huge thing.

⁷⁵ Confraternity of Christian Doctrine, aka, Catechism, provides religious education to Catholic children attending secular schools. Classes are taught by both clergy and lay people.

⁷⁶ In my study sample only two participants had asthma. Yet, among Connecticut adults, 9.4% suffer from asthma. However, the five largest cities (Bridgeport, Hartford, New Haven, Stamford and Waterbury) had asthma hospitalization and emergency department rates that were about three times higher than the rest of the state (Kaylin 2011).

⁷⁷ Although there is a supermarket (only one) in Hartford, it is located such that it is not within walking distance for most Hartford residents. Thus, if one does not have a car, one would need to take a bus, or even two buses to get to the supermarket. What is more, one in four Hartford residents live in a food

How do we—I use to work in a heart failure clinic—simple things, you know, hypertension—you’re buying all these canned beans but you have to rinse them...it’s the basics, it’s the diabetes, it’s the hypertension, it’s the asthma that we see and those are the patients that are continually coming back to us. Diabetes is huge. It’s a huge, huge issue with these—look at just America in general. So the heavier we get the more we’re pre-disposing ourselves to conditions.

I asked Julia how she thought those needs could be met.

Well I think networking...building bridges, um, knowing who has what. Again, how do we work together? How do we make Hartford healthier? We’ll do it by working together. You know a goal for mine on the van-and I’ve talked to [a board member]—and it’s just—it’s probably gonna have to wait until I get out of school, is to do some type of research project. How do we know really what works with this population...You know, how do we-how do we find-get the research done and translate it into practice? Does, you know, do some of the, um, how do we get the stop smoking program the American Lung Association has and things like that that cost to go to, how do we get that so we can give to our patients at a reduced cost or potentially for free or can we take that concept and deliver it where their coming. You know our patients are funny. They only go to different churches if they have to...I think they’re very comfortable in their community. So how do we—how do we bring things to them and how do we increase their comfort level?

Concerning health care needs Julia discussed the ACA.

Obamacare that’s coming down the road...I think there will be-if you look at Accountable Care⁷⁸ and how payment will be—it’s gonna be per patient population so that-the diabetic that has no insurance that comes in, say they’ve got a foot ulcer, he comes into the E.R. here, is utilizing funds that [the hospital] is gonna have, that patient is eventually gonna come back to us. I think down the road they’ll be more of a partnership on how do we-how do we help keep that patient out of the hospital working with the area institutions. I think—you know I’m not sure that they—some of our patients should-you know, they’ve changed the poverty limits with the [Accountable Care Organizations] ACOs and the Connecticut Insurance Exchange—you know how many patients will drop off and I—I—that’s a full board kind of, you know “what are we gonna do here?”⁷⁹

desert (Fowler 2012) and certainly points to the social origins of illness. Drewnowski (2009), for example asserts that more affluent areas have better access to full-service supermarkets, whereas low-income areas are repleat with fast-food outlest and convenience stores.

⁷⁸ Accountable Care refers to organizing and delivering health care that attempts to align improved care and incentives to outcomes, increase preventive health care, and lower cost. It is an incentive written into the ACA.

Julia was also not sure how many people would sign up for the ACA.

...the first year your fine was gonna be \$96.00. I don't know about you but if my funds are limited and I can get my health care needs met at Malta House of Care. I'll take the \$96.00 fee. I'll take the \$96.00 fine. Now three years out when it's \$500.00 or \$460 I don't remember the exact fee will they still feel that way?

As Julia pointed out, because the ACA would affect the institution where she works, she was very knowledgeable about the ACA and received information from health organizations involved in the health business sector and in health delivery. Interestingly she would like to see a time when everyone's health care needs are being met, that no one is uninsured such that there would no longer be a need for Malta House. Additionally, Julia believed everyone has a right to health care, whether someone is here legally or not. She admitted:

I'm sure we are treating patients, you know, some of our clients are not here legally. ...but you know what if they're sick I don't really care. That's not the time to deal with those types of issues. The health issues need to come first...We need to make them healthy right now...how do I keep that patient out of the E.R.? How do I keep that person healthy so that if the plan is to go back home we can get the patient back home. You know?

Along these same lines I ask Julia who has a right to health care in the United States?

Well I'm very liberal. I think everybody...how do we as a society if you come and you have breast cancer how do we not help you and take care of it. You're here for, you know, does it really matter that you're documented legally, not legally? You know? How do you let another person die in front of you when you can help them?

When I asked who should pay for health care in the United States, Julia responded:

⁷⁹ Accountable Care Organizations are "groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to their Medicare patients (Centers for Medicare and Medicaid Services 2013).

I don't know. I've never really thought about that. It's a tough one. I think it would help if we had a national number. A national ID number so that if I had blood work this week at [the local hospital] and God forbid I'm sick in California next week well all these labs looked fine. These are the medications you're on. Here's your health history. We waste dollars here. I think we waste a lot of dollars in the last six months of life. That may be if we had better services because it's not—it's scary to watch somebody die. It's hard. It's hard to say good-bye... You know there's just—there's just certain times where it's time... And even if you're 50 and you have metastatic cancer all over. Why are we being this aggressive? The patient's scared. Why aren't we holding their hand, explaining to them, having the palliative care services? Why do we need 50 million CAT Scans? So I think if we can—if we—if we decrease the waste in health care we'll decrease our cost. There'll be more funds available for those needs.

I asked Julia who deserved a right to health care in the United States and how she conceptualized these two ideas. She responded “I guess I would say they're the same...I always felt it was a right.” In fact, for Julia there wasn't anyone who did not deserve health care as a right in the United States. She explained:

...I think it's always their right. Again, I think...I don't think they become undeserving of it, I think that there is just a reality out there that we can tell people to take their meds and to do this or to do that and they don't do it and they—their health continually fails. You know? Do they have a right to get—do they—deserve to be treated if they show up in the E.R.? They're human. Yeah. I don't think you're gonna get too far. I think you look at, “OK. Well you're here. You're sick now because we told you three months ago to stop smoking, that you're cancer was gonna get worse and it did.” And you know, and maybe all we can do at this point is make them comfortable but they deserve that too. They have the right to that comfort that dignity to die with. I'm sorry they didn't do what they were supposed to do. It makes us all sad when you know you look at people and think “[Mr. Smith] could have prevented this. If you'd only done X.” You know what I mean? But—but again, that's just a sadness on my part for another human being, you know. And so I think—I—I think—I think it's always—it's—it's a right. You're the worst patient in the entire world. You come to the E.R. and you're dying and you're in extreme pain. You have the right to have some medication to be comfortable.

Some of the challenges Julia saw facing the organization included funding and getting volunteers. The successes have been the care of the patients as she said:

We've had over 26,000 patient visits [in] seven years of operation. I mean where would these people be? Success has been patients coming back and saying

“Thanks so much. I have a job now and I’m not gonna need you anymore. And...donate a hundred dollars to the Foundation.

Success has also included getting some specialty services for patients through Malta House’s connections with physicians and local hospitals. I asked Julia where she saw the organization going in five years. She would like to see, and thought the organization would have Saturday clinics.

...if you look, what jobs are opening up. Service jobs. So a lot of them are not working full time. ...How do we help those patients that can’t make the clinic hours cause if they don’t work they don’t get paid so I think that will be a working family Saturday.

Julia commented that “Malta is a wonderful organization” but like all organizations it is not perfect. She was a strong believer in continuous improvement.

In her narrative, Julia elucidated the challenges and requirements necessary to operate a free-standing health clinic. In short, it provided insight into one aspect of the legal structure of the biomedical health care system. Though Julia did not use the term liberation theology, her religious upbringing influenced her strong sense of social justice, her need to give back to the community, and to provide the best possible health care through constant improvement and best practices. Her hope there would no longer be a need for Malta House, that everyone who is here would have good quality health care, regardless of legal status, indicated her understanding of health care as a human right. Her responses to questions regarding health as a human right, and deservingness, certainly demonstrate this.

Finally, Julia was content to have met so many great people who were a part of Malta House. Indeed she ended the interview with the following comment:

I was brought up in a household where you gave back and I’m fortunate that I can give back in my own community right now and that’s how I look at it. And not

only that, meet, meet fabulous people, come—come in contact with fabulous people. So it's-it's a great thing...I'm looking forward to doing more, helping more, seeing where else our need will be.

Dr. M.

I wanted to interview Dr. M, because she was both a volunteer physician, and a member of both Malta House boards (Malta House of Care Foundation, Inc. and Malta House of Care, Inc.)⁸⁰, and thus could provide perspectives as a board member and a volunteer. Her perspective as a physician who provided patient care, in particular, provided me with a broader understanding of the issues faced by health care providers as they attempted to meet the health care needs of underserved populations. Despite her busy schedule, Dr. M. was gracious enough to allow me to interview her.

“...health care is a basic human need. Everybody has a right to have it.”

At Dr. M's suggestion I met her at a club of which she was a member. Dr. M. arrived and we proceeded to the dining room for lunch.

During lunch we chatted about Malta House and she explained to me it was part of the Order of Malta that dates back to the 12th century. Dr. M. had been a member of the Order of Malta (a Dame; the men are called Knights) since 1999. She had been volunteering at Malta House since it opened in 2006. We continued our lunch and chatted and when we were finished, although I insisted on paying the bill Dr. M. refused and paid for the lunch. We then went into one of the other sitting rooms.

I began by asking Dr. M. who had been a long time member of the board of directors of Malta House, as well as a volunteer at the mobile clinic, how Malta House

⁸⁰ For a detailed description of the organization's structure, see chapter two.

began.

The Order of Malta in the Hartford Region decided that the uninsured not receiving health care was a very real problem and that health care is a basic human need. Everybody has a right to have it... it was the two Knights that were really instrumental in, and it was their brain wave that started this.

Dr. M. stated that the funds to start Malta House of Care came from the Catholic Archbishop, who was very supportive of the idea, and from the Order of Malta. I asked

Dr. M. what the challenges were to establish Malta House of Care. She explained:

The challenges were that it was a new idea for us, it was a purely voluntary organization and to start it we needed a lot of expertise. It was time consuming. We needed to register to get a license from the Department of Health and we needed to make the decision as to where the clinic would be located and that was in all of that process the idea of the mobile clinic began. But prior to that we looked at different sites ...where we could have the clinic.

Dr. M stated the sites were chosen because Malta House wanted to have a presence in various sections of the city “so the idea of the mobile van going to the people rather than the people having to come and seek us out.”

The small group of individuals who established Malta House decided to locate the sites at Catholic churches

because of convenience the church would always have or usually has a parking lot and they always have a parish hall which we could use to register patients and as a waiting area. And as a Catholic organization we did have that relationship with the Archdiocese and the Catholic Churches in the area and that was—we felt very comfortable approaching them to see if we could use their facilities.

I asked Dr. M. how they got the word out that anyone who was uninsured could come and if there was any concern about people thinking they had to be Catholic to come to Malta House. Dr. M. responded that it was for anyone who needed it

...[a]nd we made that very clear. When we started we had very few patients because nobody knew anything about it and we gave out flyers at the bus stops and the railroad stations. And we advertised through churches and through

churches of all denominations as far as possible. And we were also interviewed by the Hartford Courant and other newspapers.

The political economic structure of the health care system in the United States is such that the charity organizations, social safety nets, and NGOs fill a void left by government institutions providing needed services for citizens it no longer provides, due, in no small measure, to the neoliberal economic model. What is more, this model has been transported to other parts of the world (Cammack 2004; Gideon 2005; Judt 2010; Maupin 2009; Pfeiffer 2004; Smith-Nonini 2000).

Dr. M. became involved with the organization because “I was a member of the Order. I had been involved with the start-up, you know and then when we opened we had a lot of work to do.”

Dr. M. continued:

...when I went there to volunteer, you know, I just kept coming back. [It] was that draw of the patients, you know. And you know when you’ve been in practice and you kind of, you know, you see somebody whose, you know, as newly diagnosed diabetes or who has had high blood pressure you want to go back to make sure that they’re you know under better control or that they, you know so they are set. And I must say the patients are so wonderful and you have no worries about filling out insurance forms and no worries about time even though at times we do have to hurry up, you know.

I asked her what the major issues she saw among the Malta House patient population. She replied “[t]he major issues are hypertension, diabetes, gastro-intestinal problems, and psychiatric problems like depression, anxiety.”

Despite the fact that most of the patients I interviewed came from other countries, they exhibited diseases of the affluent (high blood pressure, diabetes, and high cholesterol). While this supports the medical and epidemiological literature regarding the growing prevalence of these diseases in poor countries (Bonow et al. 2002;

Boutayeb 2006; Fall 2001; Mitka 2004; Yach et al. 2004), some of the immigrant narratives provided in chapter four indicate that these diseases did not arise until coming to this country. Some patient participants also admitted to mental health issues, such as anxiety, stress, and depression.

Because Dr. M. was involved with the establishment of Malta House early on, and volunteered on the mobile clinic van, she was asked to be on the board and thought this was advantageous because “when you are working on the van it is helpful to be on the board because you can tell the board what’s going on.”

When I asked Dr. M. to describe what she saw as the unmet health care needs in the community, it was apparent she had her pulse on what was going on in terms of the health needs of the community and the social causes of disease as exemplified in the following quote.

I think psychiatric illnesses is a big one. I mean, um, when you say unmet so many of these people, you know, are depressed and they have high levels of anxiety. That is because of their circumstances, you know, that so many of them are here and with their husbands or somebody else and they’re trying to do whatever work they can. They have families. When I say families, they have their children who are all back in Lima or in El Salvador. They’re trying to support them and with that too there’s loneliness and there is that fear and that anxiety about navigating any system.

While Dr. M. acknowledged the services a local mental health agency provided, she described the difficulty patients had in receiving their services.

But then again you know it’s-with the patients too, you know, it’s because of their jobs, you know, the work that they do they’re not in a position to take a day off or to leave early or you know it’s either they have to be there at 7am until five, you know, Monday through Friday.

The dearth of, and need for, mental health services was also conveyed by other staff. It was also something I came to realize through patient interviews and

participant observation.⁸¹

In addition, there were certain specialty treatments and equipment that were difficult for patients to obtain due to cost as indicated in the following quote.

And then there's some, you know conditions like for example sleep apnea and that, you know, being uninsured it's impossible to diagnose or treat because of cost issues and ongoing cost issues because they need CPAP⁸² [continuous positive airway pressure] machine and then surgery also but, you know, we can help from the point of view of getting tertiary care doctors, specialists very often who do the surgery free and anesthesiologist will also waive the fee.

Therefore, while Dr. M. could get specialists to see, and treat, patients, the equipment such as the CPAP machine mentioned above, was almost impossible for patients to procure. They could not afford it.

Continuing the discussion about the ability to afford health care, I asked Dr. M. about the ACA. Dr. M. admitted she did not know much about the law but was aware that “a lot of the decisions are going to be made at the state level.” Regarding the organization she commented: “...we haven't talked about this but we may have to change our policy and take some people who are insured and—because it's going to be very difficult to get a physician. And again I'm talking on a state level.”⁸³

As mentioned above Dr. M. believed everyone had a right to health care as it is, from her perspective, a basic need, “a basic human right.” When I asked her who, in her

⁸¹ The mental health agency is a community based mental health center, operated by the Connecticut Department of Mental Health and Addiction Services, and offers mental health services free of charge.

⁸² “CPAP, or continuous positive airway pressure, is a treatment that uses mild air pressure to keep the airways open. CPAP typically is used by people who have breathing problems, such as sleep apnea” (National Heart, Blood, and Lung Institute 2011). ““Sleep apnea...is a common disorder in which you have one or more pauses in breathing or shallow breaths while you sleep (National Heart, Blood, and Lung Institute 2012).”

⁸³ Interestingly, when I visited Malta House after implementation of the Affordable Care Act one of the volunteers mentioned that there were patients who had received health insurance through the Connecticut Health Insurance Exchange but were still being seen by Malta House because they could not get appointments with private physicians until six months from time of request and needed follow-up for their health issues and prescriptions.

view, deserved health care as a right, she replied:

Well, I think everybody does. I mean there's a lot of controversy about that. But if people can't, you know—well first of all we have to think of, you know, our own people, the people who were born here, who lived here all their lives. But then, you know, when you think of immigrants, they are here, they are not a burden on society, they are working, and the only reason they're not working is they can't find work.

Thus, for Dr. M. there was not anyone who did not deserve health care in the United States.

I asked Dr. M. who should pay for health care in the United States to which she answered:

Well, I think anybody who can afford it should pay for it and the government should provide, you know. I'm not 100% in favor of a national health care...but there can be a modified system, you know? I know in other countries like for example in Ireland you have a choice. You can buy health insurance or you can opt not to have health insurance, you know, but everybody will be given treatment. I mean you can opt to, um, get the equivalent of Medicaid and you know, go to a clinic then at the clinic if you need surgery, you know, you get scheduled for the surgery, if you need testing, whatever testing you need it's going to be done. The disadvantages are that, you know, the waiting period is going to be much longer than if you have insurance.

Dr. M. believed people should have choice to purchase health insurance or to have a government option for those who cannot or do not want to purchase health insurance. Furthermore, was not in favor of a national health care system, nor did she think such a system would work here because “the country is too big” but thought perhaps a regional public health care system may work.⁸⁴

Dr. M. was born and raised in Ireland but has lived in the United States for more

⁸⁴ The Italian health care system is organized in this way. “[Nineteen] regions and two autonomous provinces have responsibility for the organization and delivery of health services through local health units (LHUs). The regions enjoy significant autonomy in determining the macro structure of their health systems. LHUs are managed by a CEO appointed by the governor of the region, and deliver primary care, hospital care, public health, occupational health, and health care related to social care” (Donatini, Andrea, and Emilia-Romagna 2013:66).

than twenty years, and therefore was familiar with the health care systems in both countries.

As we near the end of the interview I ask Dr. M. how Malta House has changed over time. She answers “We’ve become more organized and we have become more knowledgeable of the problems facing the uninsured in Hartford and we have taken measures to cope with that and to give the appropriate care.”

I ask her to give her opinion on the major challenges facing the organization and its successes and where she sees Malta House going in the next five years and in the next ten years.

The current challenges are finance and expanding the care. The successes have been the growth and the fact that many people, like a few thousand count us as their primary care home. I see [Malta House] continuing to grow. I mean I say that kind of tongue in cheek because we don’t know about Obamacare, you know, and-but I think we will continue to grow. I see ten years we’ll still be here and you know, I think that perhaps even the next ten years we may have to move into other neighborhoods.

Finally, Dr. M. commented on the history of the Order of Malta:

...[It] started in Europe in the 12th century [for] the people that really could afford to go to Israel or that were the wealthy so it’s been associated with the wealthy and they, um, you know there is that idea, you know, which does hold true especially when you go to Europe, when you meet knights in Europe they’re very—like I remember being in England at a meeting, this is Maltese International, which is a branch of the Order of Malta, which sends disaster relief all over the world like after Katrina in New Orleans, they were there right away and they are wherever, they go to Haiti, they go all over the world but there was a young man there who just got married, we were asking, “well where did you get married?” and someone said a church and he said our private altar...And then you find, you know, meeting of the members of the Federal Association, many of them are very, you know, have very interesting backgrounds. They have been ambassadors, you know they have been CEOs of companies...but, you know, they all have that common bond that they want to help the sick and the poor.

Dr. M.’s comment indicates the aristocratic flavor of the Order of Malta, and as described earlier, it costs about \$4,000 to become a member, with membership renewal

ranging between \$1,200 and \$2,500 per year.

From interviews with participants and speaking with patients at the clinic there is an overwhelming sense that Dr. M. was not just respected as a very competent physician, but a caring, compassionate one as well and was loved by the patients. In my conversations with patients and staff, it was quite clear Dr. M. took the time to listen to her patients and their stories, and provided useful treatments and advice.

Conclusion

In this chapter I highlighted some of the struggles and challenges participants and the uninsured faced regarding their health and well-being, as well as their thoughts on the right to health care and deservingness. Additionally, I have included some narratives of immigrants to highlight their struggles and reasons why they have left their homes. Migrants have unique challenges and stresses related to obligations to their families back home, and their obligations in this country.

I also highlighted the history and challenges facing the organization as it continued its work in an unpredictable health care environment.

In the following chapter I discuss some of the salient themes that emerge from the interviews.

Chapter Five: Discussion

Introduction

The discussion here, based on my ethnographic fieldwork, consisting of interviews and participant observation, will be organized as follows: unemployment and underemployment; doing without; making ends meet; medications; home remedies; transnational medicine; illnesses of the affluent; social suffering; health, human rights, and deservingness; paying for health care; corporate profits and socialized costs; migration and the crisis of citizenship; and the Patient Protection and Affordable Care Act.

I argue that the global economic system plays a significant role in participants' 'precarity' and this precarious existence impacts negatively on their health. As distressing as lack of health insurance was for interviewees, of equal concern was the lack of full-time jobs. Moreover, immigration is another layer affecting health. I further argue the right to health is sometimes perceived as a moral register, as opposed to a juridical connotation.

Additionally, knowledge regarding the ACA was scarce among participants and there was concern about affordability once the ACA came into effect.

Finally, despite the challenges participants faced, theirs were also stories of resilience.

Unemployment and Underemployment

Since 1980, the employment situation, in the United States, has gone from industrialized wage labor to mass unemployment, and underemployment of whole

segments of the working class (Barnes 2005; Wilson 1996; 2012), what Wacquant (2010; 1993) calls “deproletarianization”. In the United States, groups that have been particularly affected are Blacks and Latinos. According to Hero and Kramer (2009:iii-10) underemployment for Latinos and Blacks was 20% and 21.3% respectively. The situation in Connecticut was not much better, as shown in Table 9.

Table 9
Connecticut Unemployment Rate and Wage Differentials

	Blacks	Latinos	Whites
Connecticut Unemployment Rate ¹	13.4%	15.7%	7.0%
Connecticut Wage Differentials ²	.72 for every dollar earned by Whites	.55 for every dollar earned by Whites	
Connecticut Labor Participation ³			
2011	67.4%	69.1%	No
2012	66.1%	66.5%	Information

¹ Source: Joseph and Rodriguez (2013:4); ² Source: Ibid:21; ³ Source: Ibid: 10-11

Indeed, as Wacquant (1993:132) notes: “...the “market” is a social fiction, but it is an interesting fiction in which not everyone has an equal interest and whose social and economic consequences are very real for whole chunks of society”. This is the situation among Malta House patients whom I interviewed. As mentioned in chapter two, most of the participants survived on very little income either because they were unemployed (65.5%) or underemployed (17.2%). As a result, participants did not have health insurance, could not afford health insurance on their own, and had difficulty meeting everyday expenses, causing yet further stress. Unemployment and underemployment as factors in health and well-being has been supported in the literature (Bambra and Eikemo 2009; Dooley 2003; Dooley and Catalano 2003; Dooley et al. 1996; Fryer and Fagan 2003; Karsten and Moser 2009).

The paramount objective of the capitalist system is to make as much profit as possible. One strategy to accomplish this is to hire employees on a part-time basis to avoid having to pay benefits that companies would pay to full-time workers. Lillian and Carol, as other participants in my study, were victims of this economic system. Carol was especially concerned because she was still paying the mortgage on her condominium and was unemployed. Indeed, her insistence that the wealthy should pay for health care implied she believed they did not pay their fair share.

Futhermore, as a consequence of the world economic system by which multinational corporations freely move across international boundaries, manufacturing jobs have moved overseas, resulting in the loss of those jobs in the United States. In addition, low wages in developing countries, in part due to lax enforcement of labor laws, propels some people to migrate from those countries to seek better wages and opportunities in the West, as evidenced by some of the narratives in the previous chapter.

Finally, for immigrants and non-immigrants in my study, their fundamental concerns were finding steady full-time employment, as mentioned above, preferably with benefits. Their insecurity and precariousness are “not a coincidental phenomenon but is endemic in the mechanism of capitalistic profit making, rendering large segments of the workforce a vulnerable, exploited and defenceless new proletariat or, according to some scholars, precariat” (Spyridakis 2013:9; see also Molé 2010:38; Standing 2014, 2014a).

Doing Without

Many of the participants expressed reluctance of seeking medical care, such as colonoscopy, orthopedic surgery, physical therapy, or seeing a cardiologist even though it has been recommended by Malta House physicians but participants cannot afford the cost of these specialized health care services. This was exemplified by Carol, Lillian, Karen, and Barabara.

In addition, there were concerns about becoming seriously ill and not having health insurance or not being able to afford care as evidenced by Catarina, Sam and Lucha from the previous chapter.

Making Ends Meet

Some of the participants I interviewed were unable to work legally, thus they were part of the informal economy, as in Juana's and Carmen's cases.

Thus, individuals decide to migrate because of lack of economic opportunities or low living standards in their home countries, and better economic opportunities and living standards in the country to which they migrate.

In addition, as described in the previous chapter, participants received material support from family, church, and other social networks (Barnes 2005; Edin 1991; Edin and Lein 1997; Stack 1974). The push-pull factors of migration led Carmen, like other immigrants I interviewed, to leave their home countries, for what they believed to be a better life.

Medications

Malta House made every effort to make sure patients were able to obtain the medications through the Patient Assistance Program (PAP), “run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medications” (RxAssist 2012). However, to be eligible, patients had to be U.S. citizens or legal residents, meet program income guidelines, and fill out an application form that was then signed by the physician. At Malta House, one of the medical assistants helped patients who would possibly be eligible to fill out the application form. For those who did not qualify for PAP, Malta House covered the cost of medications for patients who could not afford them. While Malta House did not give out medications directly, they had a contract with a local pharmacy whereby Malta House authorized the pharmacy to charge Malta House for a medication for a patient and the patient could then go to the pharmacy and get the medication free of charge.

Therefore, participants stated they did not have difficulty obtaining their medications either because Malta House provided them free of charge through a local pharmacy as described above, or because participants stated they were not that expensive. In fact, 19 patient participants (65.5%) stated that their medications were not that expensive and those medications that were, Malta House covered the cost as described above. Only ten patient participants interviewed (34.5%) stated that while they managed to pay for the medications prescribed it was difficult to do so.

Home Remedies

Although participants stated they took the medications prescribed by their

physician, half of the patient participants interviewed reported using or having used home remedies. This is consistent with other study results (Ceuterick, Melissa, et al. 2007; Chavez 2003:220-221; Kuo, Grace M. et al. 2004; Poss, Jane E. et al. 2003). They also used common herbal teas that are easily found in local supermarkets. Examples of home remedies were cinnamon in juice or ground flaxseed in juice for digestive problems; oatmeal water or liquid from grated potatoes for high cholesterol; cerassee tea, made from the cerassee plant (*Momordica charanta*) for colds or flu; and pineapple, celery, five apples, parsley and cucumber blended together as a juice for kidney stones and kidney pain. For a list of home remedies participants reported having used, see Appendix Six.

Transnational Medicine

Four of my patient participants reported having friends or family either bring medications from their home countries, or, in some cases have them shipped, either because they could not obtain them here or because it was cheaper than purchasing them here. This is not uncommon among immigrants, as noted by Menjivar (2002).

Illnesses of the Affluent

As explained by staff and board members, many Malta House patients suffer from chronic illnesses⁸⁵, such as high blood pressure, diabetes, high cholesterol, and arthritis. Appendix five provides the percentage of patient participants who reported

⁸⁵ Since Malta House's only focus is primary care, the patient population was skewed to chronic, or acute illnesses, such as flu, and sore throats that could be treated by primary care health professionals.

suffering from various illnesses. Although the term ‘diseases of affluence’ is often used to distinguish chronic diseases from infectious diseases, in most countries of the world chronic diseases are common (LeDuc Media 2011). The World Health Organization (2015) asserts that in nearly all countries of the world, it is the poor who are most susceptible to developing chronic diseases, due to, among other things, higher exposure to risks and decreased access to health care.

Social Suffering

Wacquant (1993:132) argues, for example, cardiovascular diseases and mental illness are among the morbid symptoms that are “commonly associated with entrenched poverty and with the individual and collective demoralization that such poverty invariably spawns over time.” The exercise of economic power and its impact on the physical and emotional health of participants is exemplified by Carol and Catarina, introduced in chapter four. Catarina’s narrative, for example, makes visible the consequences of social suffering. The current economic climate which has placed her in a precarious predicament of unemployment affected her health and well-being. As she indicated in chapter four, it was not until she became unemployed that she developed hypertension and pre-diabetes.

Health, Human Rights and Deservingness

The exclusion of undocumented immigrants has been a focus of health-related deservingness in the scholarly literature. For example, Viladrich (2012) analyzed key discourses employed in the scholarly literature to support inclusion of undocumented and excluded documented immigrants in health care benefits. Of note, are what

Viladrich (2012:826) terms “chilling effect” and “injustice frames”, which although have some relationship to humanitarian and social justice, privilege certain groups of immigrants over others and thus detract from the discourse of health care as a universal human right (see also Willen 2011). This “chilling effect can actually be interpreted as a symptom of immigrants’ internalized feelings of undeservingness...” (Viladrich 2012:826).

This notion of privileging certain immigrant groups over others is exemplified by Horton (2004) in her investigation of the ways in which Medicaid Managed Care created new classifications of Cubans ‘deserving’ and Mexican as ‘undeserving’ of health care in a New Mexico public hospital. Cubans were perceived as refugees both by U.S. law and the media while Mexicans were perceived as a burden on the U.S. economy and taking jobs away from law-abiding citizens (Horton 2004:474). Yarris and Castaneda (2015) argue that the category of ‘deserving’ refugee and ‘undeserving’ migrant, may be clearly differentiated in the media and in international law⁸⁶, but these distinctions are not as clear in reality. Thus, the notion of ‘voluntary’ migration is not as voluntary as portrayed in media and policy discussions. “[P]eople can be driven out of their home countries by economic desperation – that is, “forcibly” displaced by material factors besides war and natural disasters...” (Yarris and Castaneda 2015:65). Economic displacement, then, must be viewed in the broader context of structural violence and colonial histories (Quesada 2009).

Juana and Milagros were victims of economic displacement. Yet their

⁸⁶ The UN Convention on the Rights of All Migrant Workers and Members of Their Families was ratified in 2003 but no Western European countries, nor Canada, Japan, Australia, or the United States have signed on to the treaty (United Nations Treaty Collection 2016)

perspectives on a human right to health and deservingness diverged. Milagros viewed deserving of health care as those who work, “who are producing”, yet everyone has a right to health care. Her conceptualization of a right to health care is based on, as she stated “humanitarian reason”. Her notion of right to health care implied an ethical obligation to care for all in need, but deservingness, from her perspective, implied meritocracy. One may be ethically obliged to be cared for but may not merit such care. Catarina also conceptualized right to health care and deservingness in similar terms. Of note was their sense of individuals who were ‘getting something for nothing’, in this case, health care, and thus undeserved.

Juana, conceptualized right to health care in juridical terms. She did not see herself as having a right to health care because she did not *belong* here. Yet, for her, everyone is deserving of health care. One could also interpret her views as internalization of the dominant discourse of illegality.

Juana and Gloria also rationalized that if people in the U.S. go to such lengths to rescue and care for animals, i.e. their pets, why would human beings not be deserving of health care?

Many participants believed everyone had a right to health care and everyone deserved health care, although there were some caveats to this sentiment, as exemplified by Andrew. He made a distinction between a right to health care in terms of whom legally has a right to health care and right to health care on humanitarian grounds. This latter understanding for him is the same as deserving health care.

Another perspective is that those who cannot afford health care or who do not have health insurance have a right to health care, as evidenced by Liz and Carol. For

them, those who can afford health care are already exercising their right to it. However, even those who cannot afford health care have a right to it. Thus, everyone, rich and poor alike deserve health care.

Those who were perceived to be productive, had a right to health care while everyone deserved health care, was another way participants conceptualized right and deservingness, as was the case with Lucha. Everyone deserves health care because we are all human beings. One has a right to health care if and when one is a productive member of society. She went on to explain that if one is physically unable to work that person also has a right to health care.

Indeed, about half of the Latinos interviewed viewed work as an important criterion in terms of who has a right to health care or who is deserving of health care. More importantly, there was a sense of resentment or anger among these participants against those who do not work but are perceived to be capable of working and instead, are receiving public assistance. They reproduced a discourse that inscribed their identity as hard working subjects (as willing and able workers) and thus deserving and those receiving benefits as capable, yet unwilling workers, taking advantage of their status as citizens.

Of the 8 West Indian participants interviewed, 62.5% (5) did not distinguish between health care as a right and deserving health care. They believed everyone had a right to health care and everyone deserved health care. Elizabeth, Celeste and Andrew had different conceptualizations.

Elizabeth's concerns regarding a right to health care centered on economic considerations. Those who she perceived as being irresponsible did not have a right to

health care because they were receiving expensive care that, in her view, could have been avoided. Yet, she viewed deservingness as a moral/ethical issue such that even “the drunks” deserved health care.

Celeste believed only those who were U.S. citizens or legal residents had a right to health care and the “illegals” neither had a right to health care nor did they deserve health care. She reasoned that due to the economy “we don’t have room for you”. Rather than seeing undocumented as workers who pick our crops, clean our homes and hotel rooms, as Andrew does, she sees them as using up scarce resources.

To summarize, some participants did not see a distinction between right to health care and deserving health care. Others believed everyone had a right to health care but not everyone deserved health care. Alternatively, some participants believed everyone deserved health care but not everyone had a right to health care. Still others, particularly Latino participants, believed there are those who were legally entitled to health care (a juridical understanding of right to health care) but did not deserve health care. As Hafer (2012: 411) states “...people are seen to deserve rewards that are in the same proportion to their contributions...Inequitable distributions are seen as undeserved and unjust and can lead to distress...”

Paying for Health Care

Forty-seven percent of participants (16) stated it was the government’s responsibility to pay for health care with a fifth of those expressly stating they believed the wealthy do not pay their fair share and should be taxed more. This is also consistent with findings by Norton and Ariely (2011). Another 31% (9) stated it should be paid by

both the private sector, e.g. employer base or individuals, and the government, especially for those who cannot pay, and 16% (5) stated individuals should pay but there should be a range with the wealthy paying more⁸⁷ and those with low-income paying less, but that everyone should pay something. The latter two perspectives reflect the perspective that people should look to the government for assistance only if absolutely necessary. This coincides with the arguments expressed regarding a human right to health and deservingness whereby one should work and not expect government aid, and is consistent with, and a reflection of, the dominant ideology in the U.S. of individualism and improving your situation by your own efforts.

Corporate Profits and Socialized Costs

As previously mentioned, the belief that only those who work deserve health care also reflects a feeling of resentment, particularly among Latinos, that people are taking advantage of government assistance. However, the federal government gave nearly \$100 billion to companies and industries through direct and indirect subsidies in 2012 (DeHaven 2012). In addition, corporate taxes have decreased while individual taxes have increased (Thomas 1997). Thus, all of us who are living in the United States are subsidizing corporations through taxes, a process Noam Chomsky, in an interview with Simone Bruno (2008) refers to as socializing costs and privatizing profit. He states:

The system we live in should be called state capitalism, not just capitalism. So, take the United States. The economy relies very heavily on the state sector. There is a lot of agony now about socialization of the economy, but that is a bad

⁸⁷ The argument regarding taxing the wealthy more is an argument also made by, perhaps somewhat surprisingly, Warren Buffet, the fourth richest person in the world according to Forbes Magazine (2014), in a New York Times editorial (Buffett 2011).

joke. The advanced economy, high technology and so forth, has always relied extensively on the dynamic state sector of the economy. That's true of computers, the internet, aircraft, biotechnology, just about everywhere you look... So what you have is a system of socialization of cost and risk and privatization of profit. And that's not just in the financial system. It is the whole advanced economy.

Ralph Nader (2000:13) refers to the above as “corporate welfare—the enormous and myriad subsidies, bailouts, tax loopholes, debt revocations, loan guarantees, discounted insurance and other benefits conferred by government on business.”

Furthermore, one can argue that another way corporations such as Walmart and McDonald's are being subsidized is that the low wages paid employees in these establishments are not enough to meet basic needs. Their employees are the working poor and many rely on government assistance. In other words, rather than pay their employees a living wage, there is a pattern, especially in some industries, to arrange conditions so that society pays for the maintenance of their work force, while the profits produced by the labor of their workers are privatized. As mentioned above, the tax burden, as a percentage of wealth, is higher for the 99% than it is for the 1%.⁸⁸

Finally, undocumented immigrants and certain legal residents are ineligible for federal government programs, such as Medicaid or SNAP (Supplemental Nutrition Assistance Program). When the Patient Protection and Affordable Care Act was passed in March 2010, there were also certain restrictions in terms of eligibility for different categories of immigrants. These categories are based on the Personal Responsibility and Work Opportunity Act, otherwise known as the Welfare Reform Law, signed by

⁸⁸ I use the term 99% as it was used by the Occupy Wall Street movement to reflect the stark inequality between the haves and the have-nots.

President Bill Clinton in 1996.⁸⁹

Migration and the Crisis of Citizenship⁹⁰

“...exclusion operates mostly on a centuries-old caste basis, that is tolerated or reinforced by the state and by national ideology...” (Wacquant 1993:131)

Portion of song *Cladestino* (1998) by Manu Chao⁹¹

Alone I go with my sorrow	To a city of the north	Clandestine Algerian
Alone goes my sentence	I went to work	Clandestine Nigerian
To run is my destiny	I left my life	Clandestine Bolivian
To escape the law	Between Ceuta	Mano Negra ilegal ⁹²
Lost in the heart	and Gibraltar	
of the great Babylon	I'm a line in the sea	
They call me clandestine	A ghost in the city	
For not having any papers	My life is forbidden	
	So says the authority	

Juana's and Milagros' stories highlight the political-economic context of migration and the crisis of citizenship. Structural adjustment policies, free trade agreements, loss of land, and lack of jobs in home countries have forced many to migrate to the North (Chavez 2013; Millen et al. 2000). Five of the immigrant interviewees (22%) were also sending remittances home to care for family members. As Leinaweaver (2010:75) states “...migration is often initiated as a social reproduction strategy, geared explicitly

⁸⁹ Legal residents who entered on or after August 22, 1996, when the Welfare Reform Law was signed into law are ineligible for benefits until they have been legal permanent residents for at least five years (Broder and Blazer 2011; Wasem 2012). Like the Welfare Reform Law, the ACA restricts eligibility for Medicaid, in states where Medicaid has been expanded as part of the ACA, to legal permanent residents who have had legal permanent residency for at least five years, and undocumented are excluded altogether (National Immigration Law Center 2014).

⁹⁰ “Crisis in Citizenship” is taken from the title of the first chapter of the book by Stephen Castles and Alastair Davidson (2000).

⁹¹ Original Spanish lyrics are provided in Appendix Four.

⁹² Mano Negra (Black Hand) refers to late 19th century Spanish agrarian anarchist organization founded in Andalusia, Spain fighting for land reform and a transformation of Andalusian society (Lida 1969).

toward improving children's lives through, for example, the symbolic value of schooling, paid for with migrant remittances.” Lucha and Juana exemplified this state of affairs.

The saliency of citizenship manifests itself in the benefits it confers. As Chavez (2008:4) notes, citizen and non-citizen define who is included and who is excluded and used to “define community membership”. Citizenship changes the ‘other’ into ‘us’, yet this process of becoming ‘us’ is a contested process and citizenship does not necessarily guarantee membership in the ‘us’. The concept of the ‘other’ itself arises from historical processes and is a result of exclusionary practices.

Indeed, as Ngai (2004:2) points out, many Asian and Latino communities are comprised of both legal and illegal immigrants. Indeed, as was the case with my foreign born participants, coming to Connecticut was a result of social networks already established here from participants’ home countries, and more importantly from their home towns. Yet, those living in these hybrid communities have been perceived as foreigners who are unable to assimilate. This has given rise to the term “alien citizens” which Ngai (2004:2) defines as those who are born in the United States, thus are citizens in the legal sense of the term, but who are still viewed as foreign by the dominant culture (See also Chavez 2008; 2013). Yet the notion of ‘cultural citizenship’ is a way in which the residents of these communities can and do claim belonging to the nation-state (Flores and Benmayor 1997; Rosaldo 1994).

Migration, Class, and Identity

It is common for professionals who come from Latin America to work low wage jobs, regardless of education level (Canales and Pérez 2007). The middle class identity, and self-esteem, of Latin American professionals are challenged when they are

consigned to working in low wage jobs, as in Lucha's case as described in chapter four (Sabogal 2005; Sabogal and Núñez 2010).

Structural Vulnerability, Racism, and Embodied Suffering

'Documented' and 'undocumented' are terms conditioned upon specific historical, political, and economic circumstances and events (Ngai 2004). Yet not having the requisite 'document' puts Juana, and others like her, in a structurally vulnerable position. By structural vulnerability I mean "a positionality [whereby] the vulnerability of an individual is produced by his or her location in a hierarchical social order and its diverse networks of power relationships and effects. Individuals are structurally vulnerable when they are subject to structural violence in its broadest conceptualization" (Quesada et al. 2011:341).

Structural vulnerability brings into focus the limitations of the concept of agency because it compels us to examine constraints on decision making, how choices are constructed, and life options are limited and illustrates how mutually reinforcing political, economic, cultural and psychodynamic processes that predispose people and communities toward illness are embodied (Quesada et al. 2011).

Juana's bleeding feet are examples of how "illegality is expressed on and through the body [because] illegality is both produced and experienced" (Chavez 2008:25). Furthermore, the large majority of undocumented persons are uninsured, and excluded from the ACA. As Nancy Johnson (2010:45) notes, "[b]eing uninsured is a disparity by itself limiting the access of timely care as well as receiving the current standard of care."

Moreover, Latinos, particularly dark-skinned Latinos, whether documented or not,

are subject to racism and health disparities. The concept of race has been part of the global lexicon since the time of Linnaeus with his publication of *Systema Naturae* (1758) where he classified humans into four distinctive 'races'. Even into the 19th and early 20th centuries anthropologists and other scholars adhered to the notion of scientific racism, i.e. looking for traits that could be measured and quantified, with those with white skin on top of the hierarchy and darker skinned peoples on the bottom. Anthropologists themselves were at the forefront in constructing race as a valid biological category (Gravlee and Sweet 2008). Franz Boas challenged the notion of racial immutability when in 1911 he demonstrated that environment played a key role in human development. He also criticized the idea that one's 'race' had anything to do with one's character (Armelagos and Goodman 1998). Because of Boas' work and that of other anthropologists and scholars it has long been established that 'race' is a social construction and has no biological basis (Byrd and Clayton 2003; Delgado and Stefancic 2012; Gravlee and Sweet 2008; Harrison 1995; Krieger 2000; Smedley et al. 2003). And as Krieger (2000) argues, although 'race' has no meaning biologically, it is nonetheless a significant social category in which the social reality of living in a racist society is embodied.

Although the overall health of the United States population has improved in the last few decades, in terms of longevity and health outcomes, the health status of racial/ethnic minorities continues to differ from that of white Americans (Byrd and Clayton 2003; Geiger 2003; Mayberry et al. 2000). However, racial/ethnic health disparities go as far back as the colonial era in the United States and reflect the medical and social values, which correspond to the values and policies in the larger society (Byrd and

Clayton 2003). Ford and Harawa (2008a:251) point out that often one sees the term 'race/ethnicity' yet it is not clear if this is truly "a shift away from racialization or merely extends flawed racial taxonomies to populations whose cultural and phenotypic diversity challenge traditional racial classification." They therefore propose that ethnicity be conceptualized along two dimensions; a culture-specific social construct related to a group's characteristics and a dimension based on the relationship of the group within the society at large. However, where people live can either reinforce or diminish their ethnicity. Yet, race and ethnicity do intersect. For example, light skinned Latinos often identify themselves as white rather than Latino and tend to have better jobs and live in white neighborhoods. Darker skinned Latinos, on the other hand, tend to be lower on the socioeconomic ladder and live in neighborhoods of predominately black residents (Stratton et al. 2009; Waterston 2006).

Many studies have been conducted regarding health disparities for various diseases. For example, disparities exist in the diagnosis and treatment of cardiovascular disease whereby whites were found to have more accurate diagnosis and treatment than African Americans or Latinos. Similarly, African Americans are at greater risk for stroke and end-stage renal disease than whites; Latinos, African Americans, and Native Americans have higher mortality rates due to diabetes than whites (Geiger 2003; Good et al. 2003). Indeed, the most prevalent illnesses among participants were high blood pressure, diabetes, high cholesterol and problems related to mental health.

Moreover, although there has been a pattern of declining absolute inequalities, including health inequalities, in developed economies, like the United States, there has also been an increase in relative inequalities (Scambler 2012).

The ACA is an attempt to reduce health inequalities, at least among U.S. citizens and certain legal residents. Knowledge about the ACA among patient participants was minimal as discussed in the following section.

The Patient Protection and Affordable Care Act

Some participants, as exemplified by Barbara and Elizabeth, were concerned about the affordability of health insurance under the ACA passed in 2010.

As Table 10 indicates, most patients I interviewed had no knowledge of the ACA.

Table 10
Patient Participants' Knowledge of the ACA

Very Knowledgeable	Some Knowledge	Little Knowledge	No Knowledge
11% (3)	18% (5)	32% (9)	39% (11)

Of 13 Latino patient participants, only one had some knowledge of the ACA and one was very knowledgeable. Five of the 13 Latino participants (38.5%) had little knowledge and six (46%) knew nothing about the bill. However, four of the Latino participants who stated they knew little about the bill (80%) did know it excluded those who are undocumented and three of the four (75%) were themselves undocumented. Three of the eleven black participants (27.3%) had some knowledge of the ACA and only one (9%) was very knowledgeable. Three (27.3) had very little knowledge and four (36.4%) had no knowledge of the law.

The law was passed in March of 2010, but did not go into effect until January, 2014. Furthermore, despite discussion of the law on local and cable news, Gross et al. (2012) found that people's knowledge of the ACA was lacking and Morris and Forgette (2007:91) found that people viewed television news intermittently and often in a

disinterested manner. This could be why many participants claimed to know very little or at all about the law. On the other hand, those who stated they were very knowledgeable about the law admitted that besides listening to the news on television, they also read about the law in newspapers. This could be due to language proficiency. For example, only two (14.3%) of the 14 Latinos participants were fluent in English.

As discussed in chapter one, there were still 147,166 (4%) uninsured Connecticut residents as of August 2014 (Pazniokas 2014). That number dropped as of September 2015 to 137,000 (3.8%) (Hartford Courant Staff Report 2015). Furthermore, while Connecticut residents may have a deductible of \$1,000 or less, through the state's health insurance exchange, monthly premiums could cost more than \$1,000. A monthly premium of under \$500 could mean a deductible of \$6,000 (Patrick 2015).

Summary

Key findings from my study include:

- Sufferer's experience
 - Participants had to forego needed health care, such as orthopedic surgery or dental care. Moreover, participants struggled to meet financial obligations. Obtaining medications, however, was not difficult for most participants because Malta House covered the cost of medications for those who could not afford them. Malta House also covered the cost of certain lab procedures, such as lipid profiles, and fasting blood sugars, and certain x-rays. The organization also paid for glucometers and test strips for diabetics who could not afford them. The health of patients who do not have access to a clinic like Malta House would not have their medical needs met. Furthermore, those who were undocumented appreciated that Malta House provided free health care.
- Social Origins of Disease
 - As was discussed by Dr. M., and other participants, financial concerns and in the case of immigrants, separation from loved ones who were left behind, caused stress and anxiety. For example, almost half of study participants suffered from high blood pressure. Stress and diet are strongly correlated with high blood pressure. Likewise, diet is strongly correlated with diabetes, though study participants were not obese, about 30% were overweight and over half of the

participants who were diabetic reported diet as a factor. These examples point to the social origins of disease.

- Political economy
 - Privatization of corporate profits and socialization of costs has led to low wages, particularly in the service sector. Furthermore, globalization and government trade agreements have increased the free movement of transnational corporations. These features were the basis for poverty of almost 80% of my study participants, which affected their health.
- Micro-Macro (connecting sufferer's experience with political economy)
 - Having to do without needed health care, unable to afford healthy food, the stress and sadness of being separated from children and family, being unemployed or underemployed are connected to the larger political economy that impacted the health of those in my study.
- Medical pluralism
 - Because Malta House paid for medications for those who could not afford them, taking the prescribed medications was not an issue. According to Shepherd et al. (2014:581) access to prescription medications has a significant positive impact on health outcomes. Patients, however, also made use of home remedies (See Appendix Six). In addition, three participants (10%) sought health care from alternative health practitioners, specifically, chiropractors, and acupuncturists.
- Transnational Medicine
 - Fourteen percent of study participants (4) reported obtaining medications from their home countries by having them shipped or having a friend or relative bring them.
- Biomedical System
 - While participants had a trust in the biomedical system, they also sought, and used alternative therapies.
- Social networks/church communities
 - Study participants reported relying heavily on their religious faith and church communities to assist them in their efforts to meet health care needs
- Health Resources Allocation
 - As mentioned above, diet was an issue for participants, particularly those with diabetes. As mentioned in chapter two, two-thirds of study participants lived in Hartford, and Hartford is considered a food desert. Thus, getting to a supermarket is difficult.
 - Almost 90% of the patients interviewed utilized Malta House as their only source of care. This reflected Malta House's mission (2015) "to provide free primary health care to the uninsured...[with the result that] 2,200 individuals [identified] Malta House of Care as their only medical home."
- Right to health care/Deservingness
 - Five general perspectives came out in the interviews regarding the right to health care and deserving health care:
 - There was no distinction between the right to health care and deserving health care.
 - Everyone had a right to health care, but not everyone deserved health care.
 - Everyone deserved health care but not everyone had a right to health care.

- Although there were those who had a right to health care in the juridical sense, they did not deserve health care. They placed blame on the individual, rather than the unequal economic conditions that exist, such as the government subsidies provided to corporations, while they pay little or no taxes (Krantz 2014).
- Only those who were U.S citizens or were here legally had a right to and deserved health care
- What was somewhat surprising was that some of the Latino participants rationalized that since people here in the United States have such a concern for their pets and care for them so affectionately, that human beings should be afforded the same consideration. This idea of a 'family pet' and treating pets as family members was puzzling to some Latino participants. I believe this is because pets are not viewed in this way in Latin America.⁹³
- Health Policy
 - The Patient Protection and Affordable Care Act was signed into law in 2010, and went into effect January 2014. While the number of uninsured decreased in Connecticut, issues remain. For example, people were having difficulty getting appointments on a timely basis. This affected Malta House in that some patients who signed up for health insurance, but were previously uninsured and Malta House patients, were being seen at Malta House until they could get seen by their physician. Moreover, there have been debates and discussion around the issue of affordability, as discussed in this chapter. Finally, the new health care law excludes those who are undocumented.

Based on these findings, some concluding thoughts about the future are presented in chapter six.

⁹³ In my yearly visits to Ecuador as a child, and more recently my yearly visits to Mexico, I have observed that pets are important to the family, and often well cared for, but not viewed as family members. For Americans' views on their pets as family members, see Root (2002).

Chapter Six: Conclusion and Thoughts about the Future

Introduction

In this concluding chapter I elucidate the significance of my research, how the study contributed to theoretical concepts and key contributions to critical medical anthropology and anthropology in general. I conclude with thoughts about the future.

I conducted this research to learn about the health care experiences of uninsured persons living in greater Hartford, Connecticut who sought health care at a non-government, non-profit mobile clinic, and how the clinic fit into their overall strategies to meet their health care needs. This is important because Hartford is a very poor city, is a representative sample of a larger situation and points to inequalities based on poverty, ethnicity and immigration. Indeed, according to Kneebone and Williams (2012), the Hartford Metro area had the fourth highest city poverty rate in the country. Moreover, Hartford is the poorest community in Connecticut with 32% of residents very poor and another 25% poor (Connecticut Center for Economic Analysis et al. 2013).⁹⁴ Cities, which like Hartford, have high concentrations of Blacks and Latinos also experience high poverty rates (see Table 11).

This is relevant to my study as 66% of patient participants lived in Hartford at the time fieldwork was conducted. In my sample 43% (12) were below and 24% (7) were near the 2012 Federal Poverty Level and 86% (25) were Latino or Black. Because health insurance in the United States is predominantly an employer based system,

⁹⁴ The Connecticut Center for Economic Analysis et al. (2013) define very poor as an individual adult whose annual income is below \$11,000 and for a family of four (two adults and two children) the annual income is below \$21,000. A poor adult is one whose annual income is below \$22,000 and for a family of four the annual income is below \$42,000. This is slightly different from the 2010 U.S. Census Federal Poverty Threshold (U.S. Census Bureau 2010) of \$11,117 annual income for one adult and \$22,113 annual income for a family of four.

access to health care has traditionally been difficult if one was unemployed, employed by a business that did not offer health insurance, or did not work enough hours to qualify for employer based health insurance.

Table 11
Comparison of Hartford with some Cities of similar Ethnic Composition

	Black and Latino	White, not Latinos	Latinos of any racial background	Below 100% FPL	100-199% of FPL	Median Household Income
Hartford, CT	38.2%	16.7%	43.4%	33.6%	25.8%	\$29,430
Miami, FL	19.8%	11.3%	70.3%	29.9%	27.6%	\$30,375
Paterson, NJ	31.5%	9.7%	57.3%	29.1%	26.5%	\$32,707
Detroit, MI	85.4%	8.2%	7.1%	39.3%	24.2%	\$26,325
Newark, NJ	51.7%	11.8%	34.15	43.1%	30.8%	\$27,742

Source: U.S. Census Bureau (2013b)

In my study, over half of those interviewed were unemployed and about 1/3rd worked part-time and could not qualify for their employer's health insurance.⁹⁵

Theoretical Considerations

The theoretical framework of critical medical anthropology was applied to investigate the health and health care needs and challenges of study participants. Key contributions of this work are summarized below.

Social Origins of Disease and Ill Health in Light of the World Economic System

Fifty-eight percent (17) of the patients I interviewed were dealing with stress, anxiety or depression as a result of economic uncertainty, and difficulty, or inability, in meeting financial obligations, and almost 25% (6) of those interviewed stated stress as

⁹⁵ Interviews were conducted prior to when the ACA went into effect (Jan. 1, 2014).

a reason for their illness, especially high blood pressure. Unemployment or underemployment was the cause of their economic predicament. Carol's narrative, in chapter four, exemplified the social origins of illness within the context of macrolevel structures.

A world economic system perspective sheds light on this condition. In the United States, the neoliberal policies of the last three decades, the relocation of manufacturing enterprises, and outsourcing of labor have led to an exacerbated dual market system whereby middle income jobs of have become increasingly scarce and only permanent well-paid, usually high skilled, professional jobs, or low-wage service sector jobs remain, with more low-wage jobs created than the former (International Labour Organization 2015; Kimball and Scott 2014; Lee and Mather 2008; Sassen 2008; 2002; Wilson 1996; 2012). As Sager (2012:67) notes, "Tolerance of segregated markets requires that we accept exploitation within our countries and are prepared to accept legal and economic institutions that sustain a sector in which workers are not equal to the rest of the population."

Immigrant experiences are also linked to the world economic system. The policies affecting the labor market in the United States, have also impacted economies and labor in other countries⁹⁶. Most of the immigrant participants I interviewed who were working, worked in low-wage service sector jobs. Further, Sager (2012) notes that many economies are dependent on migrant labor, yet in a number of markets, immigrants make up a temporary, marginalized workforce. This is particularly true for

⁹⁶ For example, between 2001 and 2006, about 3 million Mexicans migrated to the United States as economic migrants (approximately 500,000 per year) as a consequence of thirty years of neoliberal reform in Mexico (Laurell 2015). Juana was one of these economic migrants (see Chapter Four).

undocumented immigrants.

The violence, physical and structural, of crossing the U.S. border clandestinely, as was the case for Juana, in addition to feelings of loss and displacement in the immigrant experience, can have long-term health effects (Perez Foster 2001). In fact, Perez Foster (2001:155) identifies four stages of the migration experience that may lead to significant psychological distress:

1) premigration trauma, i.e., events experienced just prior to migration that were a chief determinant of the relocation; 2) traumatic events experienced during transit to the new country; 3) continuing traumatogenic experiences during the process of asylum-seeking and resettlement; and 4) substandard living conditions in host country due to unemployment, inadequate supports, and minority persecution.

Although none of the participants in my study were seeking asylum, there were significant challenges resettling in a new land with a different language, and having to deal with feelings of hostility in the host country, as was Milagros' case in having to contend with immigration raids at her place of employment in Arizona. Finally, certainly living conditions were harsh for immigrant participants due to unemployment, as discussed in the narratives in chapter four.

Health Policy, Health Resource Allocation, and the Role of the State

Neoliberal policies affected not only labor, but health policy as well in many parts of the world (Castro and Singer 2004).⁹⁷ Neoliberalism also affected health policy in other parts of the world. In the United States, health policy underwent a significant change in 2010 with the passage of the ACA. The ACA, however, was not implemented until January 2014.

⁹⁷ For a detailed analysis of health policy reforms in Mexico, and Latin America see Laurell (2013).

Neoliberal ideology influenced health care policy in that the ACA is not a national single payer policy. As discussed in chapter one, even after implementation of the ACA, health insurance companies are still major players within the U.S. health care system through health insurance exchanges and through Medicare, due to the shifting demographic in the United States⁹⁸. Indeed, Aetna is currently looking to buy Humana Health Insurance Company, in part because Humana has triple the number of Medicare Advantage members as Aetna and 4.4 million Medicare D subscribers (Lee 2015). Through the health insurance exchanges individuals may receive government subsidies to reduce their monthly premiums.⁹⁹ Because health care in the U.S. is based on the profit motive, those with employer-based health insurance have seen co-payments and deductibles increase, with more increases expected (Kaiser Family Foundation et al. 2014a). This is also true for those who purchased health insurance through the ACA, though state insurance regulators must approve any health insurance rate increases (Cox 2015; Pear 2015).

Participants in my study who were eligible to take advantage of the ACA were concerned about how much it would cost them, as discussed by Barbara and Elizabeth.

In addition, there is still an implicit hierarchy of health insurance, with employer-based health insurance on top and Medicaid on the bottom. This is due, in large measure, to the rates paid by Medicaid for health care providers. The Medicaid rates are linked to the limited pool of private physicians willing to accept Medicaid

⁹⁸ Ortman et al. (2014) estimate that by 2050 more than 20% of the U.S. Population will be over 65 years old.

⁹⁹ Medicare D (aka Medicare Part D) is a prescription drug program for those 65 and older. The subscriber pays a monthly insurance premium for the drug benefit, or as part of Medicare A and B (Centers for Medicare and Medicaid Services, n.d.; AARP, n.d.).

patients (Becker 2015; Manthous and Sofair 2014). I argue, therefore, that the U.S. healthcare system is still “a killer commodity” (Livingston 2009).

The ACA did have an impact on Malta House. Between January and November 2014, Malta House of Care’s patient population dropped by about ten percent, approximately 450 individuals, because they qualified for Medicaid as part of the ACA (Becker 2014). However, the clinic gained about 400 new patients, mostly new immigrants. Indeed, it is estimated that even by 2016, approximately 160,000 Connecticut residents will remain uninsured (Nardin et al. 2013). They include those who are undocumented, those who do not earn enough to file a tax return, those for whom insurance would be considered too expensive to buy, and those who are legal residents who would qualify for Medicaid but are not eligible due to the five year residency rule (Becker 2013 and 2014). Thus, Malta House fills a role as a safety valve.

Medical pluralism, Culture, and Class

As explained in chapter five, some participants made use of home remedies. This was especially the case for immigrant participants. As Karen, introduced in chapter four, explained, her home remedy is something she learned from her grandmother. Likewise, Mariana, a woman I interviewed who was from Mexico, was given a recipe by her sister, as follows: mix pineapple, apples, celery and cucumber in a blender until liquid and drink it. Mariana’s sister told her this would help her pass her kidney stone and Mariana claims it succeeded. And Juana’s mother told her that for colds and flu, she should boil milk with cinnamon and rub Vicks on her chest. Fourteen percent of those interviewed (4) also made use of alternative health practitioners, such as acupuncturists and chiropractors. As Hans Baer (1989:1103) notes, those seeking

alternative therapies “often belong to lower-middle, working and even lower social classes.” This was the case for Charlie.

Struggle in Health and Health Care

The narratives highlighted in this study point to the struggles the poor and working poor deal with as they attempt to meet their health care needs while also meeting other financial obligations, including keeping a roof over their heads, and supporting families, often in far away places. Some, like Carmen and Juana were able to pay the rent behind schedule.

Contributions to Medical Anthropology and Anthropology Generally

My study pointed to the social origins of disease and ill health as they connect to individuals in light of the life course (Bartley et al. 1997) of study participants as agents in the world economic system, and members of the precariat. It further revealed the struggle they confronted in addressing their health care needs. My study also revealed the connections between migration, and migration trauma, to sufferer experience and struggle.

The U.S. commodified, and disjointed health care system, with its exclusionary practices, points to a gap in the structure, and practice of health care. The Malta House mobile van is a manifestation, and response to the ideology, practice, and structure of the health care system.

Looking Ahead

As I write, the Supreme Court heard arguments, and ruled on the King v. Burwell

case. The question before the court was whether insurance subsidies are permitted in states that rely on the federally run health exchange, HealthCare.gov. The case was brought by plaintiffs David King and three other Virginia residents who argued that the Affordable Care Act (ACA) states that subsidies are available for those enrolled in an exchange “established by the state.” The plaintiffs said they did not want be forced into buying health insurance and that the subsidies would subject them to the requirement that they purchase health insurance or pay a penalty. If the subsidies were not available they would have been eligible for a hardship exemption because Virginia uses the federally run health exchange (FactCheck.org 2015; Howe 2015; Liptak 2015). The Supreme Court ruled against the plaintiffs and upheld the federal subsidies (Chief Justice Roberts 2015; Liptak 2015a; Savage 2015). Despite the decision, the ACA could also be affected depending on the outcome of the 2016 national elections, and further legal challenges (Pear 2015a; Weisman 2015). Furthermore, although the Supreme Court decided in favor of the ACA, federal grant money will not be available at the current level to fund access health CT. Therefore, the exchange will need to find funding elsewhere (Sturdevant 2014).

The 2015 proposed budget by Governor Malloy included cuts to Medicaid. He also decreased the threshold for parents of dependent children from 201% of the Federal Poverty Level to 138%. The number of adults who would qualify would decrease by 34,200, from 169,000 to 134,800 (Sturdevant 2015).

Citing national and state stagnant wage growth and a slow recovery from the 2008 recession as factors in the 500 million dollar Connecticut state budget deficit, Governor Malloy’s 2016 proposed budget, that would take effect July 1, 2016, calls for

spending cuts, including 5.75% cuts for most state agencies (Altimari and Keating 2016; Dixon 2016; Malloy 2016). What impact the proposed budget will have on the CT Health Insurance Exchange is to be determined.

Finally, the 2016 U.S. presidential election is underway and the outcome could have an impact on the ACA and immigration policy, either negatively (repeal of ACA, increased deportation of immigrants) or positively (single payer health care system or building on ACA and comprehensive immigration reform with a path to citizenship for those who are undocumented).

APPENDIX ONE¹⁰⁰
Interview Guide for Patient Participants

I Health Concerns

001 What health problems are you having now _____?

1. When did you experience your health problem or difficulties for the first time? What happened? What happened then?

2. Where did you go first for your health problem? Tell me about your visit and what happened afterwards.

2a. [Why did you come to this agency]

2b. How did you learn about this agency?

3. Do you go anywhere else for health care? If so, where, besides this agency do you go for care? Who do you see? Tell us about your visit and what happened afterwards.

3a. Did you have any tests or treatments for your health problem? [The relevance of this question depends on the type of health problem.]

4. What do you think caused your _____? [List primary cause(s).]

5. During your visit to the doctor (or NP) for your HP, what did your doctor (or NP) tell you that your problem was?

6. Did your doctor (or NP) give you any treatment, medicine or recommendations to follow? [List all]

7. Are you able to follow that treatment (or recommendation or medicine)? If yes, how well?

7a. Where do you go for treatment?

7b. Where do you go for medicines?

8. Is there anything that makes treatment difficult to follow or work poorly? If so, what?

9. Did any other health specialists give you any treatment, medicine or recommendations to follow? [List all] [If there are none go on to question #13].

10. How are you dealing with each of these recommendations?

11. Are you able to follow that treatment (or recommendation or medicine)? If yes, how well?

11a. Where do you go for treatment,

11b. Where do you go for medicines?

¹⁰⁰ Adapted from Groleau et al. (2006)

12. Is there anything that made the treatment difficult to follow or work poorly? If so, what?
13. Do you use any home remedies for your health problem? Same question for over-the-count drugs from pharmacies.
14. Are there other occasions when you use home remedies? [e.g. teas, herbs, homeopathic medicines] If so, what and for what purpose?
15. Have you ever had a medical emergency?
- 15a. If so, what did you do? Did you call 911?
 - 15b. [If went to hospital ER] What happened at the ER?
 - 15c. Did you get a bill from the hospital? What happened then?
 - 15d. [If never had an emergency] What would you do if you had a medical emergency?
16. Where do you go for medicines?
17. Where do you go for X-Rays or other diagnostic tests?
18. Are you able to get the medicines/treatments you need? How?
- 18a. If not, why not?
 - 18b. [If yes], Was there ever a time when you couldn't get the medicines/treatments you needed? Why? What happened? What did you do?

Now I would like to ask you about health insurance.

II Health Insurance

19. Did your family have health insurance when you were growing up? If yes, what kind of health insurance did your family have?
- 19a. If no, how did your family meet the family's health care needs?
20. Do you have difficulty paying for your health care needs?
- 20a. If yes, why?
 - 20b. [If no] why not?
21. Did you ever have health insurance in the past?
- 21a. If so, what kind of health insurance did have?
 - 21b. How long have you been uninsured?
 - 21c. Why? What happened?
22. Has being without health insurance changed the way you live? If yes, how?
23. Has being without health insurance changed the way you feel or think about

yourself? If yes, how?

24. Has being without health insurance changed the way you look at life in general? If yes, how?

25. Has being without health insurance changed the way that others look at you? If yes, how?

26. What has helped you through this period in your life?

Now I would like to ask you about health reform and rights to health care.

III Knowledge about Health Reform

27. What do you know about the health reform bill that was passed in 2010 and signed by President Obama? [provisions or stipulations, inclusions, exclusions]

28. How do you know about it? [source of information?]

29. Do you think the new health reform bill will affect you in any way? If yes, how? If not, why not?

IV Rights to Health Care

30. Who should have a right to health care in the U.S.? Why?

31. Who deserves to receive health care in the U.S.? Why?

32. Do you believe there are people who do not deserve health care as a right in the U.S.?

33. Who should pay for health care in the U.S.? (employers, individuals, government, combination?)

Finally I would like to know a little bit about you.

V Basic Information

34. Tell me about yourself? Where were you born?

35. When were you born?

35a. If not U.S. born, when did you come to the U.S.? To what town or city? When did you come to Hartford?

36. Is that where you grew up?

36a. (If not, ask where person grew up.)

37. What is your ethnic background?
38. How do you identify yourself in terms of your gender?
39. Where else did you live?
40. Where do you live now?
41. How long have you lived there?
42. What is your family make-up?
43. What grade did you finish in school?
44. Are you currently working?
 - 44a. (If yes, ask where, nature of job, and how long)
 - 44b. (If no, ask Have you ever worked?)
 - 44c. (If yes, ask what kinds of jobs, where, and how long at each job).
45. Why did you leave the job/jobs?
46. What is your current household income?
 - Under \$10,000
 - \$10,001 - \$24,999
 - \$25,000 - \$39,999
 - \$40,000 - \$49,999
 - \$50,000 - \$74,999
 - \$75,000 - \$99,999
 - \$100,000 - \$124,999
 - \$125,000 - \$149,999
 - Over \$150,000
47. Have we covered everything you think is important?
Are there other people you think I should talk to?

Patient Interview Guide in Spanish

I Problemas de Salud

001 ¿Qué problemas de salud tiene Usted en este momento
_____?

1. ¿Cuándo comenzó Usted a tener problemas o dificultades con su salud? ¿Qué sucedió? ¿Qué pasó después?

2. ¿Adónde asistió Usted primero para tratar de atender su problema de salud? Platíqueme por favor acerca de su visita en aquel entonces y lo que sucedió después.

2a. [si el primer lugar no fue ésta agencia cuando & porqué llegó Usted a la agencia?]

2b. Cómo supo Usted de la existencia de la camioneta?

¿Se le hizo algún examen, prueba o tratamientos para su problema de salud? [La importancia de esta cuestión depende del tipo de problema de salud].

3. ¿Acude Usted a otro lugar para su atención médica? ¿Si es así, donde, además de la agencia, va para su atención médica? ¿A quien ve? Cuénteme por favor sobre su visita y lo que sucedió después.

3a. ¿Le hicieron a Usted algunas pruebas o tratamientos para atender su problema de salud? [La importancia de esta cuestión depende del tipo de problema de salud].

4. ¿Qué cree Usted que fue lo que causó su _____? [Enumera causas primarias]

5. ¿Durante su visita al médico (o Enfermera de Practica Avanzada) para atender su problema de salud, qué le dijo su médico (o EPA) que era su problema?

6. ¿Le dio su médico (o NP) algún tratamiento, medicina o recomendaciones a seguir? [Enúmere todos]

7. ¿Sigue Usted su tratamiento (o recomendación o medicina) sin problemas? En caso afirmativo, ¿qué tan bien lo sigue?

7a. ¿Adonde acude Usted para recibir tratamiento?

7b. ¿Adonde acuda para conseguir medicamentos?

8. ¿Hay algo que se hace el tratamiento sea difícil de seguir o que no funcione bien? Si es así, ¿qué?

9. ¿Hubo otros especialistas de salud le proporcionaron algún tratamiento, medicina o recomendaciones para seguir? [Enúmere por completo] [Si no hay, sigue con pregunta número 13]

10. ¿Cómo le está yendo a Usted con cada una de estas recomendaciones?

11. ¿Puede Usted seguir bien ese tratamiento (o recomendación o medicina)? En caso afirmativo, ¿Qué tan bien?
- 11a. ¿Adonde acude para recibir el tratamiento?
- 11b. ¿Adonde acuda para conseguir medicamentos?
12. ¿Hay algo que hizo el tratamiento difícil de seguir o que funcionara mal? Si es así, ¿qué fue?
13. ¿Utiliza Usted algunos remedios caseros para atender su problema de salud? La misma pregunta para medicinas que uno puede comprar sin receta en las farmacias.
14. ¿Existen otras ocasiones cuando utiliza Usted remedios caseros? [por ejemplo, té, hierbas, medicamentos homeopáticos] ¿Si así, qué y para qué propósito?
15. ¿Alguna vez ha tenido Usted una emergencia médica?
- 15a. En caso afirmativo, ¿qué hizo entonces? ¿Llamó al 911?
- 15b. [si acudio a la sala de emergencia del hospital ER] ¿Que ocurrió en sala de emergencia?
- 15c. ¿Recibio una factura del hospital? ¿Qué pasó entonces?
- 15d. [si nunca tuvo una emergencia] ¿Qué haría usted si tuviera una emergencia médica?
16. ¿Adonde acude usted para obtener medicamentos?
17. ¿Adonde acude Usted para tomarse radiografías u otros exámenes-diagnósticos?
18. ¿Puede Usted conseguir los medicamentos y tratamientos que necesita? ¿Cómo?
- 18a. Si no, por qué no?
- 18b. [Si sí], ¿Hubo alguna vez cuando no pudo conseguir los tratamientos/medicamentos que necesitaba? ¿Por qué? ¿Qué ha pasado? ¿Qué hizo?

Ahora me gustaría preguntarle sobre seguro de salud.

II Seguro Médico

19. Cuando era usted chico(a) ¿tenia su familia seguro de salud? ¿En caso afirmativo, qué tipo de seguro médico tenía su familia?
- 19a. Si no, ¿Cómo satisfacía su familia las necesidades de salud?
20. ¿Tiene Usted dificultades para pagar por su atención médica?
- 20a. en caso afirmativo, ¿por qué?
- 20b. [si no] ¿por qué no?
21. ¿Alguna vez en el pasado ha tenido Usted seguro de salud?
- 21a. Si es así, ¿qué tipo de seguro de salud era?

- 21b. Cuánto tiempo lleva ahora sin seguro?
21c. ¿por qué no tiene seguro? ¿Qué pasó?

22. ¿El estar sin seguro médico ha cambiado la manera en que vive Usted? Si sí, ¿Cómo?
23. ¿El estar sin seguro médico ha cambiado la forma que siente o piensa Usted de si mismo(a)? Si sí, ¿Cómo?
24. ¿El estar sin seguro médico ha cambiado la manera de que mira Usted la vida en general? Si es así, ¿cómo?
25. ¿El estar sin seguro médico ha cambiado la manera en que otros lo(a) miran a Usted? Si es así, ¿cómo?
26. ¿Qué ha sido lo que más le ha ayudado durante este período de su vida?

Ahora me gustaría preguntarle acerca de la reforma de salud y del derecho a la atención médica.

III Conocimientos acerca de la Reforma de Salud

27. ¿Conoce Usted que el proyecto de ley de reforma de salud fue aprobado en 2012 y firmado por el Presidente Obama? Si sí, ¿Qué es lo que sabe sobre del proyecto de ley de reforma de salud? [disposiciones o estipulaciones, qué está incluido/excluido]
28. ¿Cómo sabe sobre el? [fuente de información?]
29. ¿Cree que la nueva ley de reforma de salud le afectará de alguna forma? Si sí, ¿Cómo? Si no, ¿Porqué no?

IV Derecho a la Atención Médica

30. ¿Quién tiene derecho a atención médica en los Estados Unidos? Porque?
31. ¿Quién merece recibir atención médica en los Estados Unidos? Porque?
32. ¿Cree usted que hay gente que no merecen atención médica como su derecho en los Estados Unidos?
33. ¿Quién debe pagar por atención médica en los Estados Unidos? (las empresas, los empleados, el gobierno, los individuos, una combinación?)

Por último, me gustaría saber un poco acerca de usted.

V Información Básica

34. ¿Platicame un poco sobre Usted. ¿Dónde nació?
35. ¿Cuándo nació?
 - 35a. Si no nacio en los Estados Unidos, ¿cuándo llegó usted a los Estados Unidos?
¿A que ciudad ó pueblo? ¿Cuándo llegó usted a Hartford?
36. ¿Es ahí donde creció?
 - 36a. (si no, pregunte donde creció la persona.)
37. ¿Cuál es su origen étnico?
38. ¿Cómo se identifica Usted en términos de su género?
39. ¿En que otra parte ha vivido Usted?
40. ¿Dónde vive Usted ahora?
41. ¿Cuánto tiempo ha vivido Usted allí?
42. ¿Cuál es su composición familiar?
43. ¿Hasta qué grado terminó en la escuela?
44. ¿Tiene Usted trabajo ahora?
 - 44a. (en caso afirmativo, pregunte dónde, tipo de trabajo y cuánto tiempo lleva)
 - 44b. ¿(Si no, pregunte ¿Ha trabajado alguna vez?
 - 44c. (en caso afirmativo, pregunta ¿Qué tipo de trabajos, dónde y cuánto tiempo en cada puesto de trabajo).
45. ¿Porqué dejo Usted el trabajo (o los trabajos)
46. ¿Cuál es el ingreso de su hogar en este momento?
 - (Menos de \$10.000
 - \$10.001-\$24.999
 - \$25.000-\$39.999
 - \$40.000-\$49.999
 - \$50.000-\$74.999
 - \$75.000-\$99.999
 - \$100.000-\$124.999
 - \$125.000-\$149.999
 - Más de \$150.000
47. ¿Cree Usted que hemos cubierto todo lo que usted piensa que es importante?
¿Hay alguna otra persona(s) que cree Usted debiera platicar conmigo?

APPENDIX TWO¹⁰¹
Interview Guide for Staff Members

I Who

1. Tell me about yourself? What is your position within the organization?
2. How long have you been working/volunteering at this mobile clinic?
3. How long have you been working at the mobile van?
4. Why did you decide to work on the mobile van?
5. How often do you work [full time? part-time?
6. If volunteer, how often do you volunteer?
7. Why do people use Malta House?

II Health Issues

7. What are major health issues of the patients you see in the van?
- 8.. Where do patients go for Prescriptions?
- 9.. Where do patients go for X-Rays
10. Where do patients or other diagnostic tests?
11. What happens if patients can't pay for their prescriptions?
12. What happens if patients can't pay for x-rays?
13. What happens if patients can't pay for other diagnostic tests?
14. Where do the patients go for emergency care?
15. What happens to uninsured patients needing hospital care?

Prompts:

- 15a. What hospitals do they go to?
- 15b. Does the hospital give charity care? How do people find out about it?
- 15c. Do people get bills from the hospital?

¹⁰¹ Appendices two and three are adapted from Sherry and Marlow (1999)

15d. What happens if they can't pay the bill?

16. Does a patient's health coverage (Medicaid, uninsured, private insurance) affect where they go for care?

16a. How

16b. Why?

III Other Issues

17. Are there language interpretation issues of the patients you see in the van?

18. Are there cultural issues of the patients in the van?

19. Are there other issues of the patients in the van, such as transportation issues?

III Rights to Health Care

20. Who should have a right to health care in the U.S.? Why?

21. Who deserves to receive health care in the U.S.? Why?

22. Are there people who you think deserve health care but do not have a right to health care in the U.S.?

23. Who should pay for health care in the U.S.? (employers, individuals, government, combination?)

24. Have we covered everything you think is important?
Are there other people you think I should talk to?

APPENDIX THREE
Interview Guide for Organization Board Members

I. Organization History

1. Who were the key players in the organization's development?
2. (How many board members were there in the beginning and how many are there now?)
3. Where did the initial funds come from?
4. What barriers/challenges did the organization encounter in its creation?
 - 4a. What mix of funding does the organization receive?

II. Structure of the Board

5. What is the role on the board?
 - 5a. (Governance, fund raising, professional advisory, "hands on" volunteer?)
6. How often does the board meet?
7. How active is the Board in policy making?
8. What mix of funding does your agency receive?
9. What committees does the board have?
10. How active are they?

III. Your Role on the Board

11. What is your role on the Board? (Officer, committee member?)
12. What drew you to the organization?
13. How long have you served on the board?
14. Why did you decide to serve on the board?

IV. Health Care Needs

15. What are the unmet health needs in the community in your opinion?
16. In your opinion, how could these be met?

17. Who should be responsible for seeing that these needs are met?

V. Health Care Rights

18. Who should have a right to health care in the U.S.? Why?

19. Who deserves to receive health care in the U.S.? Why?

20. Are there people who you think deserve health care but do not have a right to health care in the U.S.? If so, who?

21. Who should pay for health care in the U.S.? (employers, individuals, government, combination?)

VI. Assessment of the current situation facing the Board and the Organization

22. How has the organization changed over time?

23. What are the current challenges facing the organization?

24. What are the successes?

25. Where do you see the organization going in the next five years? in the next 10 years?

Is there anything else you would like to add?

APPENDIX FOUR

Original Spanish Text of Participants' Quotes

Chapter Four

Quote from Juana

Pg. 75, Being diagnosed with diabetes and it's impact on her life trajectory:

Yo trabajaba en un Banco...Yo trabajaba en Méjico en un banco. Trabajé 17 años. Yo nada más terminé la secundaria y entre a trabajar. Ha, y como dos años de-para secretaria. Antes con la secundaria podías trabajar. Y ahora ya no. Ya no lo aceptan...Entonces me liquidaron porque querían de más estudios y yo no tenía estudios. Y yo iba a meter en otro banco y allí me hicieron muchos estudios y salí con diabetes. Entonces ya no me aceptaron porque estaba yo con diabetes. Y Usted sabe que allá en Méjico aunque uno está joven-yo no estaba tan joven. Yo tenía más de 40 años. Ya no me aceptaron. Ya no me aceptaron para trabajar. Por eso yo vine para acá. Yo soy mamá soltera. Yo tengo una niña de 26 años. A mi hija la dejé de 16 años. Yo vine porque yo necesitaba dar estudios a mi hija. Ella ya terminó. Ella es licenciada en pedagogía.

Quote from Lucha

Pg. 76, Lucha's struggle to support her daughters:

...Yo tengo dos hijas que todavía estoy atendiendo que no viven acá. Tengo dos hijas. Yo tenía tres pero mi varoncito se murió hace poco, a los 27 años...El estaba estudiando [en Peru] y se graduó y trabajo seis meses y bueno entonces yo todavía no podía traerlo acá. Entonces él me venía a ver de vez en cuando y murió en un accidente...Entonces me han quedado dos niñas. Una en Buenos Aires está estudiando medicina, le falta dos años y la otra está en Bilbao haciendo una maestría también. Entonces la situación es bien difícil allá porque no tiene empleo. En España no hay empleo. No hay empleo entonces yo tengo que ayudar todavía a mí hija...también la coas en Argentina está bien fea. Entonces todavía estoy ayudando a mis dos hijas...Entonces lo que gano no es para mí acá. Es como tuviera dos casas...La realidad económica es muy dura

Quotes from Juana

Pg. 76, How Malta House saved her life:

Yo estaba muy mala con el tiroide. Me enflaque demasiado que ya pensaban que yo ya iba morir...Yo estuve muy flaca, flaca, flaca, pero que ya mero decía "muerte no venga hoy, ven mañana...Aquí, aquí me lo detectaron...Cuando estaba yo muy flaca, flaca que no sabían lo que tenía yo hay una doctora aquí que es muy buena. Gracias a esa doctora yo estoy viva. Ellos hicieron infinidad de estudios. Me hicieron muchísimos estudios. La doctora que estoy esperando. Ella es mi doctora., yo no sé, como veinte yo creo de sangre para que vinieron a detectar que era las tiroides de que yo estaba enferma...estoy tan lejos de mi país y de la familia...porque mire porque a veces, a veces ni con dinero! Es que es tan caro aquí el medicamento. Y no te pueden vender la medicina sin receta médica. Ese es el problema.

Pg. 77, How Juana gets her medications:

Yo pago, yo pago. Yo los compro. Yo compro. Por ejemplo esa de—me cuesta barato. Me cuesta como para un mes me cuesta—antes, antes compraba yo para un mes seis dólares, seis dólares para cada medicamento. Pero últimamente le digo que me la den para tres meses para que sea un poquito—un poquito más—este-ya me cobran como veinte y cuatro, veinte y ocho, veinte, así más o menos para tres meses.

Pg. 77, Malta House pays for her insulin and test strips:

Lo que no puedo comprar y lo que es demasiado caro es la insulina. Ellos me lo dan. Ellos me regalan la insulina. Nunca he comprado la insulina. Ellos me lo dan porque me sale como ciento cincuenta y ocho para Lantus y es para un mes.

Quote from Carmen

Pgs. 78-79, Struggle to pay for food and rent:

Ahora no estoy trabajando. Pero voy-estoy preparando un os tamalitos para vender para tener para mi semana para mi comida y para juntar algo para pagar la renta...Yo rento un cuarto. Yo le conversó con el dueño. Por ejemplo ahora estoy pagando atrasado. Voy a pagar atrasado porque me toca pagar el primero pero ya hace bastante días.

Quotes from Juana

Pgs. 79-80, How she came to the United States:

Yo me vine de mojada. Yo vine caminando. Yo me vine hace diez años. Pasé la frontera. Yo me vine por Arizona. Nos venimos de mi pueblo al D.F. doce horas de camino de Oaxaca al D.F. En el D.F. tomamos un avión a—em, como se llama ese pueblo, ese ciudad. Hay, como se llama. No es Guadalajara. ¡Hay! No me acuerdo como se llama. No me acuerdo como se llama. Bueno. Llegamos. Y de allí tomamos una combi. Como una combi que nos pasó a—cerca de donde colindaba Estados Unidos con Méjico. Pero yo no sentí. Como fue de noche la caminata que me dí, yo no pasé mar. Yo no pasé río. Que dicen que pasa río. Pero fue por Arizona por donde nos hicieron pasar.

Pg. 80, Walking across the U.S.-Mexico border:

Entonces de allí, había un, hay una canción, no sé cómo se llama. Llegamos allí. Hermosillo. En Hermosillo esperamos en el avión. Hermosillo, Sonora. En Hermosillo, Sonora llegamos en el avión. Entonces de allí nos desplazaron como-porque éramos come unos 30 que venían para acá. Nosotros usamos Coyotes. Entonces de allí me dijeron que como seis horas íbamos caminar. Hay doñita, ¡caminamos más de las seis horas! ...Yo traía una maleta, que yo tire todo. Traía una biblia con fotos de mi hija. Traía yo una bolsa que donde traía medicinas, como soy diabética yo traía medicamentos, traía yo. En mi maleta traía yo batas, traía yo pantalones nuevecitos, traía yo blusas nuevas. Pero yo no sabía. Yo traía dos pantalones puestos, uno de mezclilla y otro de trabajo. Y traía yo un chamarrita y me blusa porque yo no pensé que iba hacer tanto frio.

Pg. 80, Juana's journey from her home to Mexico City and to northern Mexico:

Nosotros salimos del D.F., salimos como, no sé, como las ocho de la noche, algo así. En avión, en avión. Y de avión ya llegamos allí a donde le digo, Hermosillo, Sonora y de allí ya nos, con una van, unos carros, yo no me acuerdo. Yo sé que pasamos así. Hay Dios Mío! Y allí yo—yo traía dinero. Le digo que yo—yo—yo traía mi identificación, traía mi-mi licencia —traía yo la licencia de chofer, traía mi licencia de chofer. Traía una carterita que me regaló mi cuñada y traía mi bolsa con todos medicamentos. Pero como ya yo no podía caminar doña. Me dijeron que seis horas. Con seis horas pues podía yo. ...salimos desde las seis. La migra nos vino agarrar como a las—como a la una de la tarde—sin tomar agua, sin comer. A mí me agarró la migra. Yo traía yo unos tenis nuevos, nuevecitos...Las plantas de mis pies le entró como tierrita, como arenita. Era de noche, era muy noche. No veía nada. Yo venía entre los nopales.

Pgs. 80-81, Pain she suffered crossing the border:

Si Usted veía mis piernas come estaban llena, llena de aguante y de espinas. Yo

sufrió para entrar a éste país. Yo sufrí. ...las plantas de mis pies se me hicieron— como le puedo decir, como que se me escaldaron. Como que la carne roja, roja se me veía. Yo ya no podía caminar... Yo le dije al-a ese muchacho que venía allí-tres [Coyotes] se fueron con unos que caminaban bien, que no tenían problema y tres personas se quedaron con nosotros. Tres coyotes se quedaron con nosotros-los que no podían caminar. Hay doñita! Yo con los tenis que ya estaba sangrando mis pies. Yo ya no sabía. Yo ya le dije “[d]éjenme aquí, déjenme que me come el coyote. Ya no aguanto! Ya no aguanto! A mí me dijeron seis horas.” ¿Como van hacer caminar tanto? Y como venía un helicóptero—tra-tra-tra—, y, este, escondíamos dentro todo ese-lleño de espina, de aguate. No sé qué había allí. Estaba oscuro, oscuro.

Pg. 81, Coming during the winter

El mes de enero me vine yo y hacía frío—a fines de enero. Estaba yo en el hospital. En Arizona allí me agarraron. Se condolieron de mí. Porque yo le entregué—yo traía mil dólares, traía como dos mil dólares. No. Traía yo como mil quinientos dólares o mil dólares—algo así. Porque yo—yo fui tonta que no hice mis papeles cuando yo estaba trabajando en el banco. Cuando vi que era demasiado, muy, muy duro pues yo dije “[n]o, mejor voy a los Estados Unidos. Me voy de mojada.” ¿Porque? Para que estudie mi hija. Porque si no, no va a ser nada en la vida. Entonces me vine. Pero dije yo a ella. “Tienes que estudiar. Me vas a prometer.” “Sí mamá te voy te a prometer.” “Ok. Me voy a ir pero para que estudies no nada más para que te hagas tonta. Para que hagas algo, algo.” Entonces eso sí fue bueno, eh. Porque sí respondió.

Pg. 81, Juana caught by border agents:

Entonces yo llegue al hospital y allí me atendieron. Pero mire, yo le dije todo. Le dije “[m]ire yo soy—yo soy diabética. Ya me operé.” ...todo, todo se lo dije a ellos. Cuando vieron que está yo tan mal—yo venía con no sé cuánto de azúcar venia yo, y este, y me pusieron suero. Venía yo bien desnutrido. Pero allí, allí los de—los de—cuando nos agarró la migra nos-nos puso...a mí no me puso allí con todos los que venían atrás. A mí me-me “[m]ire”, le dije, “yo soy fulana de tal...nacé tal día. Aquí está mi identificación. Aquí está mi cartera. Ésta es el dinero que traigo. Yo traigo mil quinientos dólares. Traigo ocho cientos pesos mexicanos. “¿Y qué va hacer?” Le dije yo “Voy a ir a trabajar. Yo—yo estoy pasando porque quiero dar estudios a mi hija.” Entonces me dijeron los del—los—los—los que me agarraron. Los de la migración. “Pues Usted está muy mal.” Me cargaron. Me tuvieron que cagar porque ya no podía caminar.

Pg. 82, Her admission to the hospital:

[Los de la migra me dijeron] Señora Usted no puede caminar ya.” “No,” le dije, “ya están sangrando mis pies.” Entonces me saqué los tenis y yo venía sin nada para que ventilaran ¿no? Porque estaba llenos de sangre. Yo nada mas así andaba yo caminando aun así pero cuando ellos vieron que ya no podía yo me subieron al—al—al mismo carro eso donde—donde traían a toda la gente, bajaron a todos, a todos chequearon, a todos le pusieron a huella. A mí no. Porque yo venía muy mal. Entonces hicieron—hicieron—como le puedo decir, buscaron al cónsul de México. Yo estuve tres noches y dos días en el hospital. Y me dieron chance que yo estuviera-los de inmigración-los de-los de, este, no de inmigración, los de, este, sí es de inmigración. Me dieron 25 días hábiles para que yo estuviera en cualquier lugar en los Estados Unidos para que me—para que yo sanara.

Quotes from Milagros

Pgs. 82-83, Wages better in the United States:

Yo cuando me vine yo tenía en la Maquiladora en México pero me vine para acá. Fue mucho mejor porque es un cambio mejor. Si hubiera sido igual o peor pues vamos para México. Pero fue mejor. Siempre trabajaba, tenía mis tres trabajos.

Pg. 83, Change in political situation in Arizona:

Las cosas cambiaron mucho y...con las leyes que están allá pues con Joe Arpaio la gente son como hostigados. Ahorita está muy hostigado. Bueno desde que yo estaba allá que estaba John McCain-todavía estaba allá. La Janet Napolitano, la Secretaria Nacional de Seguridad era gobernadora de allá. Ellos tres, Joe Arpaio, John McCain y esa señora empezaron...haciendo enredadas. Y hace muchos años de eso. Años atrás pero nunca se nunca estaba tanto como ahora. No era así acoso. No era ese acoso. No era.

Pg. 83, How Milagros avoided immigration raids:

Había tiendas abierto 24 horas. Yo podía viajar a Las Vegas, a Los Ángeles, adonde me diera la gana. Podíamos viajar. Agarramos vuelo. Era diferente. Muy, muy diferente...cuando yo vine, un año antes de yo venirme en mi trabajo empezaron a caer muchas redadas, redadas, redadas...En el restaurante [donde yo trabajaba] habían muchas-varias redadas hasta que yo dije que “no, bueno, si me llegan a agarrar, la niña, yo no tengo más familia, ¿donde va quedar?” Incluso cuando yo llegue a mí trabajo-es una plaza-era una plaza de varias tiendas-la restuaran, yo mire la migración estaba de lado de donde nosotros

parqueábamos, de lado de frente. ...Y lo que yo hice fue alrededor y regresé.

Quotes from Juana

Pg. 84, Her opinion on who has a right to health care:

A los ciudadanos. Los ciudadanos. Los-los que son ciudadanos tienen derecho. Nosotros como indocumentados. Pues no tenemos—yo—yo lo reconozco que yo no tengo derecho porque yo—yo—yo no soy de aquí. Pero fíjese que aquí le dan mucho. Mucho más de lo que uno espera. Porque si no hubiera encontrado éste centro—éste centro médico, éste Casa Malta para la gente pobre—ésto es para gente que no-no tiene seguro médico y no tiene—porque uno viene acá porque no tiene los recursos. Porque si no yo voy a un médico y pago mi-mi doctor pero cuánto no me cuesta. Es mucho dinero. Lo poquito que uno gana para mandárselo a la familia se lo gasta uno en el doctor. Y—y yo estoy de acuerdo—yo estoy de acuerdo que el ciudadano tenga—tenga su seguro, tenga sus—sus beneficios. Nosotros, gracias-gracias a gente caritativa, que hay mucha gente buena este país que nosotros venimos a este lugar y nos atiende.

Pg. 86, Juana's opinion regarding who deserves health care:

Todos. Todos merecen. Todos merecemos recibir atención médica porque somos humanos. Si un perro—un perro—vea como corre los—un perro, un gato, como van corriendo los—los—los bomberos a salvar ese animal. ¿Ahora uno que es humano? ¡Imagínese!

Pg. 86, Her thoughts on who should pay for health care:

Tiene que pagar los dos [las empresas y el gobierno]...porque mire yo digo, ¿no? Que si es la empresa tiene que tener un—una cuota fija para el gobierno para que vayan sus-sus-sus, este, sus empleados al-al Seguro. Yo digo que es el gobier—que tiene que estar mutuamente los dos, el gobierno y las empresas. Sí porque—porque el gobierno también sin la cuota de la empresa no es nada. Tienen que dar-tienen que dar—los dos. Los dos tienen que dar de si.

Quote from Gloria

Pgs. 88-89, Right to health care and deservingness:

Todo persona que trabaja ¿no? y colaboran también [tienen derecho a salud médica] para que ahora y con el tiempo pues, este, le pueden atender o al mismo momento porque también si no ¿cómo? Por ejemplo la persona que

trabaja da, le quita, ¿no es cierto? de su sueldo cierta cantidad y hasta ayuda. Aunque también hay gente muy demasiada, demasiada pobre que porque no tienen que también debe ser ayudada, ¿no? Como los animalitos que veo allí en la televisión que les dan bastante ayuda a los animales entonces si se ayudan a un animal como no van ha ayudar una persona? Todos merecemos pero hay diferentes categorías, ¿no? Hay gente que tiene que si sola se puede hacer ver. Pero hay gente que trabaja que debe ser vista, ¿no? o al menos porque ya están descontando su sueldo. Están ayudando y entonces es una forma que ellos están colaborando para que se vea su salud después o en el momento.

Quotes from Lucha

Pg. 90, Fear of health issues and aging:

...por la edad que tengo pienso yo ya las cosas se vienen presentando ¿no? Los problemas de salud se vienen ya manifestando ¿no? Y me preocupa más adelante. ..Presión de la edad se va a ir dando cosas... Suponiendo que necesito una intervención cirugica que acá es mundo de dinero. Me pregunto, este, “en que deuda voy a estar yo para hacer eso ¿no?” ... digo yo “La cuenta que- me-me va a enfermar ya de otra cosa (laughter).

Pg. 91, Unable to go home to bury her son:

...no podía ir a enterar a mí hijo.

Pg. 92, Grateful to priest who helped deal with son's death:

Los padres me han ayudado mucho. Conversando con ellos. Tengo un padre muy querido y que me comprende y ellos me han vivido conmigo esta tragedia porque yo no—no podía ir a enterar a mí hijo. Yo me tuve que quedar acá. Entonces fue un domingo. Entonces solo con el cariño que ellos me tienen y que tengo otros amigos también muy cercanos, este, he podido sobrellevar esto ¿no? Ha sido el cariño de los padres—decencia—eso para mí fue muy importante. Yo no sé cómo hubiera sido de otra manera. Por eso digo ésta es mi casa.

Quote from Milagros

Pg. 92, Church paid for her dental surgery:

...cuando me hicieron cirugía de mi boca...eso fue en el Saint Francis...pero allí me mando la iglesia...pago la iglesia. La iglesia [La Iglesia de Jesús Cristo de

los Santos de los Últimos Días] pago porque ellos me mandaron allí. Creo que allí había hermanos médicos que trabajaban allí. Este no sé si son dentistas o algo así. A mí me llegó mi recibo y me dijeron que lo lleva y ellos lo pagan. Es una comunidad muy fuerte porque es mucha ayuda por la que necesita.

Quotes from Catarina

Pg. 93, Low wages at home care agency:

Tienen uniformes, diferentes uniformes, pantalones, o-tienes que cocinar para ellos, bañarlos, hacerlos comida, llevarlos a compras, todo eso. ¿Cuanto pagan? Ocho dólares y cincuenta centavos y nueve dólares y cincuenta centavos [si] tienes que limpiar la casa. No hay vacaciones. No pagan vacaciones, no pagan por las millas que usas...Yo estaba trabajando para ellos y el gobierno les paga \$17.50...No pagan por su gasolina, no pagan nada.

Pg. 94, Cause of her illness:

Bueno, yo siempre estaba sana. Debe ser, para mí, que me quede sin trabajo, la tensión, la tensión porque siempre trabajaba. Yo creo que eso porque antes nunca tenía problemas.

Pgs. 94-95, Feelings of worthlessness:

Mi dentista ya no me atiende, mi ginecólogo no me atiende si no tengo seguro médico. No me cogen si voy así, este, como se dice, si voy así como personas que no tiene seguro médico, no. El dentista, y eso que tiene años conmigo, años, y no me ha querido coger y eso que—yo le dije “aunque sea para que me limpie” y como se llama, este, “yo le pago. No coge sin seguro médico.” Un hombre que yo le he dado, como se—iba anualmente o cada seis meses para que me limpie esto. No me cogen. Ni el ginecólogo, ni el dentista. O sea si no tengo seguro no soy nadie. Y si yo voy aplicar al estado como ven que tengo casa tampoco cualifico. O sea hubiera quedado pagando renta todo el tiempo. Y esto es poco como si fuera renta. Pago setecientos dólares. Este es una re--es lo mismo que pagaría cualquier persona una renta. Y si tú ves no es una mansión, es algo chiquito. Así que sí me siento mal por no tener seguro médico. No valgo para los doctores. Sin seguro médico no valgo. Los dos me han hecho sentir lo mismo.

Pg. 95, People working, yet going to Malta House:

Yo me siento a veces un poco mal estar en Malta House porque yo digo, em,

porque hay gente que—yo veo gente que—ahí vi la otra vez como tres, cuatro personas que trabajan. Tienen un buen trabajo pero sin seguro médico y yo digo “Wow. Deje para la gente que no trabaja, que no tiene dinero, que están mal. Porque yo de verdad si yo—yo—yo estuviera trabajando yo no voy a Malta House. Porque eso es para los que necesitan de verdad. Ahí veía—ayer vi a un señor que tenía uniforme de security. Hay otros que son de bus escolares que cobran veinte dólares la hora y tienen sección ocho. Créeme que yo digo...todos trabajan pero no tienen seguro médico pero reciben dinero.

Pg. 95, Doing a payment plan:

...hay veces que tú puedes hacer plan de pago. Yo he hecho plan de pago.

Pg. 95, Feelings about going to Malta House:

De verdad me da una vergüenza. Por eso a veces pido pastillas para seis meses. ¿Por qué? Porque yo digo “no voy cada tres meses.

Quote from Lucha

Pg. 96, Commenting on her class status:

Lamentablemente las personas que yo he visto que venimos—que nos vamos quedando—las que veníamos—en mi caso, que yo vine con una visa—pero la perdí porque me quede acá—somos una minoría. La mayoría son los que vienen por México, y—y entonces, muy a mi pesar, pero esa gran mayoría que vienen por allá, sus conocimientos son mínimos. Y muchos que vienen de Centro América ni si quiera saben leer, no saben firmar, muy escaso conocimiento de escuela. Y es triste. Mucha gente joven. Mucha gente joven. Trataba yo siempre de buscar un trabajo que me permitía salir de esa masa donde ponían a todos.

Quotes from Catarina

Pg. 97, Seeing Gringos at Malta House:

Antes yo no veía Gringos [en Malta House]. Ahora veo gringos.

Pg. 97, Being harassed by collection agency:

Tengo un bill que no he pagado pero me quieren cobrar con intereses y yo le estaba pagando cincuenta, cincuenta. Y no. Me siguen llamando. Me siguen

mandando papeles y me siguen llamando por mil—mil, cincuenta creo que es. Pero me lo quieren su—me han subido como a dos mil. Y yo le digo yo te puedo pagar cincuenta, cincuenta todos los meses pero no me cobre los intereses porque no-no te voy a pagar los intereses. No es algo que yo me lo comí...Es un examen médico...Te digo me deprime eso porque yo estoy acostumbrado-como te dije antes yo no tengo deudas. Te lo juro que no tengo deudas. Estoy al día en el teléfono, al día en el cable, al día—es más corte un poco de cable y—y estoy viendo esto, que lo corto más porque desgraciadamente hay que, cómo se llama, e, reducir gastos. Pero cómo se dice esa gente me llama cada rato. Me tiene loca.

Pg. 97, Living from paycheck to paycheck:

...Yo no sabía que era vivir cheque a cheque. Nunca he sabido vivir. Ahora me toca vivir mirando “¿Hay dinero? ¿No voy a comprar, se lo compro?” Tengo que medir. Y yo nunca estaba acostumbrado a eso. Yo nunca jamás pensé estar así. Yo no quiero ni llamar a mi país para-porque antes yo siempre les mandaba, les llevaba. Ahora ni yo me puedo comprar así que tengo que—no puedo—no puedo ser—como se dice yo tengo que ayudarme yo. No—no—no—no asegura nada.

Pgs. 97-98, Catarina’s critique re: information on the Affordable Care Act:

...eso de Obama no—no—no he escuchado ningún—escúchame hasta ahora no sé cuál es—cuáles son los beneficios del plan Obama, cuál es el Obama plan, no me lo comunique, no lo sé. Creme que yo iría a todas las casas porque yo sería una buena comunicadora. Tocaría todas las puertas y decir esto es lo que ofrece Obama, esto es lo que no le conviene. A mí nadie me ha explicado ni me llaman. Eso le falta. Te digo una cosa, le falta explicar. Todo el mundo dice “Sabe que es el Obama plan?” “No sé. No entiendo, no sé.” En verdad para me no hay información.

Pg. 98, Her thoughts on right to health care:

Todo el mundo porque todos somos seres humanos y todos-nadie busca la enfermedad. La enfermedad viene y cuando uno menos lo espera y uno, como se dice, si uno tuviera, como se dice, una varita mágica para quitar las enfermedades que bueno sería. Pero nadie ésta queriendo enfermarse. No conozco alguien que quiere enfermarse. Y yo creo que todo el mundo debería-legal, ilegal, ciudadano, no ciudadano, rico, pobre, todos deberíamos tener el servicio médico.

Pg. 98, Her thoughts on who deserved health care:

Todos. Especial-yo pienso que especialmente la gente que trabajó años aquí porque hay gente que también viene y reciben todo fácil y...por ejemplo tengo un amigo que ha trabajado más de diecisiete años en el capitolio y está con órdenes de deportación y se ha enfermado. Le ha dado dos paros cardíacos, le ha dado cáncer, le ha dado como cinco, seis enfermedades y ya está para jubilarse pero que pasa? Como no es residente no le corresponde. Y él merece que lo den porque ha trabajado para este país. Merece que le den el .servicio médico. ¿Por qué? Porque ha trabajado duro. Ha limpiado el mármol. Ha limpiado las oficinas de todos los congresistas.

Pg. 98, Even if people cannot find work they should at least volunteer:

Porque hay gente que—conozco dos muchachitas que...ya les dieron disability y hablan un inglés perfecto que pudieran trabajar traduciendo, llevando papeles en un oficina, un servicio voluntario, algo para que ganen su medicina pero paran en doctor a doctor y yo no creo que sea-que están enferma. Si no lo hace para la comodidad de estar en su casa, viendo televisión y no hacer nada y reciben un cheque e ir al doctor como sin nada. Eso es lo que veo.

Quote from Maria

Pgs. 99, Those who do not deserve health care in the United States:

Si yo soy nacido aquí yo voy y solicito al estado. Hay gente-yo lo se que aquí uno y otra persona que no tiene esa ayuda médica. Ese es el buró médico. ..yo le digo a Usted...porque nosotros caminando para ir al centro médico allí afuera hay una iglesia donde es un shelter y va la gente y Usted ve gente americanos, puertorriqueños, gordos, rozagantes y todo plena de las tres de la tarde esperando que les abren el centro para entrarse a dormir ya. Gente que no produce nada que son de este país. Tienen sus papeles, pueden-pueden aprovechar todos los beneficios y todo y no. Para mí ese gente no... merecen nada. Pero sin embargo tienen de más. Porque yo le digo—yo le digo—este país por tanta ayuda daña a la gente.

Quote from Milagros

Pg. 99, Those who do not deserve health care in the United States:

...hay muchas personas que no trabajan por no trabajar. Hay muchas personas que le den ayuda por pedir para estar en las drogas, para irse a los casinos, para irse a gastar...O muchas personas que tienen sus papeles que

definitivamente les gusta vivir del gobierno. Esa gente sí la deberían de investigar y no darles ayuda. Que lo mandan a trabajar. Merece la gente que deberás están produciendo y que deberás quieren salir adelante. La gente que no quieren salir adelante y les están ayudando-esos son los que más ayudan. Pero o sea, en general derecho, todos tenemos derecho [a salud médica]...[n]osotros que vivimos aquí. Seamos o no seamos legales... Porque es una razón humanitaria.

Quote from Lucha

Pgs. 99, Right to health care and deservingness:

El derecho viene después de hacer algo. Siempre estoy hablando de gente productiva. Tenemos derecho siempre y cuando aportemos. Merecer...eso es más complejo para mí. El ser humano merece por el hecho mismo de ser humano. Todos, blanco, negro, amarillo, rico, pobre, todos merecen. Pero el derecho se adquiere por algo que se va haciendo.

Quotes from Catarina

Pgs. 99-100, Those who do not deserve health care in the United States:

Yo te dije que toda persona que está enferma debe—debería tener. Pero hay gente que no está enferma, que no necesita que debería y que tienen. Conozco gente que no tienen nada y tienen un seguro médico y reciben y reciben. Yo digo y dicen que investigan pero no investigan nada porque tienen de todo. Las uñas están hecho porque una amiga ha venido y me le ha hecho que está—que se ha quedado como se ha venido de—de otro estado y se ha practicado porque sabe—pero no es que estoy gastando en uñas porque ahora no me da para las uñas. Pero hay gente que tiene sortijas, mejores celulares, mejor carro, mejor todo y reciben ayuda del gobierno y tienen médico. Tienen buenos lentes—esto es de Malta House, lentes de Malta House que saque los lentes allí también. Pero tienen Dolce y Gabbana, tienen de marca, tienen como—yo pensaría que trabaja—que han trabajado duro para tenerlo y no. Solamente el gobierno el da todo. Le dan la máquina. Yo no tengo máquina para medirme la sangre. Ellos—yo conozco uno que tiene tres, cuatro máquinas y he visto en la farmacia que las máquinas \$280, \$350, la más barata \$150 que yo no la puedo comprar ahorita. Que me encantaría pero no la puedo comprar. ¿Qué puedo hacer?

Pgs. 100-101, Obama and job loss:

Perdóname pero lo que Obama ha hecho es perder mi trabajo.

Pg. 101, Why Catarina came to the United States:

Vine a trabajar, nada más.

Quote from José

Pg. 117, Reluctance in taking pills, and preference for acupuncture:

Yo tengo que forzarme. Tengo que forzarme...Me gusta ser libre, ser independiente, sin nada, sin nada de pastillas, sin nada de pastillas. Pero como tengo que sobrevivir en el sentido de la comida tengo que comer y a la hora de comer es como si volviese de nuevo que tengo presión alta. Hasta que no haga un ejercicio que queme calorías, un ejercicio fuerte voy a seguir preocupado. Hasta ahorita estoy preocupado porque me gusta hacer ejercicio donde sudo mucho, mucho para botar esa comida y hasta que encuentro un ejercicio donde puedo hacer eso—yo hago ejercicio en el verano—camino, ando en mi bicicleta—pero no me hace sudar, no es ejercicio fuerte.

Yo estaba llendo a un acupunturista Coreano pero no quería que yo le digo nada y no me gustó pero quiero encontrar otro acupunturista que no es muy caro porque mi presupuesto es limitado.

Quote from Gabriel

Pg. 117, Use of Naturopathic doctor:

Cuando me chequearon no encontraron nada pero estaba perdiendo peso. Perdí 30 kilos en un mes y medio y estuve hospitalizado por tres meses y casi un año y miedo en ambulatorio. En algún momento estaba tomando 24 píldoras al día y entonces tuvieron que hacer un lavado de todo el organismo, del estomago. Pero finalmente descubrieron que era el problema. Y de suerte hice un tratamiento con un médico naturista. El me estabilizo y fue que me quito las pastillas y solamente que me controla con una dieta estricta y con ejercicio porque yo generalmente subo muy rápido de peso porque soy muy tragón

Original Spanish Lyrics to Clandestino, written by Manu Chao in 1998

Pg. 159

Solo voy con mi pena	Pa una ciudad del norte	Argelino clandestino
Sola va mi condena	Yo me fui a trabajar	Nigeriano clandestino
Correr es mi destino	Mi vida la dejé	Boliviano clandestino
Para burlar la ley	Entre Ceuta y Gibraltar	Mano Negra ilegal
Perdido en el corazón	Soy una raya en el mar	
De la grande Babylon	Fantasma en la ciudad	
Me dicen el clandestino	Mi vida va prohibida	
Por no llevar papel	dice la autoridad	

APPENDIX FIVE

Medications and Illnesses Mentioned in Dissertation

Medications Mentioned in Dissertation

Cyclobenzaprine

Cyclobenzaprine is used to help relax certain muscles in your body. It helps relieve the pain, stiffness, and discomfort caused by strains, sprains, or injuries to your muscles. However, this medicine does not take the place of rest, exercise or physical therapy, or other treatment that your doctor may recommend for your medical problem. Cyclobenzaprine acts on the central nervous system (CNS) to produce its muscle relaxant effects. Its actions on the CNS may also cause some of this medicine's side effects...Cyclobenzaprine may also be used for other conditions as determined by a physician..."Although this use is not included in product labeling, cyclobenzaprine is used in certain patients with fibromyalgia syndrome (also called fibrositis or fibrositis syndrome)" (Mayo Clinic 2015). <http://www.mayoclinic.org/drugs-supplements/cyclobenzaprine-oral-route/description/drg-20063236>

Glipizide

Glipizide is used to treat high blood sugar levels caused by type 2 diabetes. It is an oral medication, that is, it is taken by mouth, unlike insulin, which can only be taken by injection (Mayo Clinic 2015). <http://www.mayoclinic.org/drugs-supplements/glipizide-oral-route/description/drg-20072046>

Glyburide

“Glyburide, is used to treat...type 2 diabetes...Glyburide...causes your pancreas to release more insulin into the blood stream” (Mayo Clinic 2015). Like Glipizide it is taken by mouth. <http://www.mayoclinic.org/drugs-supplements/glyburide-oral-route/description/drg-20072094>

Hydrochlorthiazide

“Hydrochlorothiazide is used alone or together with other medicines to treat high blood pressure (hypertension)...Hydrochlorothiazide is also used to treat fluid retention (edema) that is caused by congestive heart failure, severe liver disease (cirrhosis), kidney disease, or treatment with a steroid or hormone medicine. Hydrochlorothiazide is a thiazide diuretic (water pill). It is used to help reduce the amount of water in the body by increasing the flow of urine. It may also be used for other conditions as determined by your doctor” (Mayo Clinic 2015). <http://www.mayoclinic.org/drugs-supplements/hydrochlorothiazide-oral-route/description/drg-20071841>

Insulin

“Insulin is a naturally-occurring hormone secreted by the pancreas. Insulin is required by the cells of the body in order for them to remove and use glucose from the blood. Cells use glucose to produce energy [needed] to carry out their” functions (Ogbru et al. 2015). <http://www.medicinenet.com/insulin/article.htm>

Lisinopril

“Lisinopril is used...to treat high blood pressure (hypertension)...It works by blocking a substance in the body that causes the blood vessels to tighten. As a result, lisinopril relaxes the blood vessels. This lowers blood pressure and increases the supply of blood and oxygen to the heart” (Mayo Clinic 2015).

<http://www.mayoclinic.org/drugs-supplements/lisinopril-oral-route/description/drg-20069129>

Levothyroxine

“Levothyroxine is used to treat an underactive thyroid (hypothyroidism). It replaces or provides more thyroid hormone, which is normally produced by the thyroid gland” (WebMD n.d.). <http://www.webmd.com/drugs/2/drug-1433/levothyroxine-oral/details>

Metformin

Metformin is used to treat high blood sugar levels that are caused by...type 2 diabetes...Using metformin alone, [or with other antidiabetic medications] will help to lower blood sugar when it is too high and help restore the way you use food to make energy...To work properly, the amount of metformin..must be balanced against the amount and type of food [one] and the amount of exercise [one does]. (Mayo Clinic 2015). <http://www.mayoclinic.org/drugs-supplements/metformin-oral-route/description/drg-20067074>

Statins

Common statin drugs include atorvastatin (Lipitor), simvastatin (Zocor), lovastatin (Mevacor), pravastatin (Pravachol), rosuvastatin (Crestor)(Mayo Clinic Staff 2014:1).

<http://www.mayoclinic.org/diseases-conditions/high-blood-cholesterol/in-depth/cholesterol-medications/art-20050958>

According to WebMD "Statin drugs work by blocking the action of the liver enzyme that is responsible for producing cholesterol (WebMD 2014).

<http://www.webmd.com/cholesterol-management/side-effects-of-statin-drugs?page=1>

Illnesses Mentioned in Dissertation

Cubital Tunnel Syndrome

"Cubital tunnel syndrome -- also known as ulnar neuropathy -- is caused by increased pressure on the ulnar nerve, which passes close to the skin's surface in the area of the elbow commonly known as the "funny bone" (WebMD 2014).

<http://www.webmd.com/pain-management/cubital-radial-tunnel-syndrome>

Hypercholesterolemia (High Cholesterol)

Cholesterol is a type of fat (lipid) in the blood. If there is too much cholesterol it begins to build up in the arteries (blood vessels that carry blood away from the heart), causing a hardening of the arteries, atherosclerosis. This can narrow the arteries and make it more difficult for blood to flow through them. The buildup can also lead to dangerous blood clots and inflammation that can cause heart attacks and strokes. The two types of cholesterol are: LDL (Low Density Lipid) is the "bad" cholesterol. It's the

kind that can raise your risk of heart disease, heart attack, and stroke; and HDL (High Density Lipid) is the "good" cholesterol. It's the kind that is linked to a lower risk of heart disease, heart attack, and stroke (WebMD 2014). <http://www.webmd.com/cholesterol-management/tc/high-cholesterol-overview>

Hypertension (High Blood Pressure)

High blood pressure is a common condition in which the force of the blood against your artery walls is considered high by one's health professional. "Blood pressure is determined both by the amount of blood your heart pumps [systolic] and the amount of resistance to blood flow in your arteries [diastolic]. The more blood your heart pumps and the narrower your arteries, the higher your blood pressure" (Mayo Clinic Staff 2015). <http://www.mayoclinic.org/diseases-conditions/high-blood-pressure/basics/definition/con-20019580>

Hypothyroidism

Hypothyroidism means your thyroid is not making enough thyroid hormone. "The thyroid is a butterfly-shaped gland in the front of your neck. It makes hormones that control the way your body uses energy...Having a low level of thyroid hormone affects your whole body" (WebMD 2014).

<http://www.webmd.com/women/tc/hypothyroidism-topic-overview>

Impaired Glucose Tolerance (IGT) (pre-diabetes, aka borderline diabetes)

IGT is when one's fasting blood sugar is between 100-125 (WebMD 2014).

<http://www.webmd.com/diabetes/guide/what-is-prediabetes-or-borderline-diabetes>

Osteoarthritis

Osteoarthritis, the most common form of arthritis, occurs when cartilage on the ends of your bones wears down over time (Mayo Clinic Staff 2014).

<http://www.mayoclinic.org/diseases-conditions/osteoarthritis/basics/definition/con-20014749>

Type 2 Diabetes

A fasting blood sugar of 126 or higher is an indication of type 2 diabetes. “People with produce insulin however, the insulin their pancreas secretes is either not enough or is ineffective, and the body is unable to recognize the insulin and use it properly...When there isn't enough insulin or it is ineffective, sugar (glucose) can't get into the body's cells. When sugar builds up in the blood instead of going into cells, the body's cells are not able to function properly” (WebMD 2014).

People with diabetes have a reduced ability to take up and use glucose from the blood, and as a result, the glucose level in the blood rises. In type 2 diabetes, patients produce insulin, but cells throughout the body do not respond normally to the insulin. Insulin injections [are often] used in type 2 diabetes to overcome the resistance of the cells to insulin. In this way, the uptake of glucose by cells is increased, thus reducing the concentration of glucose in the blood” (WebMD 2014).

<http://www.webmd.com/diabetes/type-2-diabetes>

APPENDIX SIX

List of Home Remedies Participants Reported Using

For Colds/Flu

- Cerassee tea, made fro the cerassee plant (momordica charanta)
- Tea with honey and lime
- Honey in water
- Peppermint tea
- Ginger tea
- Chicken soup

For Cough and Respiratory ailments

- At bedtime, take *yerba santa* (holy herb), an herb grown in hot climates, put in a liter of milk and boil it, take it off the stove, boil it again, take it off the stove, and boil it a third time then place a cinnamon stick in it and drink it while it is hot. Then, go to bed with VICK's Vap-O-Rub on the neck and chest.

For sinuses

- 1 Tbsp ground milk thistle seed mixed with yogurt

High blood pressure:

- Garlic
- Lime juice
- Onion soaked in lime with a little eucalyptus

Diabetes

- Prickly Pear Cactus juice
- Eggplant

For cholesterol

- Green tea
- Prickly Pear Cactus juice
- Oatmeal water

- Liquid from grated potatoes

For arthritis

- A box of golden raisins in a bowl, and put enough gin to just cover the raisins. Let that sit for seven to ten days, put them in an airtight bottle and seal them and eat nine of them every day.

For kidney stones and kidney pain

- Pineapple, celery, 5 apples, parsley and cucumber blended together as a juice
- Tamarind juice from fresh, crushed tamarind seeds
- Freshly grated pineapple

For Digestive Problems:

- Cinnamon in juice or ground flaxseed in juice
- Chamomile Teas

As Liver tonic

- 1 Tbsp of ground milk thistle seed mixed with yogurt
- Tea made from the Canchalagua plant, [Schkuhria Pinnata] a plant native to South America]

For Psoriasis

- Tea made from the Canchalagua plant, [Schkuhria Pinnata] a plant native to South America]

For sleep

- Chamomile tea
- Lavender tea

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