

THE LEGAL AND HUMAN RIGHTS BASIS OF HIV POSITIVE UNDOCUMENTED
AFRICAN MIGRANTS' ACCESS TO HEALTHCARE SERVICES IN THE UK AND
US: A NON-GOVERNMENTAL ORGANIZATION BASED STUDY.

Thesis submitted for the degree of
Doctor of Philosophy
at the University of Leicester

by

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2011

To my beloved mother and father. May they rest in peace.

Abstract

This thesis established the relationship between actual practices, law and human rights in HIV positive undocumented African migrants' quest to gain health related services in the United Kingdom and the United States. The thesis establishes this through an examination of extant law and literature and an empirical exploration of actual practices. The empirical component of the thesis is based methodologically upon the Grounded Theory Method. Data was collected from various Non-Governmental Organizations within each of the respective countries.

The arguments and conclusions of the thesis hinge on the interaction between laws that facilitate or prevent access to health services under humanitarian grounds in the respective nations. The major theoretical concern identified in the study centers upon the moment at which the individual migrant loses their legal status. In the case of the UK, this generally occurs after the application and appeal for asylum have failed. In the US, the majority of persons experience this loss of legal status far earlier, since few Africans enter the country incident to asylum applications. The results of the thesis considerable inconsistencies in the implementation of law in the case of both countries, and establishes the governmental and non-governmental factors that influence the provision of such services. While services continue to be available in life threatening circumstances, there is currently no legally mandated point prior to this that care is mandated. Thus, the initially degradation of health in the case of people living with HIV/AIDS is inevitable.

The domestic laws of the UK and US are equivalent in that both guarantee care only in cases where life is acutely threatened. The functional aspects of the two systems are significantly different. In the case of the US, there are few programs that offer government funded care to even legal citizens, thus care for even legal migrants is difficult to obtain. The UK conversely is characterized by near universal access to general practitioners with patchy access to consultants who provide HIV related care. In the cases of both countries, there is a likelihood that an individual may receive HIV related care and later be denied care resulting in the eventual deterioration of their health.

The thesis concludes that there is need for reconsideration of the current approach to law in both the UK and US, given existing international human

rights declarations. In the context of HIV/AIDS, this is particularly profound given the chronic nature of the disease, its amenability to treatment, and the inevitability of death in cases where treatment is withheld.

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Acknowledgements

There are so many people who have contributed directly and indirectly to the culmination of this work. The ideas that form the basis of this thesis arise from my own formative years. I would first like to acknowledge my Mother, Karel L. Whyte, who taught me love and compassion for others. My father, James Whyte III contributed significantly to the ideas that formed the basis for this work. He was a career military man who taught me the importance of defending those who are unable to defend themselves. I was truly blessed to have parents whose lives were based upon the daily example of principled thought, speech and action. Finally, the support and love of my Wife Dr. Maria D. Whyte, and my sons Dylan Christian and Evan Noah Whyte were instrumental in my success.

The empirical phase of my thesis involved many non-governmental organizations in the United Kingdom and United States. The people at these agencies were extremely helpful in allotting time for my visits and offering me keen insight into their work. While I cannot name these agencies, I would like to acknowledge their assistance, and more importantly, the vital work that they do in support of migrants and people living with HIV/AIDS.

My studies at the University of Leicester were truly the highlight of my academic career. There are so many members of the faculty and staff who contributed to my work. I would like to first acknowledge my initial supervisor Dr. Sylvie Da Lomba whose guidance was instrumental in the development of the initial idea that later became this thesis. My greatest thanks, however, are focused on my co-supervisors Professor Jean McHale and Dr. Loveday Hodson. Professor McHale, now of the University of Birmingham was instrumental in pushing me to strive for excellence in refining my work. Her truly meticulous nature was instrumental to the development of this project. Dr. Loveday Hodson taught me to focus on the importance present in my work, and the true meaning of my empirical data. Dr. Hodson truly helped me to mesh the human rights and law components of this thesis. I thank you both for your hours of reading and patient approach to this process.

My final thanks are to the remaining faculty and staff of the Department of Law at the University of Leicester. I would like to make special mention of Mrs. Jane Sowler, who made me always feel like I was right there in Leicester, all year round. The staff was truly professional and welcoming. Your efforts made this a truly rewarding experience.

Thank you all.

Chapter 1 – Introduction

The research and ideas that are contained in this document were motivated by my many years of work with people living with HIV/AIDS during which I have been associated with both governmental and non-governmental organizations. The plight of undocumented African migrants living with HIV is one characterized by challenge and hardship in virtually every aspect of life. During my many years of working with this population I have observed many instances in which undocumented African migrants living with HIV/AIDS have suffered due to unmet medical and social care related needs. Additionally, I have observed interactions involving factors such as the fear of contagion, xenophobia and unrealistic public views regarding people living with HIV/AIDS that have resulted in the stigmatization and exclusion of migrants living with HIV/AIDS from various aspects of society. The joint consideration of HIV and the plight of undocumented migrants, coupled with my own life experiences offering services to, and advocating for, such people has led me to question the interaction between society, the law, healthcare agencies and this highly vulnerable group of people. The role of law, extent of observance of human rights and the degree to which national and international laws and human rights instruments are observed in practice form the core issues surrounding this work. This thesis, in essence, is the culmination of my many years of work with the migrant and HIV/AIDS affected communities. This project was undertaken with the major philosophical goal identifying, in an unbiased manner, the legal instruments and actual practices that contribute to or detract from the humane treatment of undocumented African migrants living with HIV/AIDS.

The purpose of this thesis is to examine the legal and human rights issues surrounding access to health services by undocumented migrants to the UK and the US. This will be accomplished through a thorough consideration of the international human rights conventions and regulatory regimes in the respective countries, followed by an empirical study of undocumented migrants' efforts to gain health and social services. Human rights are central to this thesis in that the existence of separate bodies of national laws and international human rights standards often present conflicting approaches to the treatment of vulnerable groups such as undocumented migrants. The major contribution of this thesis is the presentation of international human rights and domestic laws influencing healthcare access for undocumented migrants juxtaposed against subsequent verification of actual practices through empirical inquiry.

The notion of vulnerability, which is often seen in refugee and migrant populations, is one of the key concepts in any consideration of human rights in the context of the legal obligations of governments. Healthcare offers an ideal basis for the examination of human rights principles in undocumented migrants due to its prominent, but often ambiguous treatment within bodies of law, juxtaposed against the absolute necessity of healthcare services for individuals suffering life-threatening illness. Human rights standards, as delineated in common international legal instruments and the domestic laws of the UK and US, will form the basis for the analysis of the empirical data reported later in the thesis. In effect, this will result in a concise examination of the law in written form, and its application within the UK and US.

The thesis focuses on a very specific group with well-defined healthcare need and clear grounds for seeking to migrate. Having originated in the epicenter of the HIV

epidemic and widespread civil war, economic and racial strife, undocumented African migrants offer an ideal population for such a study.¹ This thesis will focus on undocumented African migrants living with HIV/AIDS due to the profound level of need present within this population from both a humanitarian and medical point of view. People living with HIV/AIDS offer a unique population for study due to the inevitability of health deterioration in cases where they are not able to obtain or sustain treatment for the disease. The study included an empirical component, which necessitated that a setting for the study be identified. Prospective settings included primarily governmental agencies, such as the NHS and various non-governmental organizations that offer service to this population. As previously described, this thesis was conceived in large part due to the author's experiences in working with migrants and persons living with HIV/AIDS. Much of this work occurred in agencies that provide services to this population, including both governmental and non-governmental agencies. In fact, a great deal of support is offered to undocumented migrants via non-governmental agencies. NGOs offer vital services to undocumented migrants, especially given the progressive difficulty associated with attempting to gain assistance from government. Due to the extensive representation of service providers within the NGO community, difficulties associated with gaining authorization to perform research in NHS facilities, and the lack of analogous government operated healthcare facilities in the US, NGOs were selected for the empirical component of the study.

¹ Crawley, H. *Chance or choice? Understanding why asylum seekers come to the UK*. (Refugee Council, 2010)

The Role of Non-Governmental Organizations in Societies

While the majority of this thesis addresses access to services that are administered by governments, non-governmental agencies serve a vital role in advocating for and addressing the needs of a variety of vulnerable population groups. As the empirical component of this thesis is implemented in a variety of NGOs, it is important to delineate the role of NGOs in the care of vulnerable populations such as that addressed in this thesis. Whether one considers the UK or US contexts, the case of undocumented African migrants living with HIV/AIDS represents a population that is faced with significant challenges. As governments address the global economic downturn, vulnerable people have progressively had to seek assistance from extra-governmental agencies. When one considers the global funding of health services for vulnerable populations, Non-Governmental Organizations (NGOs) comprise a significant proportion of the management and direct funding of health services.² Diminished governmental funding coupled with ever increasing need has resulted in annual increases in the role that NGOs play in vulnerable populations.³

A broad-array of organizations that range from secular private philanthropic groups to faith based organizations comprises the NGO community.⁴ NGOs, to a degree, serve as the hub for neoliberal policy implementation in many sectors, including the care

² McCoy, D., Chand, S., and Sridhar, D. "Global Health Funding: How much, where it comes from and where it goes." (2009) 24, *Health Policy and Planning*, 407 at p. 411

³ Ibid

⁴ Morgan, R., Green, A., and Gadsby E. *Religion and HIV/AIDS policy in faith based NGOs*. (University of Leeds, 2009)

and treatment of vulnerable populations.⁵ In fact, NGOs have increasingly served a role in constructing global social contracts through partnerships with government and various extra-governmental agencies, including international organizations such as the United Nations.⁶ In short, NGOs have grown to become significant providers of services to the needy, and serve a vital role in providing services that would not otherwise be available.

African migrants represent a unique population, especially in the context of those who are living with HIV/AIDS, and who lack legal status.⁷ Throughout the HIV pandemic, NGOs have served a variety of needs related to person's living with the disease, and those affected by it. Newly immigrated Africans tend to lack most resources, and given the lack of access to the formal health and social care system, often find themselves seeking care from NGOs.⁸ In fact, NGOs are often the sole remaining option for individuals who lack legal access to governmental services and who lack the financial means of purchasing care.⁹ Cuts in governmental services throughout the world, coupled with the profound needs of undocumented African migrants living with HIV/AIDS has resulted in progressively increased reliance on NGOs for basic social care and medical

⁵ Mercer, C. NGOs, civil society and democratization: A critical review of the literature. *Progress in Development Studies*, 2002, 2, 5-22.

⁶ Baogang, H., and Murphy, H. "Global social justice at the WTO? The role of NGOs in constructing global social contracts." (2007) 83, *International Affairs*, 707

⁷ Benotsch, E. G., Seal, D. W., Stevenson, L. Y., Sitzler, C., Kelly, J. A., Bogart, L. M., and Gore-Felton, C. "Stigma, AIDS and HIV prevention in Africa: Reports from community organizations providing prevention services." (2008) 18, *Journal of Human Behavior in the Social Environment*, 329 at p. 340

⁸ Ibid p. 329-331

⁹ Celentano, D. D., Beyrer, C., Davis, W. W. and del Rio, C. "The HIV/AIDS Epidemics of the Americas". From Celentano, D. D. and Beyrer, C. *Public Health Aspects of HIV/AIDS in low and middle income countries*. (Springer Publishing, 2009) p. 34-56

services.¹⁰ Further, Africans represent a distinct group with very specific needs and challenges, which often go unmet by governmental service providers.¹¹

A Description of Human Rights Law

Human rights law is a vital and often contentious area of the law, due to the interaction between national and international laws. The post World War II era, largely due to the war's associated atrocities, resulted in increased awareness and political action designed to establish broad human rights protections.¹² Human rights law, in general focuses on two primary areas that include civil and political rights, and social, economic and cultural rights.¹³ Social rights include the right to health and wellbeing, and thus, serve to promote productive and healthful life in order to promote social, economic and individual development.¹⁴ International human rights laws, in effect, provide another layer of law that establishes a framework for the preservation and observance of human rights in addition to a given nations national laws.¹⁵ Few would contend that the basis for and concepts contained

¹⁰ Biesma, R. G., Brugha, R., Harmer, A., Walsh, A., Spicer, N., and Walt. G. "The effects of global health initiatives on country health systems: A review of the evidence from HIV/AIDS control." (2009) 24, *Health Policy and Planning*, 239 at p. 250

¹¹ Prytherch, H., and Wyss, K. "Knowledge about HIV/AIDS among professionals working with migrants in Switzerland." (2010) 6, *International Journal of Migration, Health and Social Care*, 31

¹² Moravcsik, A. "The origins of human rights regimes: Democratic delegation in postwar Europe." (2000) 54, *International Organization*, 217 at p. 238-250

¹³ Donnelly, J. "Democracy, development and human rights." (1999) 21, *Human Rights Quarterly*, 608 at p. 611-617

¹⁴ Landman, T. "The evolution of the international human rights regime: Political and economic determinants." [2002], *Proceedings of the 98th Annual Meeting of the American Political Science Association*, 17

¹⁵ Knox, J. H. "Horizontal human rights law." (2008) 102, *American Journal of International Law*, 1 at p. 14-16

within this body of law lack merit. Difficulty arises, however, when national laws or a nation's actions conflict with international human rights instruments.¹⁶

The utility of human rights law is directly related to the degree to which these laws contribute to trans-national processes that directly or indirectly influence the likelihood that individuals will be treated humanely.¹⁷ International human rights laws have had positive effects on the treatment of individuals in various societies.¹⁸ Despite the positive effects of post World War II human rights laws, there have been challenges related to the interpretation and enforceability of human rights laws within various national jurisdictions.¹⁹ In fact, current human rights law focuses on legal ideals perpetuated by liberal democracies such as those represented by Western Europe and the US, thus limiting their applicability in non-western cultures.²⁰ Further, these broad reaching legal instruments are frequently very difficult to enforce, even in cases where nations have signed these documents.²¹ As social rights are a key component of the thesis, the following section will provide an introduction to social rights in the context of the thesis

¹⁶ Ibid at p. 22

¹⁷ Koh, H. H. "Why do nations obey international law?" (1997) 106, *Yale Law Journal*, 2599 at p. 2617-2621

¹⁸ Cassel, D. "Does international human rights law make a difference?" (2001) 2, *Chicago Journal of International Law*, 121 at p. 122-124

¹⁹ Ibid at p. 126

²⁰ Some authors assert that the western orientation of human rights law, renders it entirely foreign within many societies, thus limiting its adoptability within the cultural milieu of many nations. Otto, D. "Rethinking the universality of human rights law." (1998) 29, *Human Rights Law Review*, 1 at p. 16

²¹ McGinnis, J. O., & Somin, I. "Democracy and international human rights law." (2009) 84, *Notre Dame Law Review*, 1739

Social Rights in Modern Society

Social rights are a common concern when discussions of the rights and obligations of individuals are balanced against obligations borne by those governing a given society. In essence, social rights spring from the social contract between those who dwell within a society and those who govern it.²² The concept of a social contract has long been recognized and originated from the work of political philosophers such as Hobbs and Locke.²³ The primary purpose of the social contract is to provide a description of the relationship between the state and its citizens in such a way that it serves to unite the expression of the individual wills of the citizenry.²⁴ While early conceptions of the social contract failed to establish an actual legally binding contract, the notion of a social contract was nonetheless important during the establishment of modern societies. In more recent times, however, social contracts have been formalized and are characterized by an extensive infrastructure that is comprised of various highly complex social programs.²⁵ The British and European conceptions of the social contract include healthcare, however, the US approach has not included the provision of universal healthcare services.²⁶ The lack of provision of universal healthcare in the US, and provision of such services in the UK, are one of the key differences underlying this thesis.

²² Wilson, E O. *Sociology: the New Synthesis*, (Belknap Press of Harvard University Press, 2000) at p. 23-38

²³ Creuss, R. L., and Creuss, S. R. "Expectations and obligations professionalism and medicine's social contract with society." (2008) 51, *Perspectives in Biology and Medicine*, 579 at p. 581-586

²⁴ Ibid p. 581

²⁵ Katz, M. B. "The American welfare state and social contract in hard times." (2010) 22, *The Journal of Policy History*, 508

²⁶ Fazal, K. "Towards achieving lasting healthcare reform: Rethinking the American social contract." (2010) 10-09, *The University of Georgia School of Law Research Paper Series*. 2010, 1 at p. 34

Perhaps the most contentious issue surrounding undocumented migration occurs when a society reflects upon the possibility that undocumented migrants will gain access to services normally reserved for the legal inhabitants of a particular country. In the context of undocumented migration, crucial arguments center around the extent to which the social contract pertains to newly immigrated persons who lack legal status. The issue of migration presents the possibility of the perceived threat to those within societies whose inhabitants fear shortages of goods and services due to systemic stress brought about by waves of migration, even when the migrant flees their native land in fear of persecution.²⁷ The fear of strangers (eg migrants), or xenophobia is often a product of the aforementioned issues.²⁸ As democratic societies, the UK and US have prided themselves on their observation of the right to individual freedoms, even in the case of recent immigrants.²⁹ The issue of undocumented migration, however, stretches the boundaries of these freedoms, and often leads many within society to reconsider human rights in the context of resource allocation decisions. The concept of freedom, however, often finds itself at odds with a governments' responsibility to provide services as a component of the social contract. These issues beg several poignant questions. When should a person lacking legal status be authorized to receive publicly funded services, and under what circumstances? What level of need warrants assistance? When does the legal basis for intervention on humanitarian grounds override imperatives designed to preserve resources? Do resource limitations diminish the value of human rights within societies?

²⁷ Moore, W. H. "Fear of persecution." (2004) 48, *Journal of Conflict Resolution*, 723 at p. 740-742

²⁸ Yakushko, O. "Understanding the roots of negative attitudes towards immigrants." (2009) 37, *The Counseling Psychologist*, 36 at p. 40-44

²⁹ Welch, M. "Detention of asylum seekers in the US, UK, France, Germany and Italy." (2005) 5, *Criminology and Criminal Justice*, 331 at p. 336

These questions, in effect, address the issue of conditionality in the context of human rights. That is, are there conditions where vulnerable people can be denied assistance despite their urgent need of life preserving care? Does an individual's citizenship status alter the responsibility of a government to treat them in a dignified manner that fully observes a particular nations social contract? These questions form the basis for this thesis.

Definitions of Health/Health Care in the UK Context.

It is important to define the general concept of health in the countries where this thesis was focused, since differences in this philosophy can play a significant role in the approach to providing health services. The healthcare system in the UK offers universal health coverage to eligible individuals. There is an extensive system in place that covers all medical and most other health related services, albeit under tightly controlled parameters. This fact highly differentiates the system within the UK from that seen in the US. One would expect, based upon the difference in overall approaches to providing services, that health in the UK context is defined differently from that seen in the US. In the context of the US, the system focuses heavily on acute, hospital based care and disease management, and draws much of their approach from the medical model, which often stresses treatment rather than prevention of diseases.³⁰ The UK on the other hand integrates these services into a single system. This brings to light a major philosophical difference. For instance, while a US hospital might benefit financially from a patient with

³⁰ There is an interesting separation in the US system, wherein the for profit healthcare system is driven towards treatment on the basis of fee for service, while the governmental public health system is geared towards prevention. In fact, one could posit that these are competing values systems. Shi, L., and Singh, A. *Delivering Healthcare in America* (3rd ed., Aspen Publications, 2001) at p. 33-37.

cancer, the equivalent facility in the UK may suffer financial loss associated with a patient who requires extensive treatment for cancer.³¹

Early US work conceptualizing health focused on the absence of disease. Boorse provided some early arguments to the contrary in his argument that this conception of health is ‘value free’ in focusing on the biological aspects of health in purely quantitative terms.³² Instead, he argues that society interjects their individual values into any argument of what health is. Thus, health is a value-laden concept wherein society interjects meaning through the means by which they work to optimize the health of its inhabitants. This said, health in the US context continues to be defined primarily by the medical model, which continues to define health based upon disease processes or the absence thereof.³³

While issues of treatment and acute care remain the focus of the US system, many have espoused a more comprehensive approach to healthcare. McGinnis, Williams-Russo and Knickman illustrated many of the points that limit the initiation of policies that structure the system towards a more proactive approach.³⁴ They espouse an approach that integrates holistic health promotion based approaches rather than solely acute care treatment-based approaches. The US government has attempted to change the trajectory

³¹ As for profit entities, US healthcare facilities exist, in part, to generate profit for shareholders. Thus, their very design requires that they offer a broad array of services such as care for cancer patients in order to generate revenue.

³² Boorse, C. “Health as a theoretical concept.” (1977) 44, *Philosophy of Science*, 542 p. 556-560

³³ Although the authors lament the state of the US system, they acknowledge that the system is geared primarily towards a model of disease treatment, and only gives ancillary consideration to issues of prevention. Singh, A., and Shi, L. *Essentials of the US Healthcare System*. (Jones and Bartlett Publishing, 2004) at p. 44-56

³⁴ The authors detail the degree to which the current system structure fails to reach many of the most vulnerable in the US population thus resulting in lack of improvement with regard to many of the major health indices. McGinnis J. M., Williams-Russo, P. and Knickman, J. “The Case For More Active Policy Attention To Health Promotion.” (2002) 21(2), *Health Affairs*, 78

of healthcare delivery in the US through its implementation of the Healthy People initiatives in 1979. The *Healthy People* Initiative was designed to focus healthcare resources on a health promotion and disease prevention model, rather than the traditional US model that focused on the treatment of acute illness.³⁵ Despite the failure to address the vast majority of goals set forth in Healthy People 2000, the initiative has continued to attempt to alter the US healthcare landscape.³⁶

While the approach to healthcare in the UK differs substantially from that seen in the US, British conceptualizations of the concept of health do not differ greatly from that seen in the US literature. Radley and Green presented one such characterization, through their representation of illness as a transitional phase that essentially represents the absence of health.³⁷ This dichotomous view of illness, and thus health, is common to the early literature on the topic. There are, however, more complex and holistic views of health, such as that presented by Milburn. Milburn, instead of looking at health and pursuits designed to improve health in dichotomous terms, instead views health as dependant upon a myriad of socio-cultural and environmental variables which influences one's ability to attain health.³⁸ This framework is more consistent with the British approach to healthcare. Radley and Billig supported this conception of health to an extent. They introduce another important aspect of the concept that outward

³⁵ United States Department of Health and Human Services. *Healthy People 2010*. (GAO Press, 2004)

³⁶ These initiatives began with Health People 2000 and later Healthy People 2010. These documents detailed and then offered national objectives designed to alter the major health indices in the country. The thrust of the initiative was in the area of health promotion, with little focus on disease prevention. Ibid

³⁷ Radley, A., and Green, R. "Illness as adjustment: A methodology and conceptual framework." (1987) 9(2), *Sociology of Health and Illness*, 179 at p. 186-191

³⁸ Milburn, K. "The importance of lay theorizing for health promotion research and practice." (1996) 11(1), *Health Promotion International*, 41 at p. 44

representations of health that are often context dependent work to define health in the context of the individual.³⁹ Smith, Masterson and Smith further extend the concept in their argument for a comprehensive definition of the concept that focuses on health promotion above the concept of disease care.⁴⁰ This definition most closely matches the overt approach to healthcare in the UK, through its' attempt to integrate a holistic representation of health that integrates care focused on wellness rather than simply focusing on the treatment of disease.

While conceptions of health in the UK, to some degree, are consistent with those seen in the US, there are differences in both definition and practice. The issue of practice, and the overall approach to providing health services is clearly the area that differentiates the topic most clearly. This is an important distinction that cannot be downplayed, since a society's practices reflect the degree to which a concept is valued in their society. The primary area that differentiates the UK from the US is the degree to which the system in the UK focuses on health as an integrated concept that reflects on issues of wellness and holism, rather than focusing most specifically on disease management.

The Basic Human Right to Healthcare

The purpose of this section is to provide an initial consideration of the concept of healthcare as a basic human right. There appears to be a clear consensus within western societies that the maintenance of human rights is a central focus upon which many of the founding principles of western democracies are based, and are thus, worthy of protection

³⁹ Radley, A., and Billig, M. "Accounts of health and illness: Dilemmas and representations." (1996) 18(2), *Sociology of Health and Illness*, 220

⁴⁰ Smith, P., Masterson, A., and Smith, L. S. "Health promotion versus disease and care: Failure to establish "blissful charity" in British nurse education." (1999) 48, *Social Science & Medicine*, 227 at p. 231

through various means.⁴¹ While most in western societies would agree that human rights are important, there is less clarity regarding the services available within society to which individuals possess as an innate right (e.g. health services).⁴² Healthcare rights are perhaps the most contentious area of social services regimes, since there are clear linkages between the need for healthcare and safe and productive life, but less clarity regarding who may avail themselves of this right within a given country.⁴³

As a basic and simple tenant, the idea that healthcare is a basic human right has been proposed often. Difficulty, however, arises in determining the parameters through which healthcare services might be provided to all. There is a body of international law that addresses these issues. The Universal Declaration of Human Rights for instance, in Article 25, states that: “Everyone has the right to a standard of living adequate for health and well-being of himself and of his family, including food, clothing, housing and medical care”.⁴⁴ The International Covenant on Economic, Social and Cultural Rights parallels this view in Article 12, by stating that: “The states party to the covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.⁴⁵ The Committee on Economic, Social and Cultural Rights further supports this view.⁴⁶ Although each of these endorses the idea that health, and arguably health care, are basic human rights, they individually and jointly fail to provide

⁴¹ Baxi, U. *The future of human rights* (2nd ed., Oxford University Press, 2007) at p. 17-24.

⁴² Farmer, P. (2004). *Pathologies of power. Health, human rights and the new war on the poor*. (University of California Press, 2004) at p. 6-10.

⁴³ Ibid at p. 19

⁴⁴ Universal Declaration of Human Rights is clear on this point, throughout Article 25. The Universal Declaration of Human Rights 1948

⁴⁵ The International Covenant on Economic, Social and Cultural Rights (UN) 1976

⁴⁶ The International Covenant on Economic, Social and Cultural Rights (UN) 1976

a mechanism through which to establish the political and logistical framework through which a society must guarantee such rights to individuals dwelling within their borders.

There is a common concern within societies that hinges on the erosion of government provided healthcare, and limits to health related services often considered a component of the social contract.⁴⁷ Many have supported the notion of a right to health and health care based upon guarantees contained in common human rights documents⁴⁸ such as the International Covenant on Economic, Social and Cultural Rights.⁴⁹ While countries such as the US do not provide universal healthcare services, many within the US propose the lack of universal healthcare as a violation of basic human rights.⁵⁰ The fact that the US has failed to ratify many international human rights instruments related to the right to health and health care continues to be a contentious issue amongst American legal scholars who support the human right to health care.⁵¹ While many view healthcare as an absolute obligation incurred by the government alternative views are cited within the legal literature. The notion that the right to healthcare represents a duty solely on the part of government is disputed, for instance by those who would argue that the right to healthcare confers a duty on the public to engage in healthy behavior⁵² or by those who argue that the right to healthcare delineated within common human rights instruments is vague and non-binding.⁵³ The case of undocumented migrants provides an even greater

⁴⁷ Friesen, T. The right to health care. *The Health Law Journal*, 2001, 9, 204-222.

⁴⁸ Gevers, S. "The right to health care." (2004) 11, *European Journal of Health Law*, 29 at p. 31-32

⁴⁹ See Article 12.

⁵⁰ McCarrick, P. "A right to health care." (1992) 2, *Kennedy Institute of Ethics Journal*, 389

⁵¹ Kinney, E. "Recognition of the international human right to health and health care in the United States." (2007) 60, *Rutgers Law Review*, 335 at p. 337

⁵² Denier, Y. "On personal responsibility and the human right to healthcare." (2005) 14, *Cambridge Quarterly of Healthcare Ethics*, 224 at p. 227-228

⁵³ Friesen, T. "The right to health care." (2001) 9, *The Health Law Journal*, 204

challenge, since undocumented migrants often lack the legal authority to receive many services within the countries where they dwell, despite human rights based arguments that support access to such services.⁵⁴ Concerns regarding the right to healthcare in undocumented migrants often involve individuals with previous legal authorization, for instance, in the care of failed asylum seekers.⁵⁵

The extant human rights laws provide more questions than answers in that they fail to provide absolute legal parameters under which healthcare must be provided. For instance, while the aforementioned documents address health, they do not specify the provision of ‘healthcare services’ or ‘medical care’. While one might construe them to denote a clear obligation on the part of states to provide health services, they fail to set forth clear obligations on the part of states to provide such services. Thus, the vague nature of these documents leave several vital questions unanswered. In the most basic sense, these include the need to define the precise parameters under which individual states are obligated to care for an individual under solely humanitarian grounds, without respect for a person’s national origin or country of legal citizenship. These laws will be considered to the degree that they have set forth the parameters under which care must be provided without consideration of issues other than the need of the individual.

⁵⁴ Ruiz-Casares, M., Ronneau, C., Derluyn, I., and Crepeau, F. “Right and access to healthcare for undocumented children: Addressing the gap between international conventions and disparate implementations in North America and Europe.” (2010) 70, *Social Science & Medicine*, 329 at p. 231-232

⁵⁵ Cole, H, and Ohanian, L. “New Deal policies and the persistence of the Great Depression: A general equilibrium analysis.” (2004) 112(4), *The Journal of Political Economy*, 779

Examples of Undocumented Migrants' Challenges in Gaining Health Services

In order to set the stage for the thesis, this section seeks to illustrate the degree to which the issue of undocumented migrants' access, or lack of access to health care represents a significant problem in the context of the legal rights of individuals to whom these services are denied or limited. This section will do so by presenting two cases, one each from the UK and US, which delineate the struggles of undocumented migrants with HIV/AIDS in the respective countries. In the context of the argument set forth in this thesis, this will be accomplished by providing case studies in the respective jurisdictions that illustrate the degree to which irregularities in healthcare access are actually problematic. The underlying theme in the case of both countries is a common one: The difficulties associated with providing needed services to a vulnerable population who lack legal rights to such services during a time when government agencies are experiencing dire limitations to their funding base.

The political mood within the UK is one characterized by a widespread call to action in order to decrease the rates of undocumented immigration into the country.⁵⁶ This is notable given the UK's inherent limitations with regard to actually quantifying the number of undocumented migrants currently living in the country.⁵⁷ There are two key issues associated with undocumented migration in the UK context. First, there are migrants who have illegally entered and are living and working in the UK. Although this group is far smaller than the number of similar migrants in the US, they do comprise a

⁵⁶ Reeves, M., de wilt, G., Murshalie, H., Williams, P., Gill, P., Kralj, L., and Rushby, M. "Access to healthcare for people seeking asylum in the UK." (2006) 56, *British Journal of General Practice*, 306 at p. 311

⁵⁷ The British government has only recently initiated programs designed to measure and quantify the undocumented population. Seabrook, J. 'The fortress Britain myth.' *The Guardian Unlimited*. (London, 18 November 2008)

significant population. Secondly, and most importantly, are the group comprised of failed asylum seekers. Failed asylum seekers are more often seen in the UK, as compared to the US. In fact, The former Home Secretary John Reid, in 2007, launched a drive to limit undocumented migration to the UK by depriving the immigrants of any benefit from dwelling in the UK, including housing, work and healthcare.⁵⁸ The trend towards denying failed asylum seekers access to health services has continued, and has been supported within the courts.⁵⁹

The case of *R. v Brent London Borough Council*⁶⁰ illustrates the travails of an HIV positive undocumented migrant to the UK. The case involved a Brazilian national who was diagnosed with HIV disease while living in his home country. He went on to enter the UK on a visitor's visa, and remained after the expiration date of the six-month visa. After some 3 years, he became gravely ill; having failed to receive HIV related care for his entire stay in the UK. It must be noted, however, that he did not seek care out of concerns regarding the nature of HIV disease and stigma in his culture. He was subsequently hospitalized due to opportunistic infections associated with severe immune system suppression. This eventually resulted in his immigration status becoming known, and thus, he was ordered to leave the country. Unfortunately his health was failing and his consultant physician felt him too weak to travel. Consequently he was released from his publicly funded accommodations due to his illegal status. While his medical care continued to be provided, due to the life threatening nature of his illness, he had lost a

⁵⁸ *The Guardian Unlimited*, New Crackdown on Illegal Immigration, 4.4.2007.

⁵⁹ Recent court decisions as in the case of YA, a Palestinian man, were upheld by the appeals court. Lord Justice Ward held that an individual must reside lawfully in the UK for at least one year prior to receiving access to health services. Travis, A. 'Migrants amnesty would aid economy by 3 billion, says study.' *The Guardian Unlimited*. (London, 16 September 2009)

⁶⁰ *R v Brent London Borough Council; R. v L.B.C.* (1999) 31 H.L.R., 10.)

stable place to live, thus complicating his medical condition. It is important to note that the life threatening nature of his illness made his care possible. He would not have continued to receive state provided care had he been more stable. His petition to the courts was eventually successful, based upon his citation of section 21 (1)(a) of the National Assistance Act of 1948, which held that social service agencies are authorized to arrange accommodation for adults whose abilities are limited by such illnesses.⁶¹ In the end, only the very dire state of his health protected him from the cessation of treatment and deportation. He did, however suffer interruptions in his living condition and overall care regimen that were disruptive to his recovery. He went on to die of complications related to HIV soon after the adjudication of his case. This case clearly illustrates the interaction between the law and its interpretation and issues regarding the degree of illness as it relates to individual human rights.

The US system differs substantially from a structural point of view. Medical care is neither federally nor state funded, save for programs directed towards the provision of care to the elderly, the disabled or the very poor. The 2007 case of Victoria Arellano provides an illustration of the struggles experienced by individuals who lack legal status, and who have well defined needs for healthcare in the US context. The case involved Ms. Arellano, a trans-gendered woman formerly known as Victor, who was dwelling in Los Angeles California.⁶² Ms. Arellano lacked legal status having entered the US illegally. Ms. Arellano knew herself to be infected with HIV, but was well upon entering and living within the US for a period of years. While she was not eligible for medical care, she was eventually able to secure health services through a ‘free clinic’ operated by a

⁶¹ The National Assistance Act of 1948 section 21 (1)(a).

⁶² Hernandez, S. Testimony on detained immigrant’s death was misleading. *Daily Journal*. (Los Angeles, 23 October 2007)

Non-Governmental Organization operated by a group that provides health services to individuals who lack legal status.⁶³

Ms. Arellano was eventually detained due to her illegal status and was placed in an immigration detention facility in San Pedro California pending deportation.⁶⁴ Immediately upon her confinement, Ms. Arellano requested that the infirmary replace her medications, which included a variety of essential HIV therapies. The detention facility lacked the medications that Ms. Arellano had been taking, and which she had obtained from an NGO run clinic prior to being detained.⁶⁵ Following her detention, her medications were replaced with different medications, and her health coincidentally began to deteriorate.⁶⁶ Soon thereafter, she condition became very unstable, including bouts of bloody vomiting and respiratory difficulty. Her fellow detainees began to protest openly within the facility demanding that she be brought to the hospital.⁶⁷ Despite these demands, Ms. Arellano was not removed to a higher level of care and died while in the immigration detention facility. A wrongful death civil suit brought by her family was settled out of court in 2009.⁶⁸ The death and circumstances surrounding Ms. Arellano's

⁶³ Zamora, L. 'Victoria Arellano: Shackled and denied life saving medicine.' *Revolution*. (San Francisco, 10 January 2007) 1

⁶⁴ Hernandez, S. Testimony on detained immigrant's death was misleading. *Daily Journal*. 10.23.2007.

⁶⁵ The facts of this case were investigated and confirmed by the US Senate via the Department of Homeland Security. Thus, all relevant facts cited were confirmed from governmental and non-governmental sources. United States Senate Committee on Homeland Security and Governmental Affairs. Basic Medical Care at Immigration Detention Centers. Press release 5.12.2008.

⁶⁶ This was confirmed in hearings led by US Senator Robert Menendez during which it was confirmed, for instance, that the proven HIV prophylactic therapy Dapsone was replaced with Amoxicillin, a drug which is not indicated in the treatment of HIV disease. The United States Congressional Record, hearings regarding the Detainee Basic Medical Care Act of 2008.

⁶⁷ Ordovery, N. 'ICE under fire.' *Housing Works*. (Washington DC, 17 September 2008)

⁶⁸ *Arellano et al vs. United States Department of Homeland Security*. US District Court, Central District of California, 2008.

case became the driving force behind the introduction of the Detainee Basic Medical Care Act of 2008 in the US Congress.

The aforementioned cases demonstrate the challenges faced by undocumented migrants suffering from HIV/AIDS, and their associated experiences. These experiences reflect a pattern of conditional provision of services despite well-founded need for life preserving medical care. In both cases, the issue of human rights as they relate to an individual's health became a prominent concern. The cases delineate the degree to which chronic conditions, while stable for long periods of time, often progress to the point that they are life threatening. While both countries have laws that dictate that care be provided in life threatening situations, it is less clear the degree to which laws that result in the refusal or withdrawal of care to persons suffering chronic life threatening conditions is humane and in keeping with basic human rights standards. It is in this context that these cases offer a thought provoking basis for the examination of the issues contained within this thesis.

Should Undocumented Migrants Have Rights to Health Services?

Any examination of the issue of healthcare access must include an analysis of the functional aspects of access to care. One might posit that the central element of access to healthcare hinges on the supply side view that focuses on the availability of services. As well, one might focus on the individual's resources and need for health services in the context of human rights frameworks. Discussion of service availability is essential when contrasting the UK and US systems, since there are considerable differences between the two systems. While access in the UK is often limited by shortages of healthcare resources, this is not the case in the US, where there is an overabundance of health care

assets.⁶⁹ The supply-based view can be effectively summarized through the following statement: “access measured in terms of utilization is dependent on affordability, physical accessibility and acceptability of services and not merely on the adequacy of supply”.⁷⁰ This definition calls into question the mere availability of services, since these services may not be functionally available to many persons.

When considering the US, this concept is of central importance due to the exceedingly high cost of care to the individual. The UK on the other hand utilizes a system of national health care, administered via the National Health Service (NHS), which offers a comprehensive array of health services to citizens and other eligible persons. While issues specific to these healthcare systems will be addressed with greater detail in later chapters, these considerations are important to this introduction. Goddard and Smith, while lamenting inequities in health service related to difficulties for even eligible persons to gain health services, cited the lack of effective methodologies in the UK by which to identify the level of such inequities.⁷¹

While health services are often viewed as individual necessities, it is clear that some health services benefit society. For instance, preventative services such as immunization or tuberculosis control clearly benefit all within society. Many services fall under the umbrella of the public health system of a particular country. Public health is defined as ‘fulfilling society’s interest in ensuring conditions under which people can be

⁶⁹ Guilliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., and Hudson, M. “What does access to health care mean?” (2002) 7(3), *Journal of Health Services Research and Policy*, 186 at p. 188

⁷⁰ Ibid, p. 187.

⁷¹ Goddard, M, and Smith, P. “Equity of access to health care services: Theory and evidence from the UK.” (2001), *Social Science and Medicine*, 2001, 1149 at p. 1154

healthy'.⁷² This definition espouses the notion that to some degree, government has a role in ensuring that the conditions necessary to attain health exist, or at the very least, health risks are minimized. This is a difficult endeavor at best. Gostin, in his concise examination of public health law, detailed the degree to which public health seeks to control many factors over which they have little or no control.⁷³ That is, while factors such as diet, smoking and exercise are difficult to regulate under current law, issues related to communicable infectious diseases are controllable to an extent. When considering those newly arrived to a particular country, an interesting dichotomy arises. Undocumented migration represents an illegal act, however, there is benefit to society in decreasing the rates of disease amongst undocumented migrants, despite their lack of legal status. Vetter detailed the 'Health for all approach' and the 'health promotion approach', both of which imply some level of societal need to administer services of a preventative nature in order to diminish morbidity.⁷⁴ Issues of law aside, a pragmatic approach would dictate that one at least consider the systemic effect of denying one preventative care. For instance, if an individual suffered from high blood pressure, but was denied care, he or she might go on to suffer from a catastrophic event such as a Myocardial Infarction (Heart attack). This catastrophic, and often preventable event, would surely qualify one for care under humanitarian circumstances.

Public health, by definition seeks to ensure the health of a country's inhabitants. This requires that to an extent, services should be provided for the common good of

⁷² Schneider, M. J. *Introduction to Public Health*, (3rd ed., Jones and Bartlett Publishing, 2006) at p. 4-5.

⁷³ Gostin, L., O. *Public health law and ethics: A reader*. (University of California Press, 2002) at p. 130-132.

⁷⁴ Vetter, N. "What colour is your health service organization." (2006) 28, *Journal of Public Health*, 181 at p. 182

greater society rather than basing care upon one's national origin or legal status. The collective responsibility inherent to public health approaches is generally extended into limited areas of healthcare, for instance, communicable disease prevention.⁷⁵ There is clearly some benefit to society associated with offering healthcare services to the newly immigrated.⁷⁶ The public health view of service provision does not make reference to national origin, rather working towards the greater good of society from a health related point of view. That is, there is no requirement for 'legal status' in a general sense associated with most public health statutes. The public health approach offers a rough equivalent to that of human rights based approaches, in that service is provided without a focus on eligibility or resource availability. While the central arguments present in this thesis focus on human rights based conceptions of the need for access to health services, other viewpoints such as those focusing on public health based approaches will be explored in order to offer the fullest representation of issues presented in the thesis. The interaction between services that are, and are not provided, offers a keen insight into the obligations undertaken by particular nations. In this thesis the points at which care is provided by law and in practice will be examined in order to identify the degree to which undocumented migrants living with HIV disease navigate the complexities of the healthcare systems in the respective countries, and the degree to which laws either limit or facilitate their efforts.

⁷⁵ Salmon, D., and Omer, S. "Individual freedoms versus collective responsibility: Immunization decision making in the face of occasionally competing values." (2006) 3, *Emerging Themes in Epidemiology*, 1742 at p. 1744

⁷⁶ Rousseau, C., ter Kuile, Munoz, M., Nadeau, L., Ouimet, M., Kirmayer, L., and Crepeau, F. "Health care access for refugees and immigrants with precarious status: Public Health and human rights challenges." (2008) 99, *Canadian Journal of Public Health*, 290 at p. 291

An Outline of the Thesis Approach to the Problem of Healthcare Access for Undocumented Migrants

The basic structure of the thesis focused initially on laying the groundwork for a ‘black letter’ analysis of the legal and social underpinnings of the question of undocumented migration and its relationship to the healthcare system. Chapter 2 presents issues that defined undocumented migrants and their legal status within the UK and US. Chapter 3 provides a general overview of the basis of levels of access to publically funded social services by undocumented migrants. Chapters 3 and 4 outlines the legal basis for healthcare access in the US and UK respectively. Chapter 5 defines the methodology for the empirical study. Chapters 6 and 7 presents the results of the empirical study in the US and UK respectively. Chapter 8 presents the conclusions of the thesis by comparing vital issues present in the black letter and empirical data.

The empirical study comprised the basis for the comparison of the two legal and healthcare systems. This study was conducted in order to determine the way in which the law was being applied in practice in the respective healthcare systems. The design of the empirical component of the study was qualitative, and was based upon the Grounded Theory Approach.⁷⁷ Officials representing non-governmental organizations that serve the health and social care needs of migrants in the UK and US were interviewed, in order to identify their experiences in attempting to aid individual undocumented migrants in gaining health services. Analogous organizations in the US and UK were included in the study to facilitate effective comparisons.

⁷⁷ Glaser, B. and Strauss, A. *Discovery of grounded theory*. (Aldine Press, 1967) at p. 8-11.

Chapter 2 – Defining the Nature and Scope of Undocumented Migration in the UK and US.

Those who lack legal authority to remain or reside in a country are referred to by a variety of terms that describe their legal status. These include such descriptive terms as illegal immigrants, illegal migrants, illegal entrants, illegal aliens undocumented workers and undocumented migrants.⁷⁸ For the purposes of this thesis, the term ‘undocumented migrant’ will be used to describe an individual who has entered a respective country without completing the legal documents necessary to be considered a legal inhabitant of that country. The term *undocumented migrant* describes the status of individuals without the negative connotations associated with many of the aforementioned terms. This term, for instance, avoids the use of labels that have associated stigma, such as *illegal*, which are used in many politically charged environments to evoke an emotional response.⁷⁹ Further, this term will be used to refer to individuals, who, through whatever mechanism, have lost their legal authorization to remain in a country after having initial authorization to remain. This grouping includes asylum seekers who have failed in their initial application and who have failed to gain authorization to remain through the appeals process.

The purpose of this chapter is to provide a concise examination of the legal factors that define the legal status of undocumented migrants in the UK and US. While this thesis specifically addresses undocumented African migrants living with HIV/AIDS,

⁷⁸ The use of the term ‘illegal’ in the majority of labels for those who lack legal status to remain in the US is referred to by Lakoff and Ferguson in terms of a principle that they refer to as framing. Framing refers to the use of labels in order to directly influence public reflections regarding a particular topic. Thus, as much as possible this thesis refers to these individuals using the more neutral term ‘undocumented’. Lakoff, G., and Ferguson, S. *The Framing of Immigration*. (Rockridge Institute, 2006) at p. 3

⁷⁹ Ibid at p. 7-11

this chapter will assume a more general approach in order to define the legal status of those who find themselves lacking the proper documentation necessary to legally dwell within a particular nation. During this chapter, a presentation of the demographic characteristics of undocumented migrants in the US and UK will be made, to the extent that it is possible. The discussion will then move to a discussion of the legal requirements through which one obtains legal status (or conversely without which one is considered to lack legal authorization to remain in a given country).

Migratory trends to the US and UK: Laying the foundation.

The migratory trends to the UK and US will be detailed in this section.

Undocumented migration comprises the vast majority of migrants to the US. The United States Immigration and Naturalization Service, a component of the Department of Homeland Security began tracking undocumented migrants in 2005. During 2005, the department placed the undocumented migrant population between 4.6 and 5.4 Million.⁸⁰ Undocumented migration has had a profound effect on the US, and has been influenced primarily by the economic and sociopolitical climate within Mexico, Central and South America. During 2005 half, or 2.7 million, of these undocumented migrants were from Mexico, with an additional 335,000 and 165,00 respectively from the Central American countries of El Salvador and Guatemala Respectively.⁸¹ The highest percentages of these migrants are concentrated in the states of California, Texas, New York, Florida and Illinois (Listed in rank order). This is the portion of immigration that has become so

⁸⁰ United States, Immigration and Naturalization Service. *Illegal alien resident population*. (INS, 2006)

⁸¹ Ibid at p. 4

politically charged in the US, after the attacks on New York, Washington D. C. and Pennsylvania in 2001.

The UK offers a unique challenge with regards to the ability to quantify levels of undocumented migration. Until recently, the government lacked an organized apparatus by which to track and quantify the existence and characteristics of undocumented migrants. One factor that is likely adding to the problem is the annual trends with regards to asylum approval rates. These rates have decreased annually beginning in 2001, when 20% of applicants were granted asylum, until, 2004, when only 13% were granted asylum. Additionally rates of asylum applications peaked in 2000, with 80,315, and have since dropped annually, to a low of 33,960 in 2004.⁸² Regionally, the bulk of cases originate amongst migrants from Africa, Asia and the Middle East respectively.⁸³ The primary nationalities detailed in recent immigration statistics reflect that Zimbabwe, Eritrea, Iran, Somalia, and Afghanistan led the rates of asylum applications in the UK during the first quarter of 2009.⁸⁴ While it is possible to quantify rates of asylum seekers to the UK, it is a far more challenging proposition to quantify levels of undocumented migrants.

Differentiating documented and undocumented migrants.

The UK and US have established processes by which one can enter the respective countries legally. While these means will be discussed in greater depth later in this section, these include mechanisms such as the established visa process, or through the

⁸² Home Office, Immigration Research and Statistics Office. *Control of immigration: Quarterly Statistical Summary, United Kingdom-First Quarter 2006*. (The Home Office, 2006)

⁸³ Ibid

⁸⁴ Home Office, Immigration Research and Statistics Office. *Control of immigration: Quarterly Statistical Summary, United Kingdom-Third Quarter 2009*. London, England: The Home Office, 2009.

granting of asylum. Cases where one becomes undocumented vary to a degree based upon the form of entry to the country. In the case of illegal entrants, individuals are immediately undocumented with respect to the law. In the case of individuals who enter under legal circumstances, undocumented status occurs when all legal recourse to remain in the country is exhausted. This includes, for instance, failure to gain asylum and failure on appeal, or the expiration of a student visa.

The UK and US have consistently regarded themselves as leaders in the area of human rights.⁸⁵ The asylum process is a method by which one may gain dispensation to remain in a country based upon persecution within their nation of origin. Within both countries, a potential asylum seeker's status is determined by a variety of legal instruments that require one to document the grounds for asylum.⁸⁶ This decision is based largely on the status of country of origin, with designation of areas that meet the criteria for asylum being promulgated by the central government. In the UK, the Home Office maintains the responsibility for asylum determinations, and acts on such applications according to the guidelines set forth in the United Nations Convention Relating to the Status of Refugees.⁸⁷ In the US, all immigration determinations are the responsibility of the federal government and are managed primarily by the Immigration and Naturalization Service, a bureau within the Department of Homeland Security.

⁸⁵ Steiner, H., Alston, P., and Goodman, R. *International human rights in context: Law, morals, politics* (3rd ed., Oxford University Press, 2008) at p. 81-83.

⁸⁶ Joppke, C. *Challenge to the nation-state: Immigration in Western Europe and the United States*. (Oxford University Press, 1998) at p. 193-194.

⁸⁷ Under Article I of the convention the guidelines for designation as a refugee are clear in that refugee status is afforded to those who have a "well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country. United Nations Convention Relating to the Status of Refugees (1951).

Immigration in the US is regulated by the Immigration and Nationality Act under Title 8 of the Federal Code (1952). Under British law, the immigration and Nationality Directorate of the Home Office makes decisions regarding the immigration status of individuals entering the country. The process is more complicated than in the US due to the UK's European Union membership. Under EU regulations, citizens of EU member states are afforded freedom of movement within member states.⁸⁸ This was modified in the UK under Explanatory Memorandum HC1053, which required such individuals to acquire rights of permanent residence under some circumstances, particularly when one desired to remain for extended periods of time.⁸⁹

British citizenship is governed primarily by the British Nationality Act of 1981.⁹⁰ The Act offers stringent guidelines for foreign nationals who wish to obtain British citizenship. Of particular difficulty is the requirement that one maintain legal domicile within the country for a period of 5 years. Legal domicile would require one to maintain legal employment throughout this period. This requires that a Home Office Work permit, which would allow one to seek employment for a prescribed period of time, with no guarantee of ability to become a permanent resident of the country. While temporary visas do not provide one with permanent legal status, they provide the basis for one to legally remain in the country while seeking other means by which to gain full legal status.

Under the Immigration and Nationality Act, US law allows for several designations other than those determined eligible for asylum.⁹¹ Lawful permanent residence, often referred to as the 'green card' after the document provided when such

⁸⁸ Immigration and Asylum Act of 1999 (UK)(Pt 1, Sect 3A).

⁸⁹ Immigration and Nationalization Directorate, Home Office, HC1053

permission is granted, is the standard authorized means through which an individual can enter the country to make permanent residence. Individuals entering the country under this designation are generally immigrating to join a family member legally residing in the country, or incident to legal employment. After a period of permanent domicile in the country, one can begin to undergo the process of naturalization, through which full citizenship can be gained. In addition to permanent forms of immigration, one may also seek an employment authorization through which employment within the country can be obtained for a prescribed period of time. In order to be considered a documented or legal immigrant to either country, one of the following must be accomplished: 1. Designation as an asylum seeker; 2. The provision of a work permit, designating the individual as a guest worker; 3. The provision of a student or visitors visa, which allows one to remain in the country or 4. Naturalization. A migrant who fails to fulfill at least one of these parameters becomes an undocumented immigrant. It is important to consider the possibility of moving in and out of documented or legal status, due to the time limitations placed on the various visas, as the expiration of the visa might very well render one undocumented or illegal. This pattern, by which one can move in and out of legal status based upon technical issues, can represent an arbitrary set of legal instruments that do little to ensure the rights of individual persons.

Who are the Undocumented Migrants?

The global recession and regional strife inherent to many developing countries has resulted in profound increases in undocumented migration to the US, UK, and

Europe.⁹² This includes populations of over 11 million undocumented migrants in the US⁹³ and between 3 and 8 million undocumented migrants in the European Union.⁹⁴ The proliferation of undocumented migrant populations has resulted in the imposition of more stringent immigration control within developed countries at a time when the pressing need for low-cost labor has resulted in favorable conditions for impoverished migrants from the developing world.⁹⁵ These more rigorous and often militaristic border controls have acted, conversely, to encourage attempts to permanently settle in nations, rather than engage in cyclical migration based upon the availability of work and the conditions within the individual migrants' home nations.⁹⁶ The result of these conditions is a situation wherein individuals are driven to migrate, and once present in another nation attempt to remain at any cost due to fears that they may never again achieve entry. This acts to ensure high numbers of undocumented migrants attempting to dwell indefinitely in developed nations such as the UK and the US.

Migratory patterns to the UK and US are different, yet driven by many of the same forces. The US pattern has involved immigration primarily from Mexico, South and

⁹² Massey, D., and Capoferro, C. "Measuring Undocumented Migration," From Portes, A., and DeWind, J. *Rethinking Migration, New Theoretical and Empirical Perspectives*, (Berghahan Books, 2007) at p. 63-65

⁹³ Immigration and Naturalization Service. *Illegal alien resident population*. (INS, 2009)

⁹⁴ While statistics are available, there are persistent difficulties associated with identifying the true magnitude of these populations. Frattini, F. *The future of EU immigration and integration policy*. (London School of Economics, 2007)

⁹⁵ This dichotomy has resulted in an ever-increasing rate of undocumented migration in a time when governments in the west are least capable of providing for these individuals, but when humanitarian crisis in their home countries have resulted in conditions that virtually require migration as a form of survival. Massey, D., and Capoferro, C. "Measuring Undocumented Migration," From Portes, A., and DeWind, J. *Rethinking Migration, New Theoretical and Empirical Perspectives*, (Berghahan Books, 2007)

⁹⁶ De Haas, H. *Turning the tide? Why 'development instead of migration' policies fail. Working Paper: International Migration Institute, James Martin 21st Century School*, (Oxford University, 2006) at p. 7.

Central America, and to a lesser degree, Africa, Asia and Eastern Europe. US immigration must be considered with respect to two predominant forms of immigration. These include those individuals who enter through some form of legal means, and the larger group that enter illegally across the country's porous borders. Currently, immigration to the UK stems primarily from Africa, Asia and Eastern Europe.⁹⁷ Each has in common the fact that immigration patterns are heavily driven by poverty, war, social and economic strife.

The UK government has recognized the necessity of gaining information regarding the *illegally resident* population within the country. While the Home Office concedes an inability to quantify this population, they nonetheless cite that they are likely to be a substantial proportion of the population of the country. Further, they concede that this population is underrepresented in government population estimates used to plan a wide array of programs, policies and services.⁹⁸ The government has begun to research methods through which to attempt to quantify this population using a variety of approaches. While their approaches are varied, they are espousing methods commonly used in Europe and the US.⁹⁹ Using Pinkerton, McLaughlan and Salt's methods (in part) an initial estimate of undocumented migrants in the UK was made during 2005, reflecting an estimate of 430,000 individuals.¹⁰⁰ This included a range of 310,000 to 570,000

⁹⁷ From Hatton, T. Explaining trends in UK immigration. *Journal of Population Economics*, 2005, 18, 4, 719-740. The Home Office. Refugees and Asylees: 2009. Annual Flow Report, 2010.

⁹⁸ Home Office, Immigration Research and Statistics Office. *Researching the illegally resident population: workshop summary report*. (The Home Office., 2001)

⁹⁹ Pinkerton, C., McLaughlan, G., and Salt, J. *Sizing the illegally resident population in the UK*. (Home Office, 2004)

¹⁰⁰ Woodbridge, J. *Sizing the unauthorized (illegal) migrant population in the United Kingdom in 2001*. (Home Office, 2005) at p. 16-25

according to the methodologies used for the estimate.¹⁰¹ This was the first foray on the part of the Home Office designed to quantify this population.

Undocumented migrants, as a truly vulnerable population, often find themselves in unsafe conditions, wherein their very lives are placed at risk. The deaths of 23 undocumented Chinese migrants during 2004, while picking cockles in Morecambe Bay, provides an example of the conditions under which many undocumented migrants find themselves.¹⁰² While the UK government has recognized limits to their ability to quantify and track the undocumented population as early as 2001, their efforts to date have resulted in widely varying representations of the undocumented population.¹⁰³ The most recent estimates indicate that there are 618,000 migrants who lack legal status within the UK.¹⁰⁴ Other studies have placed the number of undocumented migrants within the UK in the range of 525,000 to 950,000.¹⁰⁵ More than two thirds of this number, or 442,000, are thought to dwell in the London metropolitan area.¹⁰⁶

Undocumented migration exists on a wholly different scale in the US, when compared to the UK. The demographic characteristics of undocumented migrants are interesting in the context of the US. The Immigration and Nationalization Service, a

¹⁰¹ Woodbridge, J. *Sizing the unauthorized (illegal) migrant population in the United Kingdom in 2001*. (Home Office, 2005)

¹⁰² Watts, J. 'Going Under.' *The Guardian Unlimited*. (London, 20 June 2007) 6 at p.6

¹⁰³ Home Office, Immigration Research and Statistics Office. *Control of immigration: Quarterly Statistical Summary, United Kingdom-Third Quarter 2009*. (The Home Office, 2009)

¹⁰⁴ Ibid and Travis, A. (2009). Migrants amnesty would aid economy by 3 billion, says study. *The Guardian Unlimited* (London 16 September 2009)

¹⁰⁵ These figures come from the recently released LSE study that provided statistics through the end of 2007. Travis, A. (2009). Migrants amnesty would aid economy by 3 billion, says study. *The Guardian Unlimited* (London 16 September 2009)

¹⁰⁶ Home Office, Immigration Research and Statistics Office. *Control of immigration: Quarterly Statistical Summary, United Kingdom-Third Quarter 2009*, 2009. London, England: The Home Office. Reported in Travis, A. (2009). Migrants amnesty would aid economy by 3 billion, says study. *The Guardian Unlimited* (London 16 September 2009)

federal agency, closely tracks the flow of undocumented migrants using well-established methodologies. The most current statistics indicate a total of 11.6 million undocumented migrants within the US.¹⁰⁷ These reports indicate that the majority of undocumented migrants in the US come from Mexico, with average annual increases of 290,000 from 2000 through 2008.¹⁰⁸ Asian and African migrants are less specifically quantified in these reports, but represent a total of approximately 2 million persons.¹⁰⁹

The countries of origin of undocumented migrants to the US are related primarily to geography, since the majority came from Mexico, Central and South America.¹¹⁰ The Central American countries of Guatemala and El Salvador contribute heavily to the total number of undocumented migrants as well, largely for the same reasons seen in Mexican immigration trends.¹¹¹ The US experiences a continuous flow from the Caribbean, particularly Haiti, and some of the other Caribbean nations. There is an emerging influx to the US from both Asia (primarily China and the Philippine Islands) and from Eastern Europe. Unlike the UK, the US has no reciprocal agreements or treaties that result in high levels of legal immigration, such as that seen through the European Union member states. When one considers issues of scale, the size of the undocumented migrant population in the US is significantly larger than that seen in the UK, in no small part due to geography (eg the proximity of the US to Mexico). The scale of the undocumented migrant

¹⁰⁷ This statistic is the most current available, and comes from January 2008. While the number is large, it actually represents a slight decrease from 2007, when the department accounted for a total of 11.8 million. The decrease is attributed to more stringent border controls in the states bordering Mexico. United States, Immigration and Naturalization Service. *Illegal alien resident population. January 2009*. (INS, 2010)

¹⁰⁸ Ibid at p. 4

¹⁰⁹ This statistic includes primarily East Asia, and excludes 160,00 persons of Indian origin. United States, Ibid at p. 6

¹¹⁰ Ibid at p. 6

¹¹¹ Ibid at p. 7

population in the US is roughly comparable (in scale) to that seen in the UK if one were to exclude Mexican, Central and South American numbers from the total undocumented migrant population in the US.

The imposition of tighter immigration control regimes has significantly complicated the ability of undocumented migrants to dwell in western countries. The US reaction to 9/11 was characterized by a move towards strict enforcement of pre-existing immigration law, resulting in ‘roundups’ of undocumented migrants.¹¹² This resulted in many abuses including the prolonged detention of individuals with no connection whatsoever to terrorism, but who were detained under anti-terrorism statutes.¹¹³ A variety of media reports cite problems associated with undocumented migrants actions, for instance the story of Conses Garcia Zacarias, a 35 year old undocumented Mexican migrant who killed a young girl while drunken driving.¹¹⁴ Stories such as this have resulted in extensive debates decrying both the actions of select migrants and their treatment by unscrupulous employers who often take advantage of them.¹¹⁵ The range of responses by US communities included anti-immigration initiatives that have been countered by pro-immigrant movements in cities such as San Francisco¹¹⁶. This range of

¹¹² Lichtblau, E. ‘US report faults the roundup of illegal immigrants after 9/11.’ *The New York Times*. (New York, 3 June 2003)

¹¹³ Ibid

¹¹⁴ Applebome, P. ‘Grief, fury and debate rekindled.’ *The New York Times*. (New York, 10 June 2009) at p. 7

¹¹⁵ Ibid also at p. 7

¹¹⁶ The San Francisco City Council, in this case, has welcomed undocumented migrants and is currently refusing to enforce immigration laws within their community due to human rights based opposition that they have in relation to current enforcement efforts. McKinley, J. ‘San Francisco campaign tells illegal immigrants that they are safe there.’ *The New York Times*. (New York, 6 June 2008)

responses illustrates the degree of division within US society regarding the status of undocumented migrants.

Undocumented migrants are dwelling within both the UK and US, and utilizing social services, including healthcare. While laws in both countries provide limits to undocumented migrants ability to access health and social services, the degree of limitation is often unclear. In this context, this thesis seeks to observe current practices and clarify factors that influence practices within the healthcare and legal systems of the UK and US, and then apply comparative methodologies in order to arrive at conclusions regarding the role of law.

The Legal Definition of Undocumented Migrants to the UK.

For the purposes of this paper, the term undocumented migrant is being used to characterize individuals dwelling in the country without legal authorization. It is essential, however, to consider this concept in the context of the legal system of the UK.

¹¹⁷ Fortunately, there are some very clear statutory guidelines that offer such definitions. The Asylum and Immigration Act of 1971, as amended by the Asylum and Immigration Act of 1996 offers clear guidelines for characterizing individuals who lack legal authorization or leave to remain in the country. In general, the Act defines individuals without leave to remain as illegal entrants. ¹¹⁸ These individuals fall into two major categories, which include unlawfully entering or seeking to enter the country in breach of a deportation order or of other standing immigration laws and entering or seeking to enter

¹¹⁷ MacDonald, I. A. and Toal, R. *Macdonald's Immigration Law and Practice* (6th ed., Butterworth's Publishing Ltd., 2008)

¹¹⁸ Asylum and Immigration Act of 1996 (UK) (Sect 4).

by means of deception, with the express purpose of obtaining a legal right to enter and remain in the country.¹¹⁹

The 1996 Act is clear in its classification of the various categories of illegal entrants. The most obvious are those individuals who simply enter the country without leave, through whatever means. This would include clandestine entry into the country or any act of an administrative nature (ie deception) that seeks to obtain leave for an individual to remain when no legal grounds for this exist. These cases are the most clear-cut cases of illegal entry into the country.

Undocumented migration is particularly difficult to define in cases of individuals who legally entered the country, or who obtained temporary legal status after entering the country. Examples in this context include failed asylum seekers, or individuals who have applied for leave to remain on humanitarian grounds. In both cases, petitions to remain are often denied, for instance in the case of failed asylum seekers. In these cases, the Immigration and Asylum Act of 1971 with its 1996 amendments offers clear guidance.

¹²⁰ The key in these cases is the enactment of deportation orders. In these cases, where one remains and thus finds him or herself in breach of a deportation order, the Act clearly renders this individual an illegal entrant. The UK offers a stark contrast to the US in this sense, given the geographic limitations seen in North America. That is, while many individuals can simply walk across the US border, the UK does not afford this opportunity. Thus, it is logical to assume that individuals with failed asylum and humanitarian petitions for leave comprise a substantial proportion of illegal entrants to the UK. The circumstances through which individuals lose their legal status differ

¹¹⁹ Ibid

¹²⁰ Asylum and Immigration Act of 1996 (UK) (Sect 3, Para 1).

between the two countries, which lead to significant questions regarding the individual experiences of undocumented migrants within the respective countries.

The Legal Definition of Undocumented Migrants to the US

The degree of undocumented migration differs primarily in the magnitude of numbers of undocumented migrants when considering the US context. Due to various factors, including the lack of adequate social and economic infrastructure in Mexico, Central and South America, economics has driven this form of immigration to. The problems associated with illegal forms of immigration have come to the forefront of US politics recently due to the profound influx of individuals entering the US labor market. Under the Immigration and Nationality Act, Title 8, US Federal Code (1952), individuals who enter the US without legal authorization are deemed *illegal aliens*.

The Illegal Immigration and Immigrant Responsibility Act of 1996 is the most recent legislation to this end. This Act brought forth widespread changes to the US approach to its borders, which included vastly different administrative approaches to the documentation of resident status, and ranged to controversial aspects of the bill that authorized the building of physical barriers along the southern border and the use of military style security to prevent the influx of people entering along the border with Mexico.¹²¹

Under the US system, there is long standing legislation that identifies the criteria under which individuals may legally immigrate.¹²² Although aspects of the US approach

¹²¹ This was in part enacted through the United States department of Homeland Security through The Security and Prosperity Partnership for North America; March 23, 2005. Through this act the governments of Canada and Mexico agreed to firmer border controls which included a higher degree of border security, information sharing and even physical barriers between the countries.

¹²² The general stipulations regarding legal migration to the US are summed up in the Act's text, which asserts that "unless he has been lawfully admitted to the United States for permanent

have evolved through other legislation, for instance the Illegal Immigration and Immigrant Responsibility Act of 1996, the majority of the mechanisms through which legal status can be achieved remain unchanged. The 1952 Act, does in fact establish mechanisms through which individuals may legally immigrate, however, this requires that the US congress authorize such immigration through separate legislation. For instance, in the case of Cubans, immediate refugee status is granted, while Haitians, who come from even more deplorable conditions, this is not the case despite the obvious geographic and socioeconomic similarities.¹²³

Under section 237 of the 1952 Act, there are specific criteria for those who can be deported based upon illegal status (and thus by elimination, this establishes those who may remain). Similar to the system in the UK, anyone deemed to have entered the country without prior legal authorization in the form of a visa or work permit is said to be immediately deportable. This is a sizable population that comprises the vast majority of immigrants to the US with Latin American origins. Additionally, anyone, even those who are authorized domicile but then violate US law may be immediately deported as well. Many individuals are authorized via mechanisms such as student and or work visas to remain in the US for prescribed periods of time. Once these individuals have overstayed their non-immigrant resident status, they too may be removed from the country.

residence in accordance with all applicable provisions of this chapter. The burden of proof shall be upon such person to show that he entered the United States lawfully, and the time, place, and manner of such entry into the United States, but in presenting such proof he shall be entitled to the production of his immigrant visa, if any, or of other entry document, if any, and of any other documents and records, not considered by the Attorney General to be confidential, pertaining to such entry, in the custody of the Service” Immigration and Nationality Act Sec. 101 (a) (42) 1952 (US)From Chapter 6 Section 1429.=

¹²³ This section designates Cuban nationals entering the US as eligible applicants for admission to the country under legal grounds irrespective of their method of entry. Illegal Immigration and Immigrant Responsibility Act of 1996 (US), Section 212.

The primary mechanism through which one may enter legally and eventually obtain citizenship is through the establishment of resident alien status.¹²⁴ Through this process, application is made through the Immigration and Naturalization service. People who have entered the country legally negotiate the naturalization process, in the majority of cases. For example, those with work visas that have taken the appropriate steps to establish permanent domicile in the country who go on to obtain permanent jobs, pay the tax and often marry US residents. They then negotiate a process similar to that seen in the UK, through which they obtain permanent legal status. It must be noted, that the vast majority of individuals entering from Mexico, South and Central America fail to meet the criteria for such programs.

The major difference when comparing the legal status of individuals in the US from those in the UK and their efforts to obtain legal status involves the asylum process in the US. Under the 1952 Act, congress designates specific countries whose expatriates are eligible for asylum application. Since asylum opportunities are generally very limited and subject to the whimsy of congress, the US enjoys far lower numbers of such applications.¹²⁵ Thus, there are relatively few *failed asylum seekers* in the US.¹²⁶ The vast majority of ‘illegal aliens’ in the US would be deemed under UK law to be illegal entrants who entered under clandestine circumstances.¹²⁷

¹²⁴ This process is often referred to as obtaining a ‘green card’. Immigration and Nationality Act, Title 8, US Federal Code, Chapter VII (1952),

¹²⁵ Rottman, A., Fariss, C., and Poe, S. “The path to asylum in the US, who gets it and why.” (2009) 41(3), *International Migration Review*, 3 at p. 5-9

¹²⁶ Ibid at p. 9-10

¹²⁷ Asylum and Immigration Act of 1996 (UK). (From Sect 4, Para 4).

Conclusion

This chapter has set the stage for more in depth discussion of undocumented migrant's status within the UK and US. This is essential, in that this chapter has set forth a description of undocumented migrants, which establishes their status as a vulnerable population. As a vulnerable population, concerns regarding human rights become central to any discussion of rights of the individual and state's obligation to provide services under various conditions. In the chapters that follow, a more in depth discussion of undocumented migrants is undertaken. This includes a particular focus on their legal status as it relates to their ability to gain social services and medical care. This will require a concise examination of the medical systems in the respective countries and the normal way of accessing care. Undocumented migrants will then be defined based upon their ability to gain health services within the parameters of the law, and later through empirical inquiry.

Chapter 3- Legal and Human Rights Issues Related to Healthcare Rights in the United States

A society's approach to the provision of health and social care to its inhabitants is closely related to many factors. Human rights approaches, similarly, represent a reflection of their historical, cultural and legal approach to ensuring the observation of individual rights, particularly in the case of those with the greatest need. The healthcare system in the US retains a unique structure, in that it is the largest privatized healthcare system in the world.¹²⁸ The system is characterized by a high degree of fragmentation, given the mixture between various private and government providers of healthcare services.¹²⁹ Due to its heavily privatized nature, the health care system in the US represents a major portion of the US economy. Because the healthcare system is a 'for profit' entity, the dynamics of the system reflect a business model, rather than the government services provision model that is common to the vast majority of countries in the world.¹³⁰ The issue of profit in a human services endeavor requires that one examine the financial imperatives inherent to the system. Cost is an over-riding theme in discussions of the ability of underserved populations to gain health services in the US.¹³¹ When one considers the interaction of a variety of government funded health services, public health and state

¹²⁸ The term privatized refers to a healthcare system that is based largely upon private funding for individual health services. This funding invariably comes from 'for profit' entities such as insurance companies, or from individuals who simply fund their own health services. Although the US government does fund health services for some citizens this too largely takes the form of government payment into the privatized healthcare system. Singh, A., and Shi, L. *Essentials of the US Healthcare System*. (Jones and Bartlett Publishing, 2004) at p. 8-11.

¹²⁹ Ibid, at p. 20-27

¹³⁰ Jonas, S. *An Introduction to the US Healthcare System* (4th ed., Springer Publishing Company, 2003) at p. 22-23.

¹³¹ Leiyu, S., Stevens, G., and Politzer, R. "Access to care for US health center patients and patients nationally: How do the most vulnerable populations fare?" (2007) 45(30), *Medical Care*, 206 at p. 209-209

provided insurance programs, a very convoluted picture arises. The purpose of this chapter is to explore the US approach to human rights and the provision of healthcare in order to highlight possible areas of difficulty experienced by undocumented migrants who seek to gain health related services.

Background

The purpose of this section is to examine the issues present in the literature documenting the phenomenon of healthcare access for HIV positive undocumented African migrants in the US. This is presented in order to detail what is known regarding access to healthcare according to the extant literature.

Access to health services by undocumented migrants

Undocumented migrants to the US have experienced great difficulty in gaining healthcare services.¹³² Given the fact that they are not eligible for the majority of government funded programs, and that they often lack the funds to purchase healthcare insurance, the majority of services which they gain are either directly purchased, or used without payment resulting in sizable financial debt.¹³³ Berk et al support this assertion, through their finding that the aforementioned trend resulted in relatively low rates of general practice based primary care usage amongst undocumented migrants, with similar rates of hospitalization when compared to the general population.¹³⁴ Under the US system, individuals born in the US are granted citizenship, while conversely, those who

¹³² Nandi, A., Loue, S., and Galea, S. "Expanding the Universe of Universal Coverage: The Population Health Argument for Increasing Coverage for Immigrants." (2009) 11(6), *Journal of Immigrant and Minority Health*, 433 at p. 435

¹³³ This phenomenon is partly cultural since many services gained in Mexico and Central America would require payment if they were not gained in a government run facility. Berk, M., Schur, C., Chavez, L., and Frankel, M. "Health care use among undocumented Latino immigrants." (2000) 19(4), *Health Affairs*, 51 at p. 58-61

¹³⁴ Ibid at p. 62-64

are foreign born cannot avail themselves of the full range of available services.¹³⁵

Studies have reflected upon this notion, for instance, by detailing the fact that non-US born migrant children experience far lower rates of healthcare access than those born in the US.¹³⁶ Additional studies have shown that undocumented migrants' access to all health services (including emergent, ambulatory care and hospital based) lag behind that of the general population.¹³⁷ Even migrant's at the greatest risk and who generally show high rates of healthcare service utilization, for instance the elderly, experience lower rates of healthcare insurance and healthcare utilization compared to their native born counterparts.¹³⁸ Migrants' access to private insurance lags even further behind that of the general population, largely due to regulatory and socioeconomic factors that serve to limit their ability to participate in such programs.¹³⁹

Access to HIV related services by undocumented African migrants

The rates of HIV infection amongst African migrants to the US have resulted in significant numbers of HIV positive African migrants. Studies in the US have focused on barriers to care in the US context. For instance, cultural barriers, such as fear of

¹³⁵ Fortuny, K. Capps, R. & Passel, J. S. *The characteristics of unauthorized immigrants in California, Los Angeles County, and the United States*, The Urban Institute, Washington, DC, 2007.

¹³⁶ Chang, C. "Health care for undocumented immigrant children: special members of an underclass." (2005) 83, *Washington University Law Quarterly*, 1271; Blewett, L. A., Johnson, P. J., and Mach, A. L. "Immigrant Children's Access to Health Care: Differences by Global Region of Birth." (2010) 21(2), *Journal of Health Care for the Poor and Underserved*, 13 at p. 16-20

¹³⁷ Ku, L., and Matani, S. "Left out: Immigrants' access to health care and insurance." (2001) 20(1), *Health Affairs*, 247; Fairchild, A. L. "Policies of inclusion: Immigration, disease, dependency and American immigration policy at the dawn and dusk of the 20th century." (2004) 94, *American Journal of Public Health*, 528; Nandi, A., Galea, S., Lopez, G., Nandi, V., Strongarone, S., and Ompad, D. "Access to and use of health services among undocumented Mexican immigrants in a US urban area." (2008) 98, *American Journal of Public Health*, 2011

¹³⁸ Choi, S. "Insurance status and health service utilization among newly arrived older immigrants." (2006) 8(2), *Journal of Immigrant and Minority Health*, 149 at p. 150-154

¹³⁹ Ibid at p. 159-161

disclosure of their HIV positive status within their own community often influence Africans to delay seeking care.¹⁴⁰ Additional factors that limit care were related to suspicion regarding the healthcare system, perceived racism on a systemic basis and lack of due to the aforementioned limitations to care.¹⁴¹ Finally, factors including cultural and language barriers present in US facilities are major limitations to HIV care access, particularly in the case of Francophone or native African language speakers who might otherwise seek care.¹⁴² Further, structural factors and limitations to healthcare access for undocumented African migrants greatly limit access to HIV testing and treatment modalities.¹⁴³ The aforementioned trends result in African's delaying their presentation for care until the late stages of HIV disease as compared to individuals who possessed legal status.¹⁴⁴ Their later presentation for care elucidates the detrimental effect posed by their lack of access to care. The combination of social, cultural and systemic limitations to healthcare access has significantly decreased the ability of Africans to seek care in the US.

¹⁴⁰ Foley, E. "HIV/AIDS and African Immigrant women in Philadelphia: Structural and cultural barriers to care." (2005) 17, *AIDS Care*, 1030; Akinsete, O., Sidesw, T., Hirigoyen, C., Cartwright, C., Boraas, C., Davey, C., Pessoa-Brandao, L., McLaughlin, M., Kane, E., Hall J., and Henry, K. "Demographic, clinical and virologic characteristics of African born persons with HIV/AIDS in a Minnesota hospital." (2007) 21, *AIDS Patient Care and STDs* 356 at p. 360-361

¹⁴¹ Foley, E. "HIV/AIDS and African Immigrant women in Philadelphia: Structural and cultural barriers to care." (2005) 17, *AIDS Care*, 1030 at p. 1032

¹⁴² Simbiri, K., Hausman, A., Wadenya, R., and Lidicker, J. "Access impediments to health care and social services between Anglophone and Francophone African immigrants living in Philadelphi with respect to HIV/AIDS." (2009) 12(4) *Journal of Immigrant and Minority Health*, 569

¹⁴³ Ibid at p 569-570

¹⁴⁴ Ibid at p. 572

Vulnerability and Socioeconomic Status

Due to the challenges that they face, undocumented migrants comprise a population that is considered vulnerable in the US.¹⁴⁵ While a variety of variables influence the level of vulnerability seen in the African migrant community in the US, socioeconomic factors have the most significant influence on their ability to gain vitally needed resources.¹⁴⁶ Migrants are considerably more likely to have dropped out of high school, work in occupations associated with poor pay and benefits, and live in poverty more often than their native counterparts.¹⁴⁷ When one combines the influence of poverty with migrant fears regarding detection by immigration authorities, it becomes very clear that these issues contribute heavily to the overall wellness of the undocumented migrant population.¹⁴⁸ While African American persons native to the US have experienced gradually improving levels of economic success, African migrants have continued to manifest even lower levels of access to basic services and far lower earnings than their US borne counterparts.¹⁴⁹ These racial and ethnic inequalities are significant in that undocumented migrants to the US suffer higher rates of socioeconomic deprivation even when compared to African migrants to nearby countries such as Canada.¹⁵⁰ All told,

¹⁴⁵ Goldman, D. Smith, J. and Sood, N. "Immigrants and the cost of medical care." (2006) 25(6), *Health Affairs*, 1700 at p. 1708-1709

¹⁴⁶ Derose, K., Escarce, J., and Lurie, N. "Immigrants and healthcare: Sources of vulnerability." (2007) 26(5), *Health Affairs*, 1258 at p. 1260-1261

¹⁴⁷ Ibid at p. 1258

¹⁴⁸ Okie, S. "Immigrants and healthcare-At the intersection of two broken systems." (2007) 357, *New England Journal of Medicine*, 525 at p. 525-526

¹⁴⁹ Siddiqi, A., Zuberi, D., and Nguyen, Q. "The role of health insurance in explaining immigrant versus non-immigrant disparities in access to health care: Comparing the United States to Canada." (2009) 69, *Social Science and Medicine*, 1452 at p. 1458-1459

¹⁵⁰ Siddiqi, A., and Nguyen, Q. "A cross-sectional comparative perspective on racial inequalities in health: The USA versus Canada." (2010) 64, *Journal of Epidemiology and Community Health*, 29 at p. 30

the literature indicates significant socioeconomic deprivation among African migrants to the US.

The effects of healthcare access patterns on the health and well being of African migrants.

The literature regarding undocumented migrants' health related outcomes as they relate to issues of access to health services are limited. The primary factor that results in negative health outcomes in African migrants is the fact that these individuals tend to present later in their respective disease processes due to factors limiting their access to care.¹⁵¹ In the context of the US, there are other studies that show clear health effects associated with limitations to healthcare access in Africans. These focus on correlations between the lack of citizenship in this population and the resultant health effects. One such study details the negative effect on rates of breast and cervical cancer screening and concurrently increased health risk in undocumented migrants.¹⁵² This finding was further corroborated by an additional study, which supported the notion that the lack of citizenship detracts from the ability to gain this vital form of screening.¹⁵³ While studies that reflect directly on issues of access to care in migrants are limited, studies support the notion that there is an effect associated with limiting care to African migrants.

¹⁵¹ Akinsete, O., Sidesw, T., Hirigoyen, C., Cartwright, C., Boraas, C., Davey, C., Pessoa-Brandao, L., McLaughlin, M., Kane, E., Hall J., and Henry, K. "Demographic, clinical and virologic characteristics of African born persons with HIV/AIDS in a Minnesota hospital." (2007) 21, *AIDS Patient Care and STDs*, 356 at p. 361

¹⁵² Echeverria, S., and Carrasquillo, O. "The roles of citizenship status, acculturation and health insurance in breast and cervical cancer screening among immigrant women." (2006) 44, *Medical Care*, 788 at p. 790-791

¹⁵³ De Alba, I., Hubbell, F., McMullin, J., Sweningson, J., and Saitz, R. "Impact of US citizenship status on cancer screening among immigrant women." (2005) 20, *Journal of General Internal Medicine*, 290 at p. 296

Legal aspects of access to social care in the US.

While there are major differences between the privatized US healthcare system and the nationalized healthcare system of the UK, the US maintains a robust system of social care. The social care system in the US has many similarities to the system in the UK and the majority of the developed world. While many propose that undocumented migrants provide a substantial drain on direct social assistance programs in the US, the enrollment of undocumented migrants in social programs is not authorized under current regulations.¹⁵⁴ This was not the case in the past; however, revisions of the law, particularly in instances such as the Personal Responsibility and Work Opportunity Act of 1996 served to place substantial limits on their entitlement. The lack of ability to access social services has resulted in a situation where individuals suffering from chronic disorders lack the ability to gain social care, food or housing assistance due to their lack of legal status. Life necessities are important aspects of an effective healthcare regimen, and thus, represent a further limitation to the maintenance of health for undocumented migrants who suffer from diseases such as HIV.

Structure of the US Healthcare System

The US healthcare system is complicated due to the intermingling of private and public entities involved in various aspects of health care delivery. It is important to consider that this intermingling does not represent the sort of parallel system that is seen

¹⁵⁴ Neumark, D., and Wascher, W. "Minimum Wages and Low-Wage Workers: How Well Does Reality Match the Rhetoric?" (2008) 92, *Minnesota Law Review*, 1296; Yakushko, O. "Understanding the roots of negative attitudes towards immigrants." (2009) 37, *The Counseling Psychologist*, 36

in countries such as Japan.¹⁵⁵ It is useful to examine the US system in the context of the differing levels of services and service provision settings. In this section, a discussion of the primary care system, hospital based services and public health entities will be provided.

The primary care system in the US is one that is based, in large part, on individual medical practices that are owned and operated by private entities. These private entities range from physicians in independent practice to groups owned by Health Maintenance Organizations (HMO's) or large hospitals. Within the primary care system, the underlying basis for offering services reflects a business model wherein patients maintain the full responsibility for payment for services they receive from a particular practitioner. The level of individual responsibility, however, varies depending upon the individual's health insurance or lack thereof. That is, a patient with no insurance must pay the entire cost of care, while individuals with insurance are responsible for varied levels of cost based upon co-pay required by their insurance.¹⁵⁶ Access to this system is based solely on one's ability to pay for services. Thus, the lack of financial resources can be a primary limiting factor in cases where individuals, regardless of residency status, lack the financial resources necessary to gain services. Additionally, the inability of

¹⁵⁵ In the case of Japan there is a mandated public system mirrored by a fee for service system. This creates a situation where individuals may either use the national healthcare system or purchase services out of convenience, or to avoid state mandated rationing in the state mandated system.

¹⁵⁶ Co-pay refers to an additional payment required by the insured at the point of service. That is, when they present for care they are required to pay a fee in addition to their normal insurance premium. Co-pay amounts range widely based upon the quality of insurance. This can range from a 10-20 dollar fee per visit, to a set percentage ranging from 10-30 percent of total healthcare fees.

undocumented immigrants to gain traditional mainstream jobs results in their de facto inability to obtain health insurance.¹⁵⁷

There are limited publicly funded primary care resources available. These services are funded, depending upon jurisdiction by local, state or federal governmental entities. It is important to note that these clinical settings make up a very small percentage of the US healthcare system. Additionally, these services are largely means tested.¹⁵⁸ On the local level municipalities sometimes fund local public health departments for the provision of primary care services to low-income individuals. State health departments often offer similar services in areas that lack sufficient healthcare resources.¹⁵⁹ Finally, the federal government provides primary care services to the general population through the Community Health Centers provisions of the Public Health Service Act.¹⁶⁰ Depending upon the particular jurisdiction, residency and citizenship status can be one of the determining factors in gaining primary care services from a publicly funded clinic.

The Migrant Health services Provisions of the Public Health Service Act provide for the funding of clinics that provide direct care or primary care services to migrants.¹⁶¹ The Act provides for grants to private not for profit entities, in a manner similar to that

¹⁵⁷ Ferguson, C. "Barriers to serving the vulnerable." (2007) 26(5), *Health Affairs*, 1358 at p. 1360-1361

¹⁵⁸ Means testing is a US term that refers to services that are rendered based upon ones income level. In the case of healthcare services, these programs generally render services to individuals with documented income that is below 200% of the federally set poverty income level.

¹⁵⁹ The term underserved reflects a federal term that is applied to areas that lack sufficient clinics or healthcare providers for the population in a given area. This is a very common phenomenon in rural areas and small towns distant from large population centers.

¹⁶⁰ This act funds private not for profit entities to set up and operate clinics that provide care based upon means testing. A portion of clinics under the provisions set forth in this legislation provides funding for limited amounts of healthcare provision to migrants working as farm workers. Public Health Service Act, 1946, (US), Title XVI.

¹⁶¹ The Act defines the status of and provision of services for seasonal and migrant farm workers. The act does not make provisions for the use of services by migrant workers in other non-agricultural industries. Ibid

seen with the Community Health Centers.¹⁶² This Act was created primarily to provide services to migrants working in the agriculture industry.¹⁶³ Migrant health centers are located in areas that have large populations of migrants involved in agriculture, and thus, are limited to specific geographic regions. The program is meant to be comprehensive, in that it provides for worker advocacy, environmental health, occupational health and the gamut of conventional healthcare services. In total, there are 400 of these clinics spread across the US.¹⁶⁴ They tend to be comprised of very small facilities, due to the seasonal nature of their operation, and serve primarily Latino migrants.¹⁶⁵

The US enjoys a large number of well-equipped, technologically advanced hospitals. Even the smallest municipalities enjoy the presence of one or more hospitals. Hospitals within the US, depending upon their ownership, are either “for profit” or “not for profit”. For profit hospitals tend to be owned by large healthcare corporations, while not for profit facilities are most frequently administered by universities that are funded at the state level. Regardless of profit earning status, these facilities operate largely through a business model, and must garner sufficient earnings to meet their expenses at the very minimum. In the case of for profit hospitals, they must meet expenses as well as generate profit for their shareholders. As is the case with the majority of primary care entities, individuals maintain the responsibility for costs incurred in hospitals. Again, the level of

¹⁶² The contribution of government funded migrant care is substantial according to the Kaiser Commission on Medicaid and Healthcare for the Uninsured, 2007. For instance, 2002, 125 of 843 federally funded health centers received direct funding for migrant health needs, with service to a total of 670,000 migrant and seasonal farm workers and their families.

¹⁶³ Ibid

¹⁶⁴ These are federally funded clinics that serve regional populations of undocumented migrants. Public Health Service Act, 1946, (US), Title XVI.

¹⁶⁵ Since the workers tend to migrate seasonally, many centers are opened only for brief periods of time during the planting or harvesting seasons in a given region.

financial burden is based, in part, on the type and nature of insurance possessed by an individual.

The public health system in the US is structured primarily to provide for individual, population and environmental health.¹⁶⁶ Individual services in local health departments are limited generally to preventative services, gynecologic services, and the control of sexually transmitted disease, infectious disease management and the enforcement of environmental health standards.¹⁶⁷ These clinics offer very limited services, however, they frequently offer services to undocumented migrants, particularly in the area of infectious disease control, since this has ramifications perceived to effect the general population. These services are funded by government entities (state or county), and are, at times means tested.¹⁶⁸ Many of the services available within public health departments are duplicated in fee for service settings. Thus, those with the financial resources tend to avoid care in this setting, instead opting for more individualized care in a for profit setting. Generally speaking, health departments are not structured to provide general medical services, and are not considered primary care sites. Care within these centers is often limited when considering undocumented migrants due to the combination of limited service provision (ie no primary care services) and limitations placed on such services by state government.¹⁶⁹ Further, undocumented

¹⁶⁶ Altman, S., Shactman, D., and Eilat, E. "Could the US hospital industry go the way of the US airlines?" (2006) 25(1), *Health Affairs*, 11 at p. 15-17

¹⁶⁷ Ibid at p. 19-20

¹⁶⁸ Means testing refers to a determination of one's ability to pay based upon their level of income.

¹⁶⁹ The vast majority of public health departments in the US are state, rather than Federal, entities. Thus, the mission of these institutions varies according to the state. Service provision, thus, ranges from the full range of medical services, to services focused primarily on communicable disease (ie Immunizations and/or Sexually Transmitted Disease management) and environmental health concerns (ie Clean water and food). Gallardo, E. and V. Huang, V. *Expanding Access to*

migrants tend to avoid entering governmental settings out of fear that their immigration status might be discovered and brought to the attention of law enforcement authorities.¹⁷⁰

Healthcare Finance in the US

The US healthcare finance system is unique in the world, given the multiple payer nature of the system. While all individuals maintain ultimate responsibility for the cost of their healthcare, the system is characterized by a mix of ‘fee for service’, private non-governmental insurance and government funded insurance programs. Because of the various private and public insurance programs, a fragmented system of healthcare finance is seen in the US. The purpose of this section is to examine the sources of healthcare finance in the US, while considering the pattern of access to programs by undocumented migrants.

Healthcare spending in the US is the highest in the world with per capita spending that comprises 15% of the countries Gross Domestic Product.¹⁷¹ Spending continues to rise annually with the greatest increase in expenditures in the area of hospital care, drug sending and physician and physician specialist (ie consultant) services.¹⁷² Of particular impact is the cost of prescription drugs in the US, which is rising at roughly twice the rate as other US products.¹⁷³ Given that individuals bare the cost of medications within the

Health Care Services: A Policy Brief. (California Primary Care Association, 2002); National Immigration Law Center. *Guide to Immigrant Eligibility for Federal Programs.* (National Immigration Law Center, 2002) at p 17-23.

¹⁷⁰ National Association of Community Health Centers. *Migrant and Seasonal Farm worker Access to Health Care Services and Insurance Coverage: Summary Report on Issues, Resources and Potential Solutions.* (National Association of Community Health Centers, 2003)

¹⁷¹ World health Organization. *The World Health Report.* (WHO Press, 2006) at p.2

¹⁷² Levit, C., Cowan C., Lazenby H., Sensenig A. and Catlin A. “Trends in US healthcare spending.” (2003) 2(1), *Health Affairs*, 154 at p. 160-163

¹⁷³ Goldman, D., Joyce, G., and Zheng, Y. “Prescription drug cost sharing.” (2004), 298(10) *Journal of the American Medical Association*, 61 at p. 70-74

US system, this trend has had a significant impact on healthcare access rates.¹⁷⁴ The spending characteristics inherent to the system do not bode well for future initiatives, given the nearly overwhelming burden that the system places on US society.

Prior to 1965, the US healthcare system was very different as compared to today's system largely due to the issue of finance. When Medicare legislation was signed into law in 1965, the first publicly funded healthcare plan was enacted.¹⁷⁵ The program funds the care of the elderly, based upon their lifetime contributions to the social security system.¹⁷⁶ While the plan finances healthcare services, it does so within the privatized healthcare system. Thus, the plan provides payments to a wide array of public and private entities on behalf of the plan's beneficiaries.

The 1965 legislation that resulted in Medicare also resulted in the Medicaid Program, which funds healthcare services for low-income people.¹⁷⁷ The Medicaid program is unique when compared to the Medicare program given its differing finance structure. While the program is by law, administered by the federal Centers for Medicare and Medicaid Services, it is a joint federal-state program.¹⁷⁸ Thus, while federal guidelines guide the program, both federal and state tax dollars are pooled to fund the program. Due to the shared nature of the funding, there are frequent controversies between state and federal government entities related to funding.

While Medicare and Medicaid make up the bulk of governmentally funded

¹⁷⁴ Ibid

¹⁷⁵ United States Code, 42, 1395a.

¹⁷⁶ The program funds care for citizens or legal residents who have sufficiently contributed to the system and who are 65 years old or greater.

¹⁷⁷ This program is means tested, meaning that proof of income is required to document one's financial need. United States Code, 42, 1396

¹⁷⁸ United States Code, 42, 1396.

programs, there are other programs that fund health services on behalf of the government. These include the Veteran's Administration, United States Public Health Service and various state agencies. These programs, to varying degrees, fund programs at the state level. That said, private insurance policies are the largest sector of healthcare finance after the various governmentally funded programs.¹⁷⁹ Such programs are funded jointly by employers and workers although it is possible for an individual to purchase insurance independently. While these plans are available, there are direct relationships between poverty and lack of insurance coverage, with annual drops in the ranks of the insured over the past two decades.¹⁸⁰ The association between poverty and the lack of coverage is highly related to the type of work that one secures.¹⁸¹ That is, less skilled workers tend to secure positions that do not fund healthcare coverage.¹⁸² While it is desirable for companies to supply healthcare coverage to their employees, the cost of doing so is making US companies less competitive with their overseas counterparts, particularly in the developing world. Thus, many companies are foregoing the offer of health services to their employees in order to cut cost.¹⁸³ This aspect of US healthcare finance is reaching crisis proportion, with many experts forecasting the collapse of the employee-employer

¹⁷⁹ Chernew, M., Baiker, K., and Hsu, J. "The Specter of Financial Armageddon — Health Care and Federal Debt in the United States." (2010) 362, *The New England Journal of Medicine*, 1166 at p. 1167-1169

¹⁸⁰ DeNavas-Walt, C., Proctor, B.D., and Lee, C. H. *Income Poverty and Health Insurance in the United States*. (US Department of Commerce, 2006) at p. 20-33

¹⁸¹ Neumark, D., and Wascher, W. "Minimum Wages and Low-Wage Workers: How Well Does Reality Match the Rhetoric?" (2008) 92, *Minnesota Law Review*, 1296 at p 1300-1302

¹⁸² *Ibid* at p. 1315

¹⁸³ Reinhardt, U. E., Hussey, P. S. and Gerard F. Anderson, G. F. "US Healthcare spending in the international context." (2004) 23(3), *Health Affairs*, 10 at p. 16-18

based insurance system.¹⁸⁴

When considered as a whole, healthcare finance in the US is extremely complex, with multiple layers of finance. This has resulted in varied cost and fee structures that are designed in order to maximize profit or at the very least, decrease the rate of economic losses to insurers. The problem within the system arises with the issue of the uninsured, who seek care, but are often unable to pay for it. This has resulted in a large burden for healthcare facilities that cannot turn them away (eg Hill-Burton facilities or Emergency Departments). As a result, many facilities shift cost to individuals with insurance by raising prices, thus fueling the problem.¹⁸⁵ Many smaller or rural facilities operate at substantial losses, placing in question their very existence.¹⁸⁶ The expensive nature of the system coupled with the ever-shrinking pool of insured individuals would certainly affect the future financial status of the US system.

The aforementioned challenges have resulted in a move towards extensive reforms in the US healthcare system. The very high proportion of the Gross Domestic Product attributed to healthcare has long foretold the collapse of the system due to the weight of its extreme cost.¹⁸⁷ These trends served as the impotence for the current initiatives of President Barack Obama, who upon his election began a legislative initiative driven towards healthcare reform. These initiatives were, and have been extremely controversial

¹⁸⁴ Enthoven, A. C. "Employment-Based Health Insurance Is Failing: Now What?" (2004) *Supple 3, Health Affairs*, 237 at p 243-244.

¹⁸⁵ Dobson, A, Davanzo, A., and Sen, N. "The cost-shift payment 'hydraulic': foundation, history, and implications." (2007) 25(1), *Health Affairs*, 22 at p. 30

¹⁸⁶ Bennett K.J., Moore C.G., Probst, J.C. "Estimating uncompensated care charges at rural hospital emergency departments." (2007) 23(3), *Journal of Rural Health*, 258 at p. 260-261

¹⁸⁷ Brown, L. "The amazing non-collapsing US healthcare system: If reform finally at hand." (2008) 358(4), *The New England Journal of Medicine*, 325

given disagreements between officials within both major parties (Democrat and Republican) within the US.¹⁸⁸ The major point of contention within the plan has been the proposal for an alternative insurance plan that would be subsidized by the government, and which would compete with private insurance providers.¹⁸⁹ The specter of such a program has raised significant concerns amongst conservative who characterize the initiative as a socialist takeover of the healthcare industry in the US.¹⁹⁰ After its introduction, President Obama's health plan met many of the same protests as were associated with President Bill Clinton's 1993 healthcare reform initiative.¹⁹¹ The recent death of senator Ted Kennedy indirectly resulted in a slowing of health reform within the US, by requiring a special election to fill this congressional seat. The outcome of the special election in Massachusetts altered the majority enjoyed by President Obama's party, thus resulting in greater difficulties in healthcare reform in the US.¹⁹² The result was the passage of legislation that comprises the beginning stages of a nationalized health system.¹⁹³ The initial format of the legislation calls for the establishment of means by which all US citizens will be able to gain insurance from private insurance companies at rates determined by their income levels.¹⁹⁴

¹⁸⁸ Oberlander, J. "The partisan divide." (2008) 359(8), *The New England Journal of Medicine*, 781 at p. 781

¹⁸⁹ Roehr, B. "US healthcare reform may flounder over proposal for federal insurance programme." (2009) 338, *British Medical Journal*, 1194 at p. 1194-1195

¹⁹⁰ Ibid at p. 1196

¹⁹¹ Oberlander, J. "The partisan divide." (2008) 359(8), *The New England Journal of Medicine*, 781 at p. 782-783

¹⁹² Miga, A. Democrats lose supermajority as Brown sworn in. *The Washington Times*. 5.2.2010.

¹⁹³ The Patient Protection and Affordable Care Act (2010), P.L. 111-148; The Home Care and Education Reconciliation Act (2010), P.L. 111-152.

¹⁹⁴ Ibid

Laws Governing Healthcare Access in the US

The US, as the world's sole remaining free market healthcare system, maintains a high level of personal responsibility for the purchase or finance of healthcare services. The country's laws are in many ways counter to the typical fee for service model due to the intermingling of social programs such as Medicare and Medicaid. This is especially true when one considers federal legislation, which in part, dictates issues of healthcare access based upon federal finance of healthcare and healthcare infrastructure. The focus of this section will be federal regulations that play a role in determining access to health services in the US.

Although the majority of the US healthcare system is privatized, the public need for healthcare facilities and massive capital requirements necessary to construct healthcare facilities has resulted in some level of government intervention. The primary law in this area is the Hospital Survey and Construction Act, which is known by its namesake legislators as the Hill-Burton Act of 1946.¹⁹⁵ The Act authorizes assistance to medical facilities such as hospitals. Under the Community Service Assurance section of Title VI of the Public Health Service Act, recipients of Hill- Burton funds maintain the responsibility to offer services within certain parameters that extend beyond the facility's normal approach to offering services. They must, at the very least, offer services to those residing within the facility's service area without discrimination based upon race, color, national origin, creed or any grounds not related to the individuals ability to pay. Based upon this Act, for instance, individuals who require care can present to the emergency

¹⁹⁵ Hill-Burton Act, 1946 (US) 42 United States Code 201.

departments at such facilities and cannot be denied services.¹⁹⁶ Given the fact that the majority of non-profit facilities benefited from funding related to the Act, the vast majority of such facilities are required to require services to individuals based solely on their need for service and their domicile.¹⁹⁷ Finally, the Act requires that such facilities provide, at minimum, a medical screening to individuals regardless of their immigration status. If this medical screening determined that the person was at urgent need of life saving care, the law would require the administration of care.¹⁹⁸ The cost of this care, however, would be borne by the person receiving it.¹⁹⁹

The Public Health Service Act of 1946 was adopted by the US Congress at the time that the Hill-Burton Act was enacted.²⁰⁰ Although wide ranging, the Act contains provisions that pertain directly to the provision of health services. It is in the area of care provision to those without means, also referred to as the ‘underserved’, that the Act is most applicable to the question of providing health services to individuals regardless of their immigration status. The Act establishes the legal basis for the funding of Community Health Centers designed to provide care to populations that lacked other health insurance coverage and/or the means to otherwise purchase healthcare. While the Act provides that institutions receiving service from such agencies do so within their established service area, it does not allow for residents of this area to be discriminated against based upon their immigration status. Thus, the Act establishes mechanisms by which services can be funded by the federal government, even in the case of

¹⁹⁶ Title XVI of the Public Health Service Act, 1946.

¹⁹⁷ Under the US system, the lack of regional facilities or a regional healthcare structure make it extremely difficult to limit access to healthcare based on the service area provision of the law, as healthcare providers would have to make this determination at the point of service.

¹⁹⁸ United States Code, 42, 1395dd (Emergency Medical Treatment and Active Labor Act)

¹⁹⁹ Ibid

²⁰⁰ 42 United States Code 201, 1946.

undocumented migrants. It is important though, to consider that the Act applies only to agencies that have been granted federal funding through the program, and as such, does not extend to health centers funded solely through state or local programs.

The Emergency Medical Treatment and Active Labor Act (EMTALA) was established in 1986 in order to combat the practice of *patient dumping* in which facilities would transfer patients regardless of their medical condition based primarily upon their lack of insurance or other factors that were not strictly based upon the individual's medical condition.²⁰¹ The Act is expressly related to hospitals and by its very nature, directs the administration of care within emergency departments. Under the Act, individuals are guaranteed 'an appropriate medical screening examination' with the express purpose of determining whether or not the individual is suffering from an emergent medical condition. If it is found that an individual is suffering from an emergent condition, the facility must provide life saving care within the accepted standards of care regardless of any factor other than the individual's medical condition. This includes the prohibition of discrimination based upon one's immigration status. Thus, under this Act, undocumented migrants are by law, authorized care in emergency departments when it is determined that they suffer from an emergent medical condition.

While several Federal Acts do not limit undocumented migrants access to care, there are programs that do limit care only to citizens of the US or who are permanent authorized residents of the country.²⁰² Medicare is the largest of these programs, and was

²⁰¹ The Emergency Medical Treatment and Active Labor Act (1986). 42 United States Code 1395dd from Section 1867 of the Social Security Act of 1935.

²⁰² Permanent authorized residents are those who have applied to the government and who have become resident aliens of the country. These individuals are often said to possess a 'green card' or resident alien authorization card.

designed and authorized in order to provide financing for medical care for the elderly and the disabled.²⁰³ Under the Medicaid program federal funding is provided to the states in order to offer medical services to needy individuals.²⁰⁴ Eligibility is based on financial not medical need. Individuals determined to be medically disabled receive funding under Medicare, and with the determination of financial need, receive co-insurance under the Medicaid program. While most undocumented migrants would meet the income criteria for this program, their lack of legal status precludes their participation in means based programs such as Medicaid. The lack of coverage availability for undocumented migrants under federally funded systems creates an odd paradigm wherein the federal government supports their access to care in several, but not all available medical contexts within the country.²⁰⁵

Undocumented Migrants' Access to Healthcare: Legal Developments

Issues of healthcare access for undocumented migrants have been addressed in the US legal system. The progression of changes to the US legal system have been characterized primarily by legislative actions directed towards limiting or changing the nature of access of undocumented migrants to a variety of publicly funded services. Change in this area has been driven largely by the combination of public debate over the legitimacy of undocumented migrants and their rights to such services and the need to control cost

²⁰³ Elderly are availed of coverage at age 65, while other individuals must apply for and be accepted for authorization based upon their level of disability as determined by healthcare professionals, a formalized process which is often mediated by the courts under 42 United States Code, 1395.

²⁰⁴ 42 United States Code, 1396d

²⁰⁵ For instance, hospitals are required to administer care to severely ill persons regardless of immigration status. These individuals must pay for these services. They may, however, receive free services at government funded migrant health clinics, but are not authorized to receive funded services if referral to a consultant is necessary.

associated with paying for services on behalf of individuals perceived to be failing to contribute to the tax base.²⁰⁶

Public opinion is a very strong mitigating factor in issues of immigration within the US system. Given the complicated interaction between the legislative bodies and courts in the US, it should be no surprise that public opinion, and the resultant legislation has been known to drive issues that come to the attention of the courts. Proposition 187, a voter driven initiative that found national prominence is a prime example of this.²⁰⁷ The Proposition barred undocumented migrants from receiving any publicly funded service, including education, public assistance, and any health services. The Proposition went so far as to deny post-natal services in the case in the case of infants born to undocumented migrant mothers within the US. This coupled with the ban on educational services, even for children born in the US was problematic, since, under US law, all children born within the borders of the country are by default, citizens. The Proposition was opposed by multiple political organizations, political parties and politicians, including then president, Bill Clinton.²⁰⁸ The political debate regarding the ban was heated, and was driven by fears regarding the ever-increasing number of primarily Mexican undocumented migrants within the state drove the debate over the Proposition. One

²⁰⁶ While McBride feels that issues involving asylum seekers in the US are driven by foreign policy concerns, US policy towards immigrants is driven predominantly by economic considerations. McBride, M. Migrants and asylum seekers: Policy responses in the United States to immigrants and refugees from Central America and the Caribbean. (1999) 37(1), *International Migration*, 289 at p. 300-310

²⁰⁷ This proposition was a voter based initiative that sought to limit migrant's access to social, educational and health services. The proposition passed in 1994 with a total of 58.4% of the vote, but was later bereft with legal difficulties. Proposition 187, Ballot Initiative, State of California, (US).

²⁰⁸ McBride, M. Migrants and asylum seekers: Policy responses in the United States to immigrants and refugees from Central America and the Caribbean. (1999) 37(1), *International Migration*, 289 at p.314-317

politician went so far as to state that if the proposition did not become law “the flood of illegal immigrants will turn into a tidal wave, and a huge neon sign will be lit up above the state of California that reads ‘come and get it’”.²⁰⁹ Whatever the political drive behind the Proposition it eventually passed and quickly became law. This of course set the scene for addressing some of the more controversial aspects of the proposition in the courts.

The key legal discord quickly became the divergence of State and Federal law on the issue. This is an important point, since under US Law no state may enact a law that diminishes in any way a Federal statute. The primary legal challenge that acted to limit the impact of proposition 187 was *The League of Latin American Citizens versus Pete Wilson*. The suit was brought against Pete Wilson in his capacity as governor of the state at the time.²¹⁰ This case was based almost completely on the assertion that no state may enact law that opposes or overrides a Federal statute. A primary consideration in this case was the implicitly federal duty to secure the borders. Additionally issues related to federal laws that offer limited services under some conditions to undocumented immigrants were problematic as well.²¹¹ The notion of offering services to undocumented migrants under some conditions, but not others, was consistent with the courts findings in *Plyler v Doe*.

²¹² In *Plyler*, the Federal Appeals Court initially upheld the notion that services could be limited based upon one’s immigration status. The Supreme Court, however, overturned

²⁰⁹ Miller, M. ‘Proposition 187: Fund raiser by supporters draws 100 in Orange Country.’ *The Los Angeles Times* (Los Angeles, 29 October 2010) 10

²¹⁰ *League of Latin American Citizens v Wilson et al*, 908, F. Supp. 755.

²¹¹ For examples see the Hill Burton Act and Emergency Medical Treatment and Licensure Act, both of which dictate the provision of medical care without respect to immigration status under life threatening circumstances.

²¹² This relates to the Equal Protection Clause of the 14th Amendment to the US Constitution. *Plyler v Doe* (1982), 457 US 202 (US).

this judgment, finding that the policy of denying school districts funding based upon their admitting undocumented or illegal immigrant children to schools was unconstitutional.

This argument was based upon the notion that limiting these services was contrary to the Equal Protection Clause of the 14th Amendment of the United States Constitution.²¹³

Under the Equal Protection Clause, states are prohibited from denying any person within its jurisdiction the equal protection of the laws. Hence, the state may not treat an individual in a different manner than another individual under similar circumstances. The amendment makes no reference to issues of citizenship, thus it leaves open the issue, instead pertaining only to individuals dwelling within the jurisdiction without giving consideration to their immigration status). The precedent set forth by Plyler has acted to weaken any effort to diminish one's right to services based upon issues of citizenship.

Soon after this debate, several federal legislative actions greatly modified the status of undocumented migrants, particularly in the context of their attempts to gain health or social services. The first of these was essentially a more refined (and better thought out) extension of Proposition 187. Welfare reform was initiated in 1996 in the form of the Personal Opportunity and Work Reconciliation Act of 1996.²¹⁴ The law was enacted primarily to limit spending in the area of social programs. In the context of healthcare, the main effect of the act was on the ability of newly arrived immigrants to gain services in federally funded programs. While not all federal programs were affected, the main limitation was the limitation of access to the Medicaid program.²¹⁵ As Medicaid

²¹³ Ibid

²¹⁴ AKA P.L. 104-193.

²¹⁵ Formerly, immigrants could gain Medicaid services soon after their arrival to the US, based primarily upon their low income. Under the act, however, the newly immigrated are barred from immediate enrollment in the program, and must wait a minimum of 5 years prior to their becoming eligible.

is means tested, and most migrants lack resources, this was a major limiting factor in a population that formerly relied heavily upon the program. Since this was Federal legislation, and thus exercised supremacy over similar state legislation, the program failed to fall into the pitfall experienced by proposition 187.²¹⁶ Further, by setting a waiting period for the program based upon citizenship status, the program has to date, avoided some of the issues of equal protection as dictated by the Equal Protection Clause of the 14th Amendment to the Constitution.

To an extent, the Personal Opportunity and Work Reconciliation Act of 1996 has its primary effect on those who immigrated after 1996, however, the Act had a significant effect on the level of healthcare access within both documented and undocumented immigrant groups. Ku and Matani documented profound changes in insurance rates amongst immigrants after the enactment of the Act.²¹⁷ They found that while only a small percentage of immigrants were subject to the Act, a far higher percentage failed to gain insurance. These trends were of the magnitude that indicated that a higher percentage of undocumented migrants lost coverage from both Medicaid and employment based private insurance programs.²¹⁸ Berk, Schur, Chavez and Frankel had similar findings after the act went into effect.²¹⁹ While they found low rates of insurance in this group, they also found that they continued to seek healthcare infrequently, when compared to legal immigrants, and for that matter, even when compared to other

²¹⁶ Proposition 187 attempted to limit access to joint state and federal programs. Thus, the Welfare Reform Act essentially established some of the conditions set fourth in proposition 187.

²¹⁷ Ku, L., and Matani, S. "Left out: Immigrants' access to health care and insurance." (2001) 20(1), *Health Affairs*, 247 at p. 247-250

²¹⁸ Ibid at p. 250

²¹⁹ Berk, M., Schur, C., Chavez, R., and Frankel, M. "Health care use among undocumented Latino immigrants." (2000) 19, *Health Affairs*, 51 at p. 60-64

inhabitants of their region who are not newly immigrated.²²⁰ Both studies support the negative effects of the Personal Opportunity and Work Reconciliation Act on healthcare access amongst undocumented migrants.

While federal statutes required that beneficiaries of the federally regulated Medicaid program be citizens, there was a significant flaw in the law through which states were left to determine their own methods for determining if applicants were in fact, US citizens. In all, 47 states allowed for *self declaration* of US citizenship. Thus individuals were able to simply identify themselves as US citizens, resulting in broad misrepresented of immigration status by many undocumented migrants. Under the Federal Deficit Reduction Act of 2005, States were required to obtain written documentation of citizenship status.²²¹ As a result, all current and prospective applicants for federal programs must now provide proof of their status, which has greatly decreased access to such programs. In some cases, even legal citizens who lacked these documents have been unable to provide access to programs to which they are entitled.²²² This law acted to further limit access of undocumented migrants to health care.

When the US approach to healthcare is considered a divergent approach is seen. While some instruments of the law act to deny the ability of healthcare institutions to

²²⁰ This data excludes childbirth, which represents an area of higher utilization rates for undocumented immigrants than the general population. The study also supports the proposition that migrants immigrate for economic opportunity, rather than to gain social or medical services. Ibid at p. 63-64

²²¹ Federal Deficit Reduction Act of 2005 (P.L. 109-171)

²²² American Public Health Association. *Bulletin: Medicaid Citizenship Documentation*, (APHA Press, 2007) at p. 2-18.

deny services to an immigrant, there are few programs that will pay for such services.²²³

The influence of laws such as the Welfare Reform Act of 1996, have further complicated this issue as well. Since most immigrants lack the financial resources to purchase health insurance, and since they lack the ability to gain the sort of employment that provides coverage, they may gain care that they ostensibly cannot afford. All the while, their offspring, if born in the US, have full rights of citizenship, and thus, are fully availed of publicly funded programs such as Medicaid at birth.

Human Rights Law in the United States

The case of the US is complicated by the fact that no US citizen enjoys a federally mandated right to healthcare, nor any form of universal health coverage. Thus, the laws that do ensure some access to health services do so in such a way that they prevent death in the case of emergent conditions or pending physiologic compromise.²²⁴ In the context of the US system, there are limited forms of extended access to care that are afforded specific populations. For instance, the economically challenged, in the case of the Medicaid Program and the elderly, in the case of the Medicare program.

United Nations Conventions

Arguments establishing a right to healthcare are commonly cited within international human rights instruments, for instance, Article 25 of the Universal Declaration of Human Rights, which refers to “a standard of living adequate for health and well-being.” This element of the Universal Declaration of Human Rights is further reflected in Article 12 of the International Covenant on Economic, Social and Cultural

²²³ Hill-Burton Act, Emergency Medical Licensure and Treatment Act and migrant health services legislation

²²⁴ This is established by The Emergency Medical Treatment and Active Labor Act (1986). 42 United States Code 1395dd from Section 1867 of the Social Security Act of 1935.

Rights, in a nearly identical manner. The Committee on Economic, Social & Cultural Rights further expounded on this issue by further defining their interpretation of these articles in a general comment.²²⁵ This document recognizes both the socioeconomic and health related factors that contribute to the ‘highest level of attainable health’. In paragraph 50 of the document, the Committee delineates the likelihood of harm, morbidity or mortality resulting from failure to recognize the right to health, further delineating the need to provide healthcare as a state’s obligation under section 53.²²⁶ The Committee on Economic, Social & Cultural Rights General Comment 14 document delineates obligations and a further interpretation of Article 25 of the Universal Declaration of Human Rights.

The process of enjoining international treaties requires that a given international agreement be signed by the President and later ratified by the US Senate. Historically, US Presidents have signed treaties only to find that a lack of sufficient support within the Senate. This has often been the case in the context of human rights law, often due to fundamental political differences and resistance to international influence by groups within both major US political parties.²²⁷ In the context of human rights law the US has both signed and ratified only the Universal Declaration of Human Rights (mentioned earlier), the Constitution of the World Health Organization, The International Covenant for Civil and Political Rights, and the International Convention on the elimination of all Forms of Racial Discrimination. While the treaties that the US has fully enjoined are

²²⁵ The Committee on Economic, Social & Cultural Rights General Comment 14 (2000).

²²⁶ Ibid

²²⁷ Kinney, E. “Recognition of the international human right to health and health care in the United States.” (2007) 60, *Rutgers Law Review*, 335 at p 335-338

limited, they do represent significant sources of law that espouse the view that healthcare is a fundamental human right. For instance, the Constitution of the World Health Organization stated that: “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”.²²⁸ In a similar manner, the International Convention on the elimination of all Forms of Racial Discrimination refers, albeit less directly, to the human right to healthcare. While the US has failed to fully enjoin the spectrum of treaties that affirm the human right to healthcare, they have signed and ratified UN treaties that affirm this right.

The US Constitution and Subsequent Interpretation by the Supreme Court

US law is heavily dependent upon the interpretation and application of law that originates in the country's primary founding legal document, the US Constitution and Subsequent amendments to the document.²²⁹ There is, however, one primary document that preceded the constitution. The Declaration of Independence states clearly that: “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness”.²³⁰ This quotation is notable, in that it both cites issues of the right to life and the pursuit of happiness not only as rights, but also as foundational justification for the separation of the colonies from England. Further, this statement of *rights*, which predated modern European human rights laws by nearly 200 years, is

²²⁸ The Constitution of the World Health Organization (1948).

²²⁹ The United States Constitution (1787)

²³⁰ Paragraph 2, The Declaration of Independence (1776)

worded in a way closely reflected in foundational human rights documents.²³¹ The constitution, ratified some 11 years later, provides markedly different reflection regarding social rights.

The key factor that explains the role of the early constitutional is the focus on the establishment of a civil government, rather than as a charter of individual human rights.

²³² In that context, the initial framework set forth in the US Constitution failed to provide any guidance regarding social rights such as the right to healthcare.²³³ Limitations to the document, in the area of individual civil and social rights, began to change as the document evolved. The initial evolution of the document occurred with the addition of the first ten amendments, often referred to as the Bill of Rights.²³⁴ According to the US Constitution, the Supreme Court, serves as the highest level of the justice system, and serves as the primary court charged with interpretation of law in the context of constitutional matters. As such, decisions of the court serve to establish precedents that are enforceable as laws in every state. In the context of rights, the court has established through precedent that fundamental rights are those that are delineated “explicitly or implicitly” by the constitution.²³⁵ The Constitution does, however, have a clause referred to as the General Welfare and Common Good Clause, which has served as the

²³¹ For examples see The International Covenant Economic, Social and Cultural Rights (UN) and the The Universal Declaration of Human Rights (UN).

²³² Gunnar, W. P. The fundamental law that shapes the United States health care system: Is universal health care realistic within the established paradigm. (2006) 15, *Annals of Health Law*, 151 at p. 170-174

²³³ Ibid at p. 177-178

²³⁴ The Bill of Rights is a term used to describe the first 10 amendments to the US Constitution. These were enacted in 1791, 4 years after the ratification of the original document.

²³⁵ *San Antonio Independent School District v Rodriguez*, 411 US, 1, 33 (1973)

Constitutional basis for public health initiatives, but has never been interpreted in a way that provides universal health services.²³⁶

While the Constitution has not been interpreted broadly to guarantee health rights to the population as a whole, it has established precedents that establish health as a right in a variety of cases. The 8th Amendment to the Constitution forbids excessive, bail, fines or cruel or unusual punishment.²³⁷ Supreme court decisions, in the context of the 8th Amendment tend to focus on decency and the provision of basic and humane standards of treatment to prisoners.²³⁸ Later the court affirmed the unconstitutionality of deprivation of medical care, and affirmed a positive obligation on the part of government to care for prisoners²³⁹ and established the primary concern being the suffering associated with such deprivation.²⁴⁰ While the Constitution fails to interpret any universal right to healthcare, it is interesting that current laws establish the inhumanity associated with the deprivation of health care in the case of convicted prisoners on the grounds of suffering, without extending similar rights to inhabitant of the country.

Statutory Law in the US Context

Human rights instruments, such as those described in the previous sections, set forth a vague right to health and standard of living. The actual instruments, however, do not set parameters for the way that this should be guaranteed. While The Committee on Economic, Social & Cultural Rights General Comment sought to further expound on the right to health services, actual mechanisms for the provision of such services remain

²³⁶ US Constitution, Article I, Section 8.

²³⁷ 8th Amendment, US Constitution (1787).

²³⁸ For instance, *Gregg v Ga*, 428, US, 153, 173 (1976), which established the prohibition against unnecessary and wanton pain.

²³⁹ *Revere v Massachusetts General Hospital*, 463, US, 239 (1983)

²⁴⁰ *Estelle v Gamble* 429 US, 102 (1976)

absent from the documents. Thus, the US system appears to offer lifesaving care (eg EMTALA), and does not result in direct harm either through the lack of provision of health services or failure to provide such services, at least in emergency situations. Since no US citizen is afforded universal access, undocumented migrants find themselves in roughly identical circumstances to these individuals. In a sense, all inhabitants of the US live in circumstances that are inherently counter to The Committee on Economic, Social & Cultural Rights in General Comment 14. There are, however, a profound lack of legal precedence's to support claims directly linked to the lack of provision of universal health services in the US. To date, EMTALA has not sustained successful challenges in the US courts regarding its adequacy in providing care to persons dwelling in the US.

United Nations Treaties

The US has exhibited a pattern by which international human rights treaties are frequently given limited consideration. The US, however, has signed but failed to ratify the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.²⁴¹ Despite their failure to ratify these instruments, an examination of them in the US context offers useful basis for comparison to the UK approach to these instruments. The International Covenant on Civil and Political Rights, details several rights that pertain to health and wellbeing. Article 6 establishes the inherent right to life and prohibits the arbitrary deprivation of life.²⁴² Additionally, Article 7 of the Covenant uses wording that is nearly identical to than provided for in the European Convention on Human Rights in prohibiting torture, cruel,

²⁴¹ International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1966)

²⁴² International Covenant on Civil and Political Rights (1966), Part III, Article 6.

inhumane or degrading treatment.²⁴³ In essence, the International Covenant on Civil and Political Rights provides no elements that directly refer to healthcare.

The International Covenant on Economic, Social and Cultural Rights, however is a far more specific document in that it provides direct consideration of healthcare related needs. Article 12 of the Covenant refers directly to the provision of healthcare services.

²⁴⁴ Wide ranges of specific forms of healthcare are referred to including references to occupational health, child health (reduction of still-birth), environmental health, and the prevention of communicable diseases.²⁴⁵ Further the article refers to the establishment of “The creation of conditions which would assure to all medical service and medical attention in the event of sickness.”²⁴⁶ In reviewing these aspects of the Covenant, it must be stated that no reference or requirement is detailed wherein citizenship status plays a role in the determination of the rights delineated in the document. In the context of the US, the limited provision of public health related services, coupled with the provision of emergent care (see EMTALA), only loosely conforms to the spirit of the International Covenant on Economic, Social and Cultural Rights,

Analysis of the Current US Position in the Context of Human Rights Law

The US position on the provision of healthcare in the context of human rights law is fraught with contradiction. While US law contains no provision that requires the provision of health services to all, the law provides for healthcare under a variety of circumstances. For instance the poor (under Medicaid) and the elderly (under Medicare) receive services as mandated by law. Even the constitution is inconsistent, in that under

²⁴³ International Covenant on Civil and Political Rights (1966), Part III, Article 7.

²⁴⁴ International Covenant on Economic, Social and Cultural Rights (1966) Article 12.

²⁴⁵ Ibid , Article XII 2 (a) through (c)

²⁴⁶ Ibid , Article XII 2 (d)

the 8th Amendment prohibition against cruel or unusual punishment, the Supreme Court has a consistent pattern of precedents preventing denial of medical services. Additionally, as in the case of the International Covenant on Economic, Social and Cultural Rights, the US has failed to provide any level of service that even remotely represents the provision of universal healthcare. When one considers these facts in the context of laws that require the provision of treatment under emergent circumstances, a very inconsistent pattern arises. For instance, while an undocumented migrant would be denied publicly funded care, it would be provided under emergency circumstances, or if said persons was a prisoner.

Conclusion

The US health and social care system is, at best, a fragmented system with multiple mechanisms for financing health services. The system offers many challenges to legal inhabitants of the country who require social or medical care. The intricate nature of the system presents recent undocumented migrants with a profound challenge when one considers attempting to gain services. This is further complicated by the very expensive nature of services within the system, and the lack of financial resources on the part of most recent immigrants. The legal system also introduces a confounding variable given the many contradictions in the system. For instance, statutes that require the provision of care and simultaneously prevent funding. Thus, the functional and legal environments inherent to the system are prohibitive in many ways to recent immigrants. The progression of laws appears to support the notion that healthcare services will become progressively less available to undocumented migrants. The extant literature that

addresses healthcare for undocumented migrants details a significant pattern of service limitation amongst this population.

Chapter 4-Legal and Human Rights Issues Related to Healthcare Rights in the United Kingdom

The United Kingdom utilizes a governmentally administered single payer healthcare system, based upon the principle of universal access to services by all legal inhabitants of the country. The healthcare system in the UK is an integral component of a network of social care entities that provide the gamut of services to the countries citizenry.²⁴⁷ This social care system is very different from the US system described in the previous chapter. The primary structural similarities lie in the social care systems, which are governmentally administered in both countries. In the context of this thesis, social care is comprised of a wide range of social services offered by a particular government. The purpose of this chapter is to provide a concise description of the UK approach to human rights and the provision of health care, followed by the presentation of key comparisons between the UK and US systems. The chapter will include a presentation of the extant literature regarding healthcare access for undocumented migrants in the UK. In the following section, key issues regarding human rights laws in the UK will be presented.

Human Rights Law in the United Kingdom

The purpose of this section is to detail the relationship between various sources of human rights law and access to health services for undocumented migrants in the UK. This will conclude with an analysis of the relationship between UK and European law regarding social rights such as healthcare and reflection on the current position of the UK on the issue of health care access for undocumented migrants in the UK.

²⁴⁷ Hughes, D., and McGuire, A.” Legislating for health: The changing nature of the NHS” From Dingwall, R., and Fenn, P. *Quality and Regulation in Health Care*. (Routledge, 1992) at p. 24-30

The Human Rights Act

The Human Rights Act was adopted in 1998 and became fully enforceable on 2 October 2000.²⁴⁸ The Human Rights Act, in essence, is a simple legal instrument that makes it unlawful for any public entity to act in such a way that is counter to the European Convention on Human Rights.²⁴⁹ The other key provision of the Act is the requirement that judges recognize precedents set by the European Court on Human Rights.²⁵⁰ Inherent to this aspect of the law is the requirement that the domestic courts review legislation and determine if it is compatible with the Act.²⁵¹ While the courts cannot override such legislation, they can declare it incompatible.²⁵² The declaration of incompatibility does not invalidate the particular legislation. Instead the declaration acts to increase the likelihood of a claimant's success in the domestic courts or on appeal to the European Court on Human Rights.²⁵³ While the Act serves to preserve the sovereignty of the parliament, it offers a domestic framework for the enforceability of the European Convention. In the context of healthcare, it is necessary to examine the European Convention on Human Rights for specific areas of law that pertain to the issues under consideration.

European Conventions

Because of the existence of the Human Rights Act in the UK, the European Convention on Human Rights is the most binding of the international human rights laws when considering the enforcement of human rights within the UK. The European

²⁴⁸ Human Rights Act of 1998 (UK)

²⁴⁹ The European Convention on Human Rights (1950)

²⁵⁰ Human Rights Act of 1998 (UK), c 42, Sec 2.

²⁵¹ Ibid, sec 4.

²⁵² Ibid, sec 4

²⁵³ Ibid, c 42, sec 6.

Convention on Human rights was drafted in 1950 and was enacted in 1953.²⁵⁴ The Convention was based largely on the inspiration provided by the Universal Declaration of Human Rights in the aftermath of World War II and the associated concerns regarding human rights principles.²⁵⁵ The Convention is focused on the preservation of basic human rights and freedoms, and thus, applies to a wide range of civil and social rights. In the context of the current study, however, the examination will be focused on Article 2, the right to life and Article 3, the prohibition against torture.²⁵⁶

Article 2 of the Convention establishes protection of individual's right to life under the law.²⁵⁷ The key legal principle associated with this aspect of the Convention is related to the intentional deprivation of life. Thus, the Convention serves to protect individuals from situations in which their lives are threatened by intentional acts. Article 3 of the convention, similarly focuses on intentional acts of torture. The exact wording employed in the Convention is important, since it focuses not only on torture, but also on acts that are inhumane or degrading.²⁵⁸ Together, Articles 2 and 3 of the Convention provide significant protection against intentional acts that result in direct harm. In the context of healthcare, it is key that an expectation of intent involving a degree of certainty regarding such harm exists.

United Nations Treaties

While early United Nations instruments such as the Universal Declaration of Human rights were non-binding, later legislation established binding elements to nations

²⁵⁴ The European Convention on Human Rights (1950)

²⁵⁵ The Universal Declaration of Human Rights (1948)

²⁵⁶ The European Convention on Human Rights (1950)

²⁵⁷ Ibid, sec 1, Article 2

²⁵⁸ The European Convention on Human Rights (1950), sec 1 Article 3 stated that "No one shall be subjected to torture or to inhuman or degrading treatment or punishment".

that were party to these conventions.²⁵⁹ Chief amongst these were the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, both of which were adopted in 1966.²⁶⁰ Both of the aforementioned instruments very closely reflect the tenants espoused by the European Convention on Human Rights.

The International Covenant on Civil and Political Rights, details several rights that pertain to health and wellbeing. In a manner almost identical to Article 2 of the European Convention on Human Rights, Article 6 establishes the inherent right to life and prohibits the arbitrary deprivation of life.²⁶¹ Additionally, Article 7 of the Covenant uses wording that is nearly identical to than provided for in the European Convention on Human Rights in prohibiting torture, cruel, inhumane or degrading treatment.²⁶² In essence, the International Covenant on Civil and Political Rights provides no elements that directly refer to healthcare.

The International Covenant on Economic, Social and Cultural Rights, however is a far more specific document in that it provides direct consideration of healthcare related needs. Article 12 of the Covenant refers directly to the provision of healthcare services.

²⁶³ A wide range of forms of healthcare are referred to in the document, including references to occupational health, child health (reduction of still-birth), environmental health, and the prevention of communicable diseases.²⁶⁴ Further the article refers to the

²⁵⁹ The Universal Declaration of Human Rights (1948)

²⁶⁰ International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1966)

²⁶¹ International Covenant on Civil and Political Rights (1966), Part III, Article 6.

²⁶² International Covenant on Civil and Political Rights (1966), Part III, Article 7.

²⁶³ International Covenant on Economic, Social and Cultural Rights (1966) Article 12.

²⁶⁴ Ibid , Article XII 2 (a) through (c)

establishment of “The creation of conditions which would assure to all medical service and medical attention in the event of sickness.”²⁶⁵ In reviewing these aspects of the Covenant, it must be stated that no reference or requirement is detailed wherein citizenship status plays a role in the determination of the rights delineated in the document. When one considers the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights in tandem, a cogent prohibition against mistreatment and a requirement to provide care to the sick materializes.

The Dialogue Regarding Social Rights in Europe

The UK and Europe led an important period after World War II during which social rights were greatly expanded in keeping with emerging human rights law.²⁶⁶ The extant human rights laws offer clear guidelines for the provision of healthcare to vulnerable populations such as migrants, however, considerable dialogue regarding social rights for migrants continues in the UK and Europe. Mobilization against the liberalization of policies that seek to convey broader social rights to immigrants have been driven in Europe primarily by the strength of right wing political entities in various countries.²⁶⁷ Perhaps the greatest concern on the part of authorities and amongst many

²⁶⁵ Ibid Article XII 2 (d)

²⁶⁶ Whelan, D., and Donnelly, J. “The west, economic and social rights, and the global human rights regime: Setting the record straight.” (2007) 29, *Human Rights Quarterly*, 908 at p. 930-938

²⁶⁷ Howard, M. M. “The impact of the far right on citizenship policy in Europe: Explaining continuity and change.” (2010) 36, *Journal of Ethnic and Migration Studies*, 735 at p. 715-739

political pundits is the influence of *welfare tourism* on the cost associated with the provision of such services to non-citizens.²⁶⁸

Studies have shown that the framing of arguments regarding welfare regimes and the distribution of government funds, rather than the changes in ethnic diversity influenced by immigration, plays the major role in public perception regarding the inclusion of immigrants in the welfare system.²⁶⁹ Even under circumstances where government officials reflect positively regarding the maintenance of social rights for migrants, such views are fragile, and are often negatively influenced with minimal pressure from constituent groups.²⁷⁰ Perceptions regarding migrants' access to services and motivation for gaining them are often misperceived. For instance, the phenomenon of *welfare tourism* is notable given that studies have failed to link country's welfare regimes and rates of migration solely to gain social services.²⁷¹ Interestingly, rates of participation in social programs have not been linked to the magnitude of benefits provided²⁷², and have shown diminished rates among migrants, especially when one considers migrants of color.²⁷³ The available data reflects that fear regarding *welfare tourism* is unfounded.

²⁶⁸ Corrigan, O. "Migrants, welfare systems, and social citizenship in Ireland and Britain: Users or abusers." (2010), 39, *Journal of Social Policy*. 415 at p 415-418

²⁶⁹ Mau, S., and Burkhardt, C. "Migration and welfare state solidarity in Western Europe." 2009, 19, *Journal of European Social Policy*, 213 at p. 214-216

²⁷⁰ Bay, A., and Pedersen, A. "The limits of social solidarity: Basic income, immigration and the legitimacy of the universal welfare state." (2006) 49 *Acta Sociologica*, 419 at p. 430-436

²⁷¹ Morissens, A, and Sainsbury, D. Migrant's social rights, ethnicity and welfare regimes. (2005) 34, *Journal of Social Policy*, 637 at p. 640-644

²⁷² Corrigan, O. "Migrants, welfare systems, and social citizenship in Ireland and Britain: Users or abusers." (2010), 39, *Journal of Social Policy*. 415 at p. 420-427

²⁷³ Morissens, A, and Sainsbury, D. Migrant's social rights, ethnicity and welfare regimes. (2005) 34, *Journal of Social Policy*, 637 at p. 645-647

The results of the dialogue regarding social rights for migrants are varied when one compares developments in western nations. There has been a general pattern of convergence where migration policies are concerned, wherein migration and asylum have been progressively more difficult to attain.²⁷⁴ There has been, however divergence in the area of access to social services in countries, with some nations, such as Sweden, maintaining levels of access that are roughly equivalent to those afforded in the past, and countries such as the UK.²⁷⁵ These trends reflect that migrants from developing nations are far more likely to experience diminished social rights and access to needed services than migrants from developed nations.²⁷⁶ Further, a variety of factors provide a *de facto* barrier to service utilization even when social services and healthcare are available including administrative, cultural and language based barriers to obtaining service.²⁷⁷ Throughout Europe and the UK there is a pattern wherein, even when people are entitled to services they often suffer significant difficulties in accessing them due barriers enacted by various government officials.²⁷⁸

Analysis of the Current UK Position in the Context of Human Rights Law

The UK, largely due to the Human Rights Act, has an established means of legal review and appeal in the case of laws that are found to violate aspects of human rights

²⁷⁴ Sainsbury, D. "Immigrants' social right in comparative prospective: Welfare regimes, forms of immigration and immigration policy regimes." (2006) 16, *Journal of European Social Policy*, 229 at p. 240-244

²⁷⁵ Ibid at p. 230

²⁷⁶ Koettl, J. A., and Sabates-Wheeler, R. "Social security regimes, global estimates and good practices: The status of social protection for international migrants." (2009) 4, *World Development*, 455 at p. 458

²⁷⁷ Stanciole, A. E., and Huber, M. "Access to health care for migrants, ethnic minorities and asylum seekers in Europe." (2009), 1, *European Center Policy Brief*, 1 at p. 2

²⁷⁸ Carens, J. "The rights of irregular migrants." (2008) 22, *Ethics and International Affairs*, 163 at p. 165-166

law. Most specifically, this pertains to the European Convention on Human Rights. The Convention offers significant protections, particularly as they pertain to the protection of life and protections that protect individuals from mistreatment. While the Convention offers the most legally enforceable aspect of the law, there are laws that speak directly to positive obligations undertaken by the UK government specifically regarding healthcare. The International Covenant on Economic, Social and Cultural Rights is a prime example of this sort of human rights legislation since it speaks directly to the provision of healthcare. In effect, the government of the UK has significant positive obligations regarding a wide array of social rights, which include healthcare. Despite these obligations, however, there remains discourse that focuses on issues related to resource preservation and fears regarding migration. The struggle between states obligations and issues related to resource allocation in these times of austerity will certainly fuel dialogue regarding these factors for years to come.

Background

The purpose of this section is to examine the extant literature regarding key aspects of the experiences of undocumented migrants as they relate to the themes encompassed by the thesis. This will provide vital background information for the analysis of the empirical aspect of the study.

Socioeconomic Status

Newly immigrated persons, whatever their origin, tend to fall in the lower levels with regards to socioeconomic status. In fact, failure of an asylum application renders one destitute in a large proportion of cases, often resulting in a profound lack of access to

basic necessities.²⁷⁹ Even in cases where African migrants enter the UK legally, they often face considerable difficulty in their quest to gain legal employment due to barriers inherent to the system that grants work permits.²⁸⁰ With over a third of HIV positive failed asylum seekers reporting no income, and the remainder reporting highly limited resources, poverty is a reality for the vast majority.²⁸¹ Further complicating the issue of poverty is the profound destitution associated with the failed asylum application,²⁸² That is, loss on appeal generally results in loss of eligibility to social care benefits, resulting in complete destitution in most cases.²⁸³ Significant numbers of failed asylum seekers go on to become homeless, and experience few rights to social care services after the failure on appeal.²⁸⁴ The combination of poverty that pre-exists entry to the UK, difficulty in gaining legal employment, and deprivation of social assistance after the failure on asylum requests results in significant destitution for the majority of African migrants to the UK.

Access to health services by undocumented migrants

There are few highly quantitative studies that reflect on usage patterns and demographics associated with undocumented migrants' efforts to gain health services in the UK. Medecins Du Monde, in 2008, completed a study of 11 European countries that included data reflecting a sample of undocumented migrants in the London area.²⁸⁵ The

²⁷⁹ Lewis, H. *Still Destitute: A Worsening Problem for Refused Asylum Seekers*. (Joseph Rowntree Charitable Trust, 2009)

²⁸⁰ Doyle, L. "I hate being idle": *Wasted skills and enforced dependence among Zimbabwean asylum seekers in the UK*. (Refugee Council, 2008) at p. 11-23

²⁸¹ Crusaid Hardship Fund. *Poverty Without Borders: A Report on Poverty, HIV and Migration*. (Crusaid Hardship Fund, 2008) at p. 2-7

²⁸² Refugee Survival Trust and British Red Cross. *21 Days Later: Destitution and the asylum system*. (Refugee Survival Trust, 2007) at p 1-6

²⁸³ Ibid at p 19-21

²⁸⁴ Refugee Council. *Hungry and homeless: The impact of the withdrawal of state support on asylum seekers, refugee communities and the voluntary sector*. (Refugee Council, 2004)

²⁸⁵ Chauvin, P., Parizot, I., and Simonnot, N. *Access to healthcare for undocumented migrants. In 11 European Countries*. (Medecins Du Monde, 2008)

data from this study reflected a population that was comprised of 46.3% women and 53.7% men, with a mean age of 37 years. The country of origin of those included in the sample included 36.1% from Africa, with the vast majority originating in Sub Saharan Africa. The majority of persons contained in the UK sample had been present in the country for 5 years (25.9%) with a significant number (25%) having been present for 2-3 years. These statistics reflect a population comprised primarily of failed asylum seekers. The majority (69%) of undocumented migrants had been subjected to violence in the past. Chronic medical problems were reported in 25.9% of cases, with 75% reporting having delayed treatment for acute or chronic medical problems. In total, 69.7% reported no current access to health services.

The most significant change in healthcare access regarding the newly immigrated occurred in 2004, when free access to care for visitors was strictly prohibited.²⁸⁶ This development had the effect of establishing the requirement that healthcare providers within the UK begin to make determinations of eligibility for services, often placing them at odds with both established human rights standards and their own professional ethics.

²⁸⁷ The stated reason for restricting this care was based upon financial concerns related to the concept of *health tourism*.²⁸⁸ To date, there is no empirical evidence that links the cost attributed to *health tourism* and the savings associated with restriction of service.²⁸⁹ The denial of services to undocumented migrants, and the association of this population

²⁸⁶ Yates, T., Crane, R., and Burnett, A. "Rights and the reality of healthcare charging in the United Kingdom." *Medicine*, (2007) 23(4), *Conflict & Survival*, 297 at p. 300-304

²⁸⁷ *Ibid* at p. 300-302

²⁸⁸ Harris, R. *The Exclusion of Failed Asylum Seekers from Free NHS Care: A Policy Analysis and Impact Assessment*. (International Health and Medical Education Centre, University College of London, 2005) at p. 3-6

²⁸⁹ *Ibid* at p. 11

with severe poverty and need has become a focus of contention amongst many involved in the healthcare debate in Europe.²⁹⁰ While precise causes have not been identified, there have been broad inconsistencies in the implementation of procedures designed to regulate undocumented migrants access to services.²⁹¹ Even in cases where care is authorized, for instance, during appeal of denial of an initial asylum application, accessing care can be very difficult due to the myriad administrative requirements associated with accessing services.²⁹² The result of such practices is the lack of uniformity in charging procedures, which serves to influence migrants in need to refrain from seeking care.²⁹³

The administrative burden associated with the registration process has limited the rates of registration even amongst those with legal grounds to seek authorization for care.²⁹⁴ Hargreaves et al performed a study regarding the use of health services on the part of various international migrants within the UK, with the primary objective of differentiating between the health utilization of EU/Irish and groups from refugee producing countries.²⁹⁵ Participants from refugee producing countries included large numbers of Africans. The major factor found to differentiate these groups was the issue of registration, with 58% of Africans maintaining current registration with a GP, as

²⁹⁰ Yates, T., Crane, R., and Burnett, A. "Rights and the reality of healthcare charging in the United Kingdom." *Medicine*, (2007) 23(4), *Conflict & Survival*, 297 at p. 299

²⁹¹ Hargreaves, S., Frieland, J., Gothard, P., Saxena, S., Millington, H., Eliahoo, J., Feuvre, P, and Holmes, A. "Impact on and use of health services by international migrants: Questionnaire survey of inner city London A&E attenders." (2006) 6, *BMC Health Services Research*, 1 at p. 13

²⁹² Kelley, N., and Stevenson, J. *First Do No Harm: Denying Healthcare to People Whose Asylum Claims Have Failed*. (Oxfam Refugee Council, 2006) at p. 9-14

²⁹³ *Ibid* at p 13-16

²⁹⁴ Lewis, H. *Still Destitute: A Worsening Problem for Refused Asylum Seekers..* (Joseph Rowntree Charitable Trust, 2009) at p. 23

²⁹⁵ Hargreaves, S., Frieland, J., Gothard, P., Saxena, S., Millington, H., Eliahoo, J., Feuvre, P, and Holmes, A. "Impact on and use of health services by international migrants: Questionnaire survey of inner city London A&E attenders." (2006) 6, *BMC Health Services Research*, 1 at p 2-3

compared to only 32% of Irish or EU participants. This phenomenon was further supported by research performed by Reeves et al.²⁹⁶ Hargreaves et al later reported that, in a sample of GPs in London, only 26.1% reported maintaining ineligible *foreign visitors* on their registration rolls, resulting in approximately 3000 pounds sterling in financial losses on a monthly basis.²⁹⁷ A complicating factor associated with access to GP care is associated with the association between undocumented migrants, complicated healthcare needs and the intensity with which they access services, all of which have resulted in many GPs having avoided registering this population in order to preserve resources.²⁹⁸ These studies support the notion that that many undocumented African migrants, despite their immigration status, are able to access limited health services through GP based clinics.

There is an overall pattern of limitations to access to healthcare services beyond the GP care level, due to current patterns of regulation.²⁹⁹ There were fewer studies identified which reflected upon patterns of access to services in government run specialty clinics (eg consultant care). One such study, performed by Cooke et al examined the ability of immigrants to gain services through infectious diseases clinics. In their study, they identified the presence of only limited numbers of these persons who were able to arrange specialty care in these clinics, and reflected upon the late presentation with severe

²⁹⁶ Reeves, M., de wilt, G., Murshalie, H., Williams, P., Gill, P., Kralj, L., and Rushby, M. "Access to healthcare for people seeking asylum in the UK." (2006) 56, *British Journal of General Practice*, 306 at p. 307-308

²⁹⁷ Hargreaves, S., Frieland, J., Gothard, P., Saxena, S., Millington, H., Eliahoo, J., Feuvre, P, and Holmes, A. "Impact on and use of health services by international migrants: Questionnaire survey of inner city London A&E attenders." (2006) 6, *BMC Health Services Research*, 1 at p 16

²⁹⁸ Lewis, H. *Still Destitute: A Worsening Problem for Refused Asylum Seekers*. Joseph Rowntree Charitable Trust, York, England, 2009.

²⁹⁹ Kelley, N., and Stevenson, J. *First Do No Harm: Denying Healthcare to People Whose Asylum Claims Have Failed*. (Oxfam Refugee Council, 2006) at p.16-22

infections in the case of immigrants.³⁰⁰ This study supports the notion that care is limited for this population, and when possible, is accessed later in the disease process. While this study offers helpful data in the context of the current study, there are no other studies identified in the UK context for the purposes of the current study.

Access to HIV related services by undocumented African migrants

While the previous section reflected upon access to healthcare services in general, this section seeks to explore the literature that pertains to people living with HIV/AIDS and their quest to gain access to healthcare services. Africans who enter the country and apply for asylum often experience profound difficulties in gaining both social care and medical services.³⁰¹ Studies related to African migrant's efforts to gain HIV related services reflected that Africans tended to initially seek services while they had access to care incident to an application for asylum and subsequent appeal.³⁰² Erwin, Morgan, Britten, Gray and Peters examined access to care issues in this population. Their findings revealed that, due to low perceived risk, Africans were often treated later than their white

³⁰⁰ The authors support the notion that there is a transfer point at the time that individuals lose their legal status during which many are able to continue seeking care. Cooke, G., Hargreaves, S., Natkunarajah, J., Sandhu, G., Dhasmana, D., Eliahoo, J., Holmes, A. and Frieland, J. "Impact on and use of an inner-city London infectious diseases department by international migrants: a questionnaire survey." (2007) 113, *BMC Health Services Research*, 8 at p. 11

³⁰¹ Refugee Council. *A study of asylum seekers with special needs*. (Refugee Council, London, 2005) at p. 13

³⁰² Cooke, G., Hargreaves, S., Natkunarajah, J., Sandhu, G., Dhasmana, D., Eliahoo, J., Holmes, A. and Frieland, J. "Impact on and use of an inner-city London infectious diseases department by international migrants: a questionnaire survey." (2007) 113, *BMC Health Services Research*, 8 at p. 14-15

counterparts, but received care after actual diagnosis at roughly the same interval.³⁰³

These findings were supported by earlier studies by O'Farrell et al and Saul et al.³⁰⁴

While this section focuses on governmental factors that limit access to care, studies have revealed significant behavioral factors that relate to the experience of living with HIV/AIDS. Perceived stigma, or the fear that their privacy may be violated often results in African migrant's failure to seek care.³⁰⁵ A history of cultural stigmatization, frequently within the country of origin has been shown to increase the likelihood of failure to seek services even when they are available.³⁰⁶ Perceived stigma is a significant factor influencing African migrant's efforts to gain HIV care services.

Governmental initiatives that serve to limit access to consultant care have been met with varied levels of acceptance on the part of healthcare workers within the NHS.³⁰⁷ For instance, prominent groups of healthcare practitioners have protested their status as 'enforcers' within the new system, and have been advocating for leave to continue treating HIV/AIDS patients who require care.³⁰⁸ Despite healthcare worker objections to denying care to persons living with HIV/AIDS, multiple instances of denial of care for

³⁰³ Erwin, J., Morgan, M., Britten, N. and Peters, . "Pathways to HIV testing and care by black African and white patients in London." (2002) 78, *Sexually Transmitted Infections*, 37 at p. 37-39.

³⁰⁴ O'Farrell, N., Lau, R., Yoganathan, K., Bradbeer, C., Griffin, G., and Ponziak, A. "AIDS in Africans living in London." (2005) 71, *Genitourinary Medicine*, 358; Saul, J., Erwin, J., Bruce, J., and Peters, B. "Ethnic and demographic variations in HIV/AIDS presentation at two London referral centres 1995-9." (2000) 76, *Sexually Transmitted Infection*, 215

³⁰⁵ Refugee Council. *A study of asylum seekers with special needs*. (Refugee Council, London, 2005)

³⁰⁶ Ndirangu, E., and Evans, C. "Experiences of African immigrant women living with HIV in the UK: Implications for health professionals." (2009) 11, *Journal of Immigrant Minority Health*, 108 at p. 110-114

³⁰⁷ Lewis, H. *Still Destitute: A Worsening Problem for Refused Asylum Seekers..* (Joseph Rowntree Charitable Trust, 2009) at p. 12-14

³⁰⁸ Gazzard, B., Anderson, J., Ainsworth, J., and Wood, C. *Treat with respect: HIV, public health and immigration*. (All Party Parliamentary Group on AIDS, 2005) at p 19

known HIV/AIDS patients have been documented within the NHS.³⁰⁹ Treatment denials in cases involving persons living with HIV/AIDS have increasingly been viewed as human rights violations amongst groups advocating for migrant populations.³¹⁰ The denial of such services has been repeatedly protested at all levels by organizations seeking to advocate for the treatment of persons living with HIV/AIDS regardless of immigration status.³¹¹

The effects of healthcare access patterns on the health and well being of African migrants.

Widely available publications related to undocumented migrants' access to health services are limited. This is largely due to the virtual absence of quantitative means through which to track the activities of the undocumented. Thus, the literature in this area is limited in amount and breadth. Erwin and Peters provided a cogent approach to the care of HIV positive African migrant through their supposition that the effective management of HIV disease as a public health imperative.³¹² That is, the management of individual's viral burden diminishes the likelihood of further disease transmission.

The primary effect of limits to access to care in African migrants in the UK has been associated with delays in presentation for HIV related services. Studies have shown that 80% of migrants experience difficulty in maintaining good health, particularly in

³⁰⁹ Power, L., Azad, Y. and Fortier, E. *Campaign on Access to HIV Services for all Migrants to the UK*. (Terrence Higgins Trust, 2004) at p 2-7

³¹⁰ Cherfas, L. *Negotiating Access and Culture: Organizational Responses to the Healthcare Needs of Refugees and Asylum Seekers living with HIV in the UK*. (Refugee Studies Centre, 2006) at p. 7-13

³¹¹ UK Aids and Human Rights Project. *HIV and Human Rights in the UK: The Right to Remain Free of Inhumane and Degrading Treatment*. (UK Aids and Human Rights Project, 2005) at p. 31-33

³¹² Erwin, J. and Peters, B. "Treatment issues for HIV+ Africans in London." (1999) 49, *Social Science & Medicine*, 1519 at p. 22-24

cases that involve person's with illness or disability, as is seen in those living with HIV/AIDS.³¹³ These delays result in delayed treatment, and thus, increase the odds of immune system degradation. Burns et al investigated the causes of poor patterns of service utilization amongst Africans.³¹⁴ The findings of this study support the notion that access to specialty care, combined with GPs inadequacies in addressing HIV disease is problematic. Additionally, the authors cited factors such as cultural insensitivity and failure to coordinate care with social support organizations as problematic.³¹⁵ The current study is supported by the notion that individuals fail to gain long-term care in the GU Medicine clinic system and thus fall to the care of the GPs who are ill equipped to care for persons who are HIV positive. Boyd et al further supports these findings, corroborating the fact that later presentation for testing decreases progression to care.³¹⁶ Finally, Chadborn et al were the first researchers to show that short-term mortality was influenced negatively by this pattern of late presentation.³¹⁷

Recent Developments within the NHS

It is not possible to fully consider the structure of the healthcare system within the UK without first giving consideration to the pattern of reforms over recent times. The most recent and significant systemic change within the NHS occurred with the enactment

³¹³ Penrose, J. *Poverty and asylum in the UK*. (Oxfam, 2002) at p. 27

³¹⁴ Burns, F., Imrie, J., Nazroo, J., Johnson, A., and Fenton, K. "Why they wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social services by African migrants in Britain." (2007) 19, *AIDS Care*, 102 at p. 103-104

³¹⁵ Ibid at p. 104-105

³¹⁶ Boyd, A., Murad, S., O'Shea, S., de Ruiter, A., Watson, C. and Easerbrook, P. "Ethnic differences in the stage of presentation of adults newly diagnosed with HIV infection in south London." (2005) 6, *HIV Medicine*, 59 at p. 61

³¹⁷ Chadborn, T., Delpech, V., Sabin, C., Sinka, K., & Evans, B. "The late diagnosis and consequent short-term mortality of HIV infected heterosexuals (England & Wales, 2000-2004)." (2006) 20, *AIDS*, 2371 at p. 2377-2388

of the National Health Service and Community Care Act in 1990. This Act, through the establishment of trusts and a new form of financing for primary care services, established a new approach to healthcare based upon the establishment of *internal* markets.³¹⁸ This period of reform resulted in changes to the political-regulatory mechanisms responsible for administering NHS policies, resulting in broad differences between the regulatory regimes within the countries that comprise the UK.³¹⁹ This almost certainly guaranteed a period of instability within the NHS due to the interaction of service needs and funding shortfalls (Ibid). Further, the methods by which the system finances and administers services have resulted in concerns regarding the relationship between the considerable taxpayer resources expended on health services and the degree to which health consumers are able to play a role in decisions regarding the services that they require.³²⁰

In the period following the 1990 reforms, the Blair Labour government, as one of its primary initiatives began working towards further reform within the NHS. This reform began to come to fruition in 1997 with the release of a White Paper on the issue.³²¹ The focus of the White Paper entitled ‘*The New NHS*’ involved initiatives driven to re-establish the national prominence of the NHS while establishing a system wherein national standards would provide guidelines for healthcare that was controlled at the local level.³²² This development represented a significant refinement of the National Health

³¹⁸ National Health Service and Community Care Act in 1990 (UK), Chapter 6, Part 3.

³¹⁹ Hughes, D., and Vincent-Jones, P. Schisms in the church: National health systems and institutional divergence in England and Wales. (2008) 49(4), *The Journal of Health and Social Behavior*, 400 at p. 408-410

³²⁰ Hughes, D. Financial incentives and barriers to access. From Guilliford, M., and Morgan, M. *Access to Healthcare*. (Routledge, 2003) at p. 114-117.

³²¹ The Secretary of State for Health. *The New NHS. Modern, Dependable*. (NHS,1997) at p. 16-33

³²² Ham, C. *Health policy in Britain*. (5th ed., Palgrave MacMillan, 2004) at p. 9-17

Service and Community Care Act of 1990. These reforms, in part, were to be based on a system of national-local partnerships that served the purpose of tailoring services to the needs of beneficiaries of the system. The Secretary of State for Health, in 1997, deemed this system as “One based on partnership and driven by performance”.³²³ Under the White paper, the following objectives for reform were established.

1. To renew the NHS as a truly *national* health service.
2. To make the enforcement of national health standards a local responsibility.
3. To drive the NHS to work in partnership with other organizations.
4. To increase efficiency through a focus on organizational performance.
5. To cut bureaucracy.
6. To change the focus of the NHS to one of quality in order to renew the public trust in the healthcare system.

The Evolution of Performance Improvement and Finance Initiatives in the NHS

Under the new structure, The Blair Labour Government sought, over successive years to increase healthcare capacity through structural changes accompanied by incremental funding increases.³²⁴ The result perplexed many observers in that the initiative, despite its goals, failed to achieve the increases in capacity that were forecast under this approach. This pattern of restructuring moved the NHS in the direction of the US system

³²³ The Secretary of State for Health. *The New NHS. Modern, Dependable*. (NHS,1997)

³²⁴ The primary development in regards to the interaction between cost and quality was to enact initiatives driven towards creating motivators on the local level that would fuel initiatives driven towards establishing savings while increasing the quality of care.

in that factors such as performance and capitation have come into play.³²⁵ Performance, from an organizational point of view, was defined so that funding was to be allocated based upon the nature and quality of services provided within a region.³²⁶ Thus it was essential that organizations increase their number of patient contacts in order to maintain funding. Capitation, on the other hand has to do with contracting for services by hospital providers, which is a process of bargaining whereby primary care and other healthcare providers agree to provide services for a set price.³²⁷ The mechanism whereby prices to individual primary care providers was at dictated rates of reimbursement was initially introduced in National Health Service and Community Care Act in 1990 and was refined in later legislation.³²⁸ The use of set rates was similar to the US Diagnostic Related Groups, which dictate payment based upon the individual patient's health problem or surgical procedure rather than by individual services provided or days of care rendered in hospital.³²⁹

While the UK maintains a single payer national healthcare system, there has been a persistent progression for the past 20 years, which mirrors aspects of the US system.³³⁰

³²⁵ Capitation is a term that refers to the provision of 'set prices' for services based upon usual and customary rates of providing services to a given population. Ham, C. *Health policy in Britain*. (5th ed., Palgrave MacMillan, 2004)

³²⁶ National Health Service and Community Care Act in 1990 (UK).

³²⁷ Klein, R. "The troubled transformation of Britain's National Health Service." (2006) 355(4), *New England Journal of Medicine*, 409; Maynard, A., Street, A. Seven years of feast, seven years of famine: Boom to bust in the NHS. (2006) 332, *British Medical Journal*, 906

³²⁸ National Health Service and Community Care Act in 1990 established funding initiatives for payment levels for services and goods that represented a significant change in healthcare provision. For instance, the establishment of indicative amounts for medicines and medical products required for providing care.

³²⁹ Diagnostic Related Groups reflect a form of payment that sets a fee based upon the actual diagnosis rather than the cost of providing care. These were introduced in the US in order to control the cost of providing care under government programs such as Medicare. Shi, L., and Singh, A. *Delivering Healthcare in America* (3rd ed., Aspen Publications, 2001) at p. 199-201.

³³⁰ Hughes, D. "Financial incentives and barriers to access". From Guilliford, M., and Morgan, M. *Access to Healthcare*. (Routledge, 2003) at p. 104.

The problem in the UK system, as in many healthcare systems, was associated with the lack of spending control during this period of growth, which was particularly profound in the area of salaries for healthcare and support staff.³³¹ Even as the capacity of the system improved, and many performance indices showed increased levels of service, the need for budgetary discipline, and hence budget cuts has become apparent.³³²

Current Structure of the NHS

The structure of the ‘new NHS’ reflects upon the precepts discussed earlier in the paper. While the system remains centralized, it features several aspects that provide for a greater variety of local control and partnership that appear to serve the role of enabling the healthcare system to meet local needs. For the purposes of this study, the structure of the NHS in England will be discussed. While the NHS, is at its most basic level a national organization with some degree of centralized control, the new structure has worked to minimize this effect. As a result, 10 Strategic Health Authorities (SHA) have been established to coordinate care in specific areas.³³³ That is, the health authority serves the dual role of planning services specific to a local area while ensuring that agencies in these areas are performing optimally. Within the areas controlled by the various Strategic Health Authorities, there are trusts established in each of these areas that are responsible for various areas of direct service provision. The largest components of this are the Acute and Primary Care Trusts.³³⁴ The Acute Care Trusts manage the hospital systems in a given area and are responsible for their direct care activities and

³³¹ Hughes, D., and McGuire, A.” Legislating for health: The changing nature of the NHS” From Dingwall, R., and Fenn, P. *Quality and Regulation in Health Care*. (Routledge, 1992)

³³² Ibid at p. 24-25

³³³ This structure was established by the National Health Service Act of 2006 (UK).

³³⁴ This is established within National Health Service Act of 2006, Chapter 2, Section 18.

administrative functions. The Primary Care Trusts fulfill a similar role, except that they coordinate, contract and administer clinical services in primary care settings.³³⁵ The Ambulance Trusts maintain the responsibility of enabling access to emergency care within the Strategic Health Authorities. The Mental Health Trusts manage the provision of psychiatric care, with a good bit of crossover with the Care Trusts that provide social services and assistance needs within a health services area. Finally, the Foundation Trusts are public benefit corporations designed to provide health services within select communities.³³⁶

In the context of this project several factors within the system are important to consider. While issues of access to care are directed by national statutes, they are administered locally. There are several competing motivators on the local level. The Strategic Health Authorities direct the administration of services within their regions; however, they lack the ability to alter funding of these services directly.³³⁷ The Department of Health, conversely, funds services based upon a weighted capitation formula designed to adequately fund needed services within a particular region. Funding levels are dictated largely by the Advisory Committee on Resource Allocation (ACRA), in part based upon the number and type of legal recipients of care in a region.³³⁸ This leads to a situation whereby the Strategic Health Authorities seek to provide services

³³⁵ The range of services offered by the primary care trusts is broad, and is essentially characterized by services provided in free-standing clinics or agencies. These include General Practitioner Practices, Dentists offices, Opticians, Pharmacy services and various other services.

³³⁶ From the National Health Service Act of 2006, Chapter 5, Section 30.

³³⁷ To a degree, the lack of ability to alter the financial structure and revenue necessary to administer the system may in fact influence decreased levels of access to care within the NHS. Hughes, D., and McGuire, A. "Legislating for health: The changing nature of the NHS" From Dingwall, R., and Fenn, P. *Quality and Regulation in Health Care*. (Routledge, 1992)

³³⁸ National Health Service and Community Care Act of 1990, Chapter 19, Part 2, Sections 19 and 20.

based upon funding provided based on a number of factors including the size of the beneficiary pool within a region. Thus, it is unlikely that the health Strategic Health Authority would choose to engage in policies that may result in expenditures that are not completely consistent with those dictated by law since such expenditures might result in funding shortfalls. While it may be desirable to increase service availability and decrease waiting times, the offer of services to ineligible individuals may have the opposite effect. The influx of ineligible patients could increase waiting time, thus decreasing performance (and eventually funding).³³⁹ The outcome may very well be an increase in patients with overall decreases in funding.

Laws Governing Healthcare Access in the UK

The legal framework that originally established the basis for *universal* healthcare access in the UK was the very legislation that established the NHS. The National Health Service Act of 1946 came into effect in 1948. This initial legislation established the NHS, as we know it today. While the National Health Service Act of 1997 and 2006 respectively have resulted in alterations to the way that the organization is structured and implemented, little has occurred to alter the way in which services are rendered to migrants. Rather, a tighter framework for monitoring and adhering to regulations that limit the provision of free services to ineligible parties was adopted. This trend towards obtaining payment on the part of overseas visitors to the UK became a profound factor

³³⁹ Torres-Cantero, A., Miguel, A., Gillardo, G, and Ippolito, S. Healthcare provision for illegal immigrants: May health policy make a difference? (2007) 17(5), *European Journal of Public Health*, 483 at p. 484

influencing the provision of healthcare with the introduction of the National Health Service, Charges to Overseas Visitors Amendment in 2004.³⁴⁰

The key factor that determines whether one is eligible for services within the UK is the establishment of ordinary residence within the UK. Ordinary residence is at face, simple, denoting that one has established residence for the purpose of dwelling within the UK for the purpose of engaging in work or the routines of life.³⁴¹ This differs from entering the UK for the purposes of a holiday or recreation, even if the recreation is engaged in for a long period of time. In essence, the establishment of ordinary residence in the country exceeds the requirements imposed by one's national origins. In order to establish ordinary residence, however, one must have entered the country legally.

Asylum seekers to the UK frequently access the NHS while their applications are pending. Under the Nationality, Immigration and Asylum Act of 2002, they are eligible to receive free primary care and hospital services within the NHS.³⁴² Free access to services continues throughout the period during which their asylum case is active. When the individual asylum seeker's case is denied, and subsequently appealed, they continue to receive these services at no cost, however, at such a time that they fail on appeal, they lose access to NHS.³⁴³ Instead, while they await return to their nation of origin, they experience a more limited form of access to services. Under National Health Services Act of 2006 undocumented migrants were denied free access to healthcare services. This component of the Act, however, was appealed in the case of *R versus the Secretary of*

³⁴⁰ National Health Service, Charges to Overseas Visitors, Statutory Instrument 2004 Number 614.

³⁴¹ Immigration and Asylum Act of 1999, Chapter 33, Part 1 Section 2.

³⁴² Immigration and Asylum Act of 2002, Part 3, sections 43 and 44.

³⁴³ Nationality, Immigration and Asylum Act of 2002, Part 3, Section 43.

State for Health.³⁴⁴ This appeal established that they may continue to receive care in General Practitioner clinics, but may not be registered. The lack of registration plays a vital role in consultant and hospital care, since registration is required at these healthcare facilities. Thus, individuals who have lost on appeal may gain basic health services through the GP, but often have a great deal of difficulty accessing consultant care, which is often required by persons suffering from HIV/AIDS.

Whether or not one is a legal recipient of free services, there are ‘humanitarian’ considerations that play a role in the administration of care to an individual. Immediately necessary treatment is deemed that treatment required to stabilize a health condition that requires immediate attention to preserve life.^{345 346} This includes emergent health conditions and childbirth. These conditions may be treated on an emergent basis without proof of ability to pay.³⁴⁷

An examination of the Nationality, Immigration and Asylum Act of 2002 sets forth a grim reality when considering the status of individuals in the UK.³⁴⁸ While, as this work previously documents, a subset of undocumented migrants are illegal entrants, many simply became ‘illegal’ after a period during which they were in full possession of legal status. Undocumented migrants lack legal authorization to receive healthcare services within the UK, and thus, cannot be fully registered. While some GPs continue to provide them service, this lack of registration is a key element which limits their access to

³⁴⁴ While this appeal supported the ban on free health services for undocumented migrants, it did serve to offer circumstances, such as the possibility of harm, under which a healthcare provider such as a GP has the ability to provide health services. *R (YA) v Secretary of State for Health*, (C1/2008/108) on 30 March 2009.

³⁴⁵ National Health Service, Entitlement to NHS Treatment, March 2006.

³⁴⁶ National Health Service Act of 1946 (UK)

³⁴⁷ Nationality, Immigration and Asylum Act of 2002, Part 3, Section 43.

³⁴⁸ Immigration and Asylum Act of 2002, Part 1, Section 11.

care.³⁴⁹ In essence, their only means of gaining care on a consistent basis is to wait until their condition deteriorates to the point that it is life threatening, at which time they will be able to gain care. This care, however, is not offered free of charge.

Legal Developments in the UK

There have been significant developments within the UK courts related to the status of undocumented migrants. During this section, significant cases will be reviewed in. These cases will be addressed according to their relationship to the topic of healthcare rights for undocumented migrants, with in depth consideration being given to key portions of the case law.

Case law focusing on access to social care

While the legal position of undocumented migrants within the UK appears to be clearly delineated, it is essential that a discussion of current developments with regards to the social care rights of undocumented migrants be made. When discussing social care in the context of the UK, it is necessary to address social services in the context of the safety net available to those in dire need for whatever reason. This is especially important when considering individuals who are undocumented migrants, and who have defined needs, as is the case with people living with HIV/AIDS. In *R. v Hammersmith and Fulham LBC*, a group of asylum seekers challenged the denial for assistance under the National Assistance Act of 1948.³⁵⁰ The claimants had failed to file for asylum upon their entry to UK, but found themselves in great need and without resources. They applied to local

³⁴⁹ Under the National Health Act of 2002 they may remain enrolled with GP practices after losing their legal status, but have a highly limited ability to enroll in such practices if they had never possessed legal status.

³⁵⁰ *R. v Hammersmith and Fulham LBC Ex p. M* (1996) QBD (UK).

authorities, essentially based on their lack of money and need for care, and were denied based upon their failure to inform the Secretary of State of their entry into the country in a timely manner. Judicial review of the initial decision was requested based upon the local authorities interpretation of amendments to the Asylum and Immigration Act of 1996, which they felt negated such assistance. Notably, the court felt that the grounds for denial, and the local authorities application of the concept of “need for care and attention” were too narrow, and thus, the plight of these individuals, even if due to a lack of financial resources, warranted the provision of services.³⁵¹ The case is important in the context of the current study due to the court’s guidance that disregarded issues of legal status, alternatively finding that individual need warranted the provision of social care services. This case is an interesting parallel to similar case law in the healthcare arena.

R. v Brent London Borough Council, which was highlighted in the introductory chapter, offers another interesting insight into the interaction between legal status and healthcare access.³⁵² The case involved a Brazilian national who was diagnosed with HIV disease while living in his home country. He was a legal entrant to the country but had subsequently overstayed a visitor’s visa, thus losing his legal status. He eventually became gravely ill and was subsequently hospitalized. This resulted in his status becoming known, and thus, he was ordered to leave the country. At this time his health was failing and his consultant felt him too weak to travel. While his medical care continued to be provided, due to the life threatening nature of his illness, he had lost a stable place to live thus complicating his medical condition. His petition to the courts for relief related to his removal from accommodation and denial of social services support

³⁵¹ *R. v L.B.C.* (1999) 31 H.L.R., 10 (UK)

³⁵² *R. v L.B.C.* (1999) 31 H.L.R., 10 (UK)

was eventually successful, based upon his citation of section 21 (1)(a) of the National Assistance Act of 1948, which held that social service agencies might arrange accommodation for adults whose abilities are limited by such illnesses. This finding was made irrespective of his immigration status, in keeping with *R. v Hammersmith and Fulham*. R continued to receive health services based upon his grave health condition and the life preserving nature of these treatments at this point in his disease. This case failed to focus on issues of healthcare rights, and instead focused upon the guidelines offered by the National Assistance Act of 1948. While limited in their breadth, the case law regarding access to social care in undocumented migrants with HIV/AIDS reflected a trend towards the provision of care under dire circumstances.

D. v United Kingdom and N. v Secretary of State for the Home Department: Key exemplars in the case law.

An examination of the extant case law reveals two key cases that demonstrate the interaction between the law, undocumented migrants and HIV disease. These cases provide an important reflection of the changes that characterize the HIV epidemic, particularly in the context of law. The cases, *D v United Kingdom* and *N v United Kingdom* will be detailed in the sections that follow.³⁵³

D v United Kingdom in 1997 offers a compelling argument for healthcare rights in the case of migrants.³⁵⁴ The case involved a national of St. Kitts, who was imprisoned in the UK for drug related offenses. Following 6 years of imprisonment, during which he behaved well, he was released from prison and subsequently remanded to immigration

³⁵³ *D v United Kingdom* (1997) ECHR 30240/96 (UK) and *N v United Kingdom* (2008) ECHR 26565/05.

³⁵⁴ *D v United Kingdom* (1997) ECHR 30240/96 (UK)

detention due to his criminal history. D was subsequently ordered deported to St. Kitts.

A key factor in the case was, of course, D's HIV infection, which was diagnosed during his imprisonment as a result of his having fallen ill with an AIDS related illness.

In fact, D never recovered an acceptable level of immune system function, and continued to suffer from various AIDS defining conditions throughout the remainder of his prison stay.³⁵⁵ Upon his release on bail, D found accommodation in a charitable facility operated by the Terrence Higgins Trust that provided accommodation, food and support services to people like D, who was effectively homeless, and without the physical ability to work, due to the advanced stage of his disease. Further, he was afforded emotional support at his facility. The presence of emotional support, given D's need for end of life care, is important, since government authorities had confirmed D's lack of family support in St. Kitts. Based upon the facts presented in the case, had he remained in this facility, he would have died during his time in this facility due to the advanced stage of his illness.

By the time of his placement in immigration detention, his consultant physicians agreed that his condition was grave, even with treatment, and that any interruption in his treatment would considerably increase the likelihood of D experiencing unnecessary suffering. Based upon the likelihood that an interruption in his treatment would result in death, application was made to the European Court of Human Rights. Of vital importance to the case was the availability of written documentation from authorities in St. Kitts confirming the lack of services appropriate for the treatment of D. Further, confirmation was made regarding the lack of treatment availability in St Kitts through regional

³⁵⁵ AIDS defining conditions are conditions that are extremely rare in immune competent persons. In the case of D., he contracted multiple chest and skin infections, including *Pneumocystis Carinii* Pneumonia.

International Red Cross authorities. All told, the evidence in the case supported the notion that D was very near the end of his life, and that there was no possibility of appropriate medical care, family or emotional support available in St. Kitts.

The courts in the United Kingdom found against D based largely upon aspects of The Immigration Act of 1971, which clearly prohibited D's presence in the country. Further, the Home Office issued additional guidance in 1995, which disallowed the notion that HIV infection itself served as a condition that would prevent deportation.³⁵⁶ As a matter of policy, the Home Office would not consider the extenuating circumstances in D's case, which were detailed in the previous sections. Thus, D appealed the ruling in the domestic courts to the European Court of Human Rights. A key factor in the application is the fact that no argument was made on the part of D's solicitors regarding danger to D's life, based upon deportation. In fact, the court documents reveal agreement by both the legal teams regarding the inevitability of D's death. The argument that D's legal team based their appeal upon hinged on the likelihood that D would have arrived in St. Kitts to spend his remaining days in pain and social isolation, which would result in extensive suffering until the time of his death. The government, conversely, contended that all suffering on the part of D would be directly attributable to his terminal disease. Further, the government conceded that there were limited healthcare services available in St. Kitts.

Application was based upon the European Convention on Human Rights (1950) Article 3 prohibition against mistreatment, which D's solicitors contended should prevent the government from expelling D in a way that would guarantee that he would find himself in inhumane conditions, wherein he could not work, gain shelter, obtain the

³⁵⁶ Immigration and Nationality Department, Home Office. *Policy Document BDI 3/95*

comfort of caregivers or family and gain even basic medical care. Further, the arguments hinged on legal precedence that forbid such treatment even in cases of gross misconduct on the part of the person in question.³⁵⁷ Article 2 of the European Convention on Human Rights was cited as well, based upon the ramifications of separation from medical care that deportation would represent.³⁵⁸ One of the key aspects of the case, related to the *present condition* of D, which was precarious, given the likelihood of his death. The fragility of D, from a medical point of view, was later illustrated by his death soon after the conclusion of legal proceedings. Despite his dire condition, the court, in finding that Article 3 was violated, found the Article 3 claim inseparable from the Article 2 claim, and thus, considered examination of the case under Article 2 unnecessary. Further, the court found that plaintiff's claims under Article 8 of the convention raised no separate issue.

The case of D offers several vital points of consideration, based upon the legal and historical facts surrounding the case. From a historical point of view, the case occurred at a time when HIV therapies were highly limited based upon today's standards. Further, therapies were not commonly available in undeveloped nations. The fact that D was very near death played a vital role. Thus, the lack of treatment availability in St. Kitts, coupled with his dire condition, set up a circumstance under which the violation of Article 3 was very clearly delineated to the court. The very clear points in this case, including D's very dire condition at the time of the adjudication of the case, the clear lack

³⁵⁷ In *Ahmed v. Austria*, Ahmed, a Somali asylum seeker was imprisoned based upon criminal misconduct, and was subsequently placed under a deportation order, despite the great likelihood of his torture and killing in his native land based upon his participation in a political opposition group. The court found that the likelihood of harm, coupled with Austria's previous granting of asylum were grounds to block deportation. *Ahmed v. Austria* (1996) ECHR 25964/94.

³⁵⁸ Article 2 of the ECHR is the right to life.

of healthcare resources in his country of origin, and the certainty of suffering associated with his deportation offered a very clear legal precedence upon which future legal arguments could be based.

The case of *D. v United Kingdom* set some very clear legal precedents which would certainly be cited in future cases. The ongoing HIV epidemic, coupled with the continued presence of large numbers of undocumented migrants in the UK set the stage for such a case. *N v Secretary of State for the Home Department* in 2003, began as a pivotal domestic case involving N. an HIV patient who was a Ugandan citizen, who although originally severely ill and in the final stages of HIV/AIDS had recovered to an extent with treatment.³⁵⁹ N sought to remain in the UK on the grounds of the likelihood that sufficient care would not be available in her home country, and was denied. During this time, she was also hospitalized and found to be extremely ill with HIV/AIDS. With treatment however, N. made substantial gains, and progressed to the point that she had the possibility of decades of life with continued treatment. In a manner similar to *D. v United Kingdom*, she invoked Article 3 of the European Convention on Human Rights. Despite the similarities in the two cases, the Immigrations Appeal Tribunal found that N. failed to meet the exceptional level of danger on deportation as was seen in *D. v United Kingdom*, despite the fact that the cessation of treatment would eventually result in death. Thus, the Tribunal found that, unlike the case of D., N. was not in sufficiently grave a condition that article 3 and its ban on maltreatment could serve as the grounds for removal of the deportation order.

³⁵⁹ *N v Secretary of State for the Home Department* (2003), Court of Appeals (Civil Division) (UK).

The basis for the decision of the courts in the UK could be best summed up in Lord Hope's assertion regarding the case, when he asserted that: "Any extension of the D. principles would have the effect of affording all those in the applicant's condition a right to asylum in this country". Baroness Hale, went further in her rationale for the decision by citing the failure of the legal test represented by the decision in D, since the applicants condition was stable, and further, there was no clear guarantee that treatment would not be available in the applicant's homeland. The case was eventually appealed to the European Court of Human Rights.

While the European Court on Human Rights acknowledged the serious nature of N's illness they denied the appeal based upon several key factors. The court, interestingly, acknowledged that appropriate therapy was available only in limited quantities in Uganda. While acknowledging this fact, they went on to make assertions regarding the acuity of N's current illness, citing that she was not critically ill at the time of appeal. This fact, in the eyes of the court, rendered any statement forecasting the health related consequences of lost therapy conjecture, in that no completely concrete determination of the course of illness might be made. One of the key factors cited in the majority opinion was the court's statement that the fact that the departing nation's healthcare was superior to that of the receiving country, did not in itself represent the grounds to withdraw a deportation order. In fact, in the majority opinion, the court cited key aspects in the case of D, that were not present in the case of N, to the degree that the exceptionally serious circumstances seen in D were not met in the case of N. For instance, D was near death, and would have been removed to a situation in which D would have suffered immediate and severe degradation in his health. Further D would

have lost accommodation, social support or means of gaining comfort in his last days. In short, the court in D recognized that D would have met his death with a level of suffering that was inhumane. The case of N did not represent an equivalent degree of suffering, and thus, was not seen as sufficiently exceptional to meet the tests provided by the D precedent. This aspect of the case was notable, as the court, while stating that the expulsion of N to Uganda would certainly have deleterious effect, the temporal proximity of that effect to the deportation would be unclear.

The state's actions in the case hinged upon the lack or presence of appropriate care in Uganda. This component of the case was heavily based upon *D v United Kingdom*. In D, the crucial fact hinged upon the acuity of illness in the case, and the lack of available services within St. Kitts to address D's needs upon arrival in the country. The aforementioned fact tends to be pervasive in the body of law related to access to medical care since the law tends to require a determination of the level of acuity of illness and the availability of reasonable continuity of care in such cases. This aspect of N. was certainly not unique in the context of the law.

In any case, arguments on the part of the Secretary of State hinged upon several facts. Key to these arguments was the relatively recent developments within the area of HIV care in Uganda. This included the institution of a system of public subsidies to facilitate the availability of Anti-Retroviral Therapy in Uganda. This system, however, has been able to offer access to care for roughly half of those in need. Despite this fact, N's appeal was denied, and the case was subsequently heard by the European Court of Human Rights.³⁶⁰

³⁶⁰ *N v United Kingdom* (2008) European Court of Human Rights (Application Number 26565/05)

The issue of acuity, or the degree of illness is an important concept in this aspect of the law. This concept is inextricably linked to current developments in medical care. *D v United Kingdom* occurred nearly a decade prior to the case of *N*. This decade saw major developments in the area of Anti-Retroviral Therapy. One could posit that *N* would not likely have recovered to the degree that she did under the conditions that were present when *D* became ill, and thus, they would likely have found themselves under very similar circumstances. The ironic element of the finding of the European Court was the fact that, during her hospitalization *N* would likely have been eligible for protection, however, her clinical improvement after treatment removed the likelihood of immediate harm resulting from her removal from treatment. As HIV is a chronic and currently incurable disorder, the lack of treatment will certainly result in a return to this state. The lack of certainty regarding the availability of therapy in Uganda, despite that fact that resources are available for only half of those who require them, lacks the level of certainty required by the court in the context of Article 3.

The court, in *D*, was unanimous in their decision to block the deportation. An examination of the dissenting judges (Tulkens, Bonello and Spielman) in the case of *N* is a useful means by which to further examine these cases. The dissenting opinion had several points of law on which the dissenting judges differed greatly from the majority. One of the primary points upon which they differed was based upon the supposition on the part of the majority that the harm in this case emanated from a naturally occurring illness, rather than as a result of the actions of the state. The dissenting judges cited *H.L.R. v France*, a case in which the European Court established that non-state actors that

represent real sources of danger to individuals, and where the state cannot mitigate such dangers, may well rise to the level of violation of Article 3.³⁶¹ Further, the minority in the case disputed the application of the exceptional nature of suffering present in D, instead arguing that other precedents have established a less severe view of the need for suffering in cases that meet the criteria of Article 3. The judges provided the following expert from *Price v United Kingdom*, to illustrate this point: “Where treatment humiliates or debases an individual, showing lack of respect for, or diminishing his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual’s moral or physical resistance, it may be classified as degrading and fall within the prohibition in Article 3”.³⁶² Perhaps the most fervent area of disagreement present in the minority opinion relates to the assertion on the part of the majority that “inherent to the whole convention is the search for a for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individuals fundamental rights.”³⁶³ The dissenting judges were fervent in their claim that individual rights in such a case exist independent of issues of general interest to the community. The minority in the case of N provided strong arguments supporting the assertion that N did meet the criteria for protection under Article 3, despite the legal tests set forth in D. It is important to note that no case filed with the European court, since D, has met the extreme criteria present in the legal test represented by D.

Case law focusing undocumented migrants with diseases other than HIV

³⁶¹ *H.L.R v France* (1997) ECHR 24573/94.

³⁶² *Price v United Kingdom* (2001) 5493/72.

³⁶³ *N v United Kingdom* (2008) European Court of Human Rights (Application Number 26565/05)

While the thesis focuses on the care of persons infected with HIV, there have been significant rulings that relate to the general issue of healthcare services for undocumented migrants. In *Mitfari v Secretary of State for the Home Department*, the case focused on the deportation of an individual based upon his medical condition and medical needs.³⁶⁴ In the case of *Mitfari*, however, the claimant was a failed asylum seeker, which is a profound contrast when considering the criminal background of *D*. *Mitfari* was to be deported, but claimed that his psychiatric difficulties were sufficiently exceptional that return would violate Article 3 and Article 8 of the Human Rights Act of 1998.³⁶⁵ The adjudicator initially found that, in light of the precedents cited, the conditions that *Mitfari* cited were not sufficiently exceptional to warrant, for instance the claim that his return to Kosovo would constitute torture. Although the case was eventually heard on appeal to the Immigration Appeal Tribunal, no errors in law were found sufficient for the tribunal to overturn the original decision, thus, deportation was warranted in the case. In the context of access to healthcare in these individuals, both of whom lacked legal status to remain in the UK, the acute and life-threatening nature of illness highly differentiated *Mitfari* and *D*. The courts acted, in the case of *Mitfari*, largely based upon the precedence set in *N. v Secretary of State for the Home Department*.

Later cases were similar in their attempts to invoke human rights legislation in the context of the health of a claimant whose health is at question in the context of a deportation proceeding. *R v Secretary of State for the Home Department* involved *R*, a

³⁶⁴ *Mitfari v Secretary of State for the Home Department* (2005), Court of Appeal (Civil Division (UK)).

³⁶⁵ European Convention of Human Rights, 1998. Article 3 is the prohibition of torture while Article 8 is the right to respect for family or private life.

Kurdish Iraqi who had been refused asylum in Germany, and eventually claimed asylum in the UK.³⁶⁶ While the Secretary of State for the Home Department initially found against R., and ordered deportation, R. argued on appeal that based upon Article 8 of the European Convention on Human Rights the Secretary of State could not certify that R's return to Germany would not result in a violation of R's rights under Article 8.³⁶⁷ R was unable to avoid deportation due to the lack of a severe or life threatening condition.

While many of the legal arguments in these cases have been made within human rights frameworks, an innate focus on the immediate expectation that harm would occur due to a deportation action. This included, almost universally, the requirement that individual cases be judged based upon the immediacy of degradation of the individual's health status. The need for a case to be 'exceptional' is in keeping with current UK regulation that requires that care be provided during life threatening episodes. This component of the law is illustrated throughout immigration case law on the topic, wherein the constant imperative to demonstrate the exceptional nature of individual cases is apparent.

In summary, the case law regarding issues of access to care for undocumented migrants to the UK, in total, heavily relies on the acuity or degree of illness balanced against the proximal harm associated with government action. That is, a case such as *D v United Kingdom* has a very direct association with harm and suffering of a person very near the end of their life represents the only clear instance of relief provided to an undocumented migrant suffering from HIV/AIDS. The assortment of other cases detailed in this document, however compelling, failed to gain dispensation of any kind for these

³⁶⁶ *R v. Secretary of State for the Home Department* (2005) House of Lords (UK).

³⁶⁷ Article 8 is the right to respect for family or private life.

individuals. The extant case law sets an important precedent, in that actions on the part of the government must induce direct harm or suffering, independent of the pre-existing disease process in order to gain relief for an individual suffering a similar plight to that of N. That is, one would need to identify a way in which the government's action negatively affected the disease course in a way resulting in suffering that is directly attributable to such an action. In essence, the slow decline normally associated with HIV disease has been found insufficient as grounds to prevent a deportation action in such a case.

A comparison of the legal mechanisms for healthcare access in the UK and US.

The legal framework that ensures healthcare access within the UK is based largely upon the very statutes that were used to establish the current healthcare system within the country. The National Health Service Act of 1946 came into effect in 1948. This initial legislation established the NHS as we know it today. While the National Health Service Act of 1997 and 2006 respectively have resulted in alterations to the way that the organization is structured and implemented, little has occurred to alter the way in which services are rendered from the viewpoint of the person seeking care

Rather, a tighter framework for monitoring and adhering to regulations that limit the provision of free services to ineligible parties has been adopted. This trend towards obtaining payment on the part of overseas visitors to the UK became a profound factor influencing the provision of healthcare with the introduction of the National Health Service, Charges to Overseas Visitors Amendment in 2004. The result of these regulations is a system wherein all eligible persons are to receive health services funded and provided by the state. The amendment of 2004, which altered the way that overseas visitors were considered, essentially transfers the responsibility for the funding of service

to overseas visitors, except in cases where they originate from other European Union countries. The result of this legislation was a system of universal coverage for legal inhabitants of the UK, with limitations and requirements for individual responsibility for services rendered on the part of ineligible persons.

Like the system in the UK, there was a time in the not too distant past when undocumented migrants could gain limited services through programs such as Medicaid and Medicare. Attempts to limit these services were met with early and abrupt judicial opposition, such as was the case with Proposition 187 in California, in which the State of California usurped the Federal Government's power to regulate immigration during the state's denial of Medicaid services to migrants. Later, in *Plyler v. Doe*, attempts to deny services to migrants were supported by the Equal Protection Clause of the 14th Amendment of the United States Constitution.³⁶⁸ While *Plyler* applied primarily to educational services, the case established the notion that the equal protection clause served all persons subject to the law, including undocumented migrants. These arguments, however, were countered by the Federal government in the promulgation of the Personal Opportunity and Work Reconciliation Act of 1996. The act not only put into place limitations that applied to undocumented migrants, it went so far as to deny all governmentally funded social services to even lawful immigrants to the country during their first half decade of domicile within the US. To date, there have been no successful challenges made to this statute. Currently, the sole programs within the federal system which allow the provision of services to undocumented migrants are funded through the Public Health Service Act through programs such as the Community Health Centers and

³⁶⁸ The Equal Protection Clause prevents different treatment of individuals within a jurisdiction even when their citizenship status differs.

Migrant Health Clinics offer federally funded healthcare for undocumented migrants.³⁶⁹

These programs offer a highly limited number of clinics, and offer very limited functional access to undocumented migrants.

The US, much like the UK, has firm guidelines for the provision of life saving care. The Emergency Medical Treatment and Active Labor Act was established in 1986.

³⁷⁰ The Act prohibits a US practice often referred to as patient dumping. This Act involved the removal of uninsured patients from healthcare facilities due to their inability to pay. Under the act, these individuals must receive, at minimum, a medical evaluation and life saving care prior to discharge from a facility. The Act does not provide guidelines or any form of funding that would result in payment for such services. The Act functions within the US context much in the same way that Article 3 of the European Convention on Human Rights functions in the UK. From a functional point of view, each of the laws prevents mistreatment by means of service denial during life threatening illness or injury.

UK and US laws as they relate to established human rights law.

A consideration of the manifestations of law regarding health access in the UK and US, from a human rights point of view is interesting due to the US approach to human rights law, and the limited number of treaties that the US has both signed and ratified. The Universal Declaration of Human Rights was clear in its statement in Article 25, reflecting: “Everyone has the right to a standard of living adequate for health and well-being of himself and of his family, including food, clothing, housing and medical

³⁶⁹ 42 United States Code 201

³⁷⁰ 42 United States Code 1395dd

care”.³⁷¹ The International Covenant on Economic, Social and Cultural Rights further espouses this view in Article 12, by stating that: “The states party to the covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.³⁷² The Committee on Economic, Social and Cultural Rights also endorses this view.

Conclusion

The health and social care systems in the UK is structured and equipped to provide the full range of services to authorized person. The literature review detailed clear limits to access for undocumented migrants. These limitations stem from components of the current regulatory regime in the UK in the areas of immigration and healthcare law. The immigration system in the UK allows for individuals to apply for asylum. During this process, health and social care services are made available to individual migrants. Difficulty arises in cases where one has entered the country without legal status, or has lost their right to healthcare services based upon a failed asylum application. Current regulations, as detailed in this section are further tightening the parameters for access to ‘overseas visitors’ to the UK.³⁷³ Based upon the case law, more recent developments indicate a trend towards ensuring that health services are provided in cases where immediate harm related to the lack of such services will result. The case law, both domestic and European addresses the issue of acuity of illness independent of human rights concerns.

³⁷¹ Universal Declaration of Human Rights is clear on this point, in the statement in Article 25.

³⁷² The International Covenant on Economic, Social and Cultural Rights.

³⁷³ Essentially, overseas visitors include anybody who has not established ‘ordinary residency’ in the country.

Chapter 5 - Methods

There have been limited studies that have examined undocumented African migrants' living with HIV/AIDS efforts to gain access to healthcare services. The empirical component of this thesis had as its focus the need to determine actual practices within the healthcare system related to their efforts to gain care. This was accomplished through the use of the Grounded Theory Method³⁷⁴ in an examination of the practices and experiences of workers within Non-Governmental Organizations that provide health and social services to undocumented African migrants and/or persons living with HIV/AIDS. This setting and sampling plan were selected primarily to access the extensive experiences of NGO employees, who invariably possess a direct knowledge of many individual cases in which health services were required by undocumented migrants under circumstances where services were not readily available under the normal rules governing the respective healthcare systems. NGO employees, as well, possess intimate experiences regarding their client's quest for needed resources. While national laws and international human rights instruments provide parameters for consideration of undocumented migrants' experiences in gaining healthcare, there are currently few sources of data that document the actual experiences of undocumented migrants. Thus, the empirical data gained through the current study addressed gaps in what is known about the experiences of this highly vulnerable population.

³⁷⁴ The Grounded Theory Method originated with the 1967 work of Glaser and Strauss. The method focuses on the study of social processes through the integration of various forms of data gained through observation and fieldwork. While the method has been refined by various authors, it remains at base, an inductive method through which to discover and analyze the presence of basic social process related to a host of topics. The methodology will be further expounded upon later in this chapter. Glaser, B. and Strauss, A. *Discovery of Grounded Theory*. (Aldine Press, 1967)

The interaction between immigration and human rights law is very complex in the UK and US contexts. Given differences in the systems, and the need for comparability, a very specific population, undocumented African migrants living with HIV/AIDS, was selected for inclusion in the study. While many health-related challenges face undocumented migrants, it was desirable to target a group with well-established healthcare needs, and who exist on both sides of the Atlantic. African people, having originated at the epicenter of the HIV epidemic, and one of the most unstable regions in the world, offer an ideal population for the examination of these issues.³⁷⁵ The empirical component of this thesis will examine healthcare access amongst undocumented HIV positive African migrants dwelling in the UK and the US. This offers a population in which human rights related concerns are profound, and offer a unique opportunity to analyze the impact of law, disease and the need for assistance in the context of legal frameworks.

There were practical considerations associated with this phase of the study that were associated primarily with access to information regarding sensitive research subjects such as undocumented migrants. The current political and legal environments within the US and UK are rife with imperatives to identify undocumented migrants. Fears regarding the possible detection of individual undocumented migrants and the possibility that their status would be identified played a peripheral role in the selection of NGO employees as the primary source of data for the study. Additionally, individual undocumented

³⁷⁵ While the European and US effect on the global HIV pandemic is significant, the prevalence rates within Africa continue to far exceed these rates. These rates have substantially been influenced by the high rate of infection amongst African migrants, many of whom come from Sub Saharan Africa. Buchbinder, S. "HIV epidemiology and prevention interventions." (2007) 15(2), *Topics in HIV Medicine*, 26 at p. 28

migrants' fears regarding their legal status and possible repercussions associated with refusal to participate in the study could result in the perception of coercion, which may have resulted in participation under unethical conditions. Given the lack of similar studies in the literature, there were few examples, particularly in the UK context, which offered insight into methods by which this community could be accessed in a beneficial way, without raising issues regarding their highly sensitive status in the respective countries where they dwell. In the US context, gaining access to this population is easier due to the legal and social underpinnings of immigration in the US; however, undocumented migrants in the US context are suffering ever-increasing levels of scrutiny due to the current political environment.

Aims of the Empirical Study

The primary aim of the empirical phase of the study is to develop a theoretical model that explains the phenomenon surrounding the efforts of undocumented African migrants living with HIV/AIDS to access health services in the UK and US respectively. The primary aim of the study will be addressed through the employment of the Grounded Theory Method. Following development of theoretical models which explain the basic social processes present in both systems, a comparison will be made in the final chapter with the goal of determining the differences and similarities present within the data as it relates to undocumented migrant's activities in seeking healthcare, and the degree to which legal mechanisms in the respective countries are reflected in the actual experiences of undocumented migrants.

The following specific aims will be addressed:

1. To examine cases where health services are gained and determine the most common modalities wherein African migrants living with HIV/AIDS gain access to health services.
2. To determine the concordance between current regulatory instruments and actual practices in the UK and US regarding undocumented African migrants living with HIV/AIDS endeavors to gain health services.
3. To determine the similarities and differences in the legal and functional approaches to the provision, or lack of provision of healthcare services to African migrants living with HIV/AIDS in the UK and US.

Research Design

A qualitative research design based upon the Grounded Theory Method was used throughout the conduct of this thesis. The thesis used a combination of a survey-based component that was designed to elicit demographic information, and a series of interviews that were conducted in order to gain greater depth in the data. Data was collected from workers at Non-Governmental Organizations (NGOs) that offer assistance to undocumented migrants. Specifically, NGO workers selected at the various sites included in the study were those engaged in service coordination and case management. These workers were selected based upon their extensive contact with clientele, and associated familiarity with the experiences of undocumented African migrants.³⁷⁶

³⁷⁶ Case management professionals interact with the clientele of a particular agency in order to ensure comprehensive provision and coordination of services. These individuals are the primary professionals charged with direct interaction with the given population being serviced by a

Specific matrices containing detailed descriptions of the agencies included in the UK and US phases of the study are contained later in this chapter. Each of the agencies was visited by the researcher in person, and included the interview as described above as well as a short tour of each of the agencies. The tour was never requested, but instead, was spontaneously offered by personnel at each of the respective agencies. This allowed for the compilation of data for the demographic questionnaire regarding services and facilities, and was included in the aforementioned matrices contained later in this chapter.

During the formative phases of the project, consideration was given to various data sources appropriate to the Grounded Theory Method. Possibilities included, for instance, direct observation or client interactions and focus group interactions. Several factors lead to the selection of interviews and the collection of simple demographic information regarding the participants. First and foremost, there were concerns by both the researcher and the university regarding the vulnerable nature of African migrants. Due to human subjects related concerns, data collection involving direct interaction or observation of undocumented migrants was forbidden, thus limiting the ability to record NGO worker-client interactions. Further, there were functional limitations associated with the geographic dispersal of NGO sites, in that it was not possible to form focus groups of multiple case workers from multiple sites. In the end, the decision was made to focus data collection on individual interviews as previously described. All interviews were transcribed into type written manuscripts in order to facilitate coding. The type-written interviews were then thematically coded, in order to group commonly occurring themes.

particular agency. Shelton, R., Golin, C., Smith, S., Eng, E., and Kaplan, A. The role of the HIV/AIDS case manager; Analysis of a Case management and adherence training program. (2006), *AIDS Patient Care and STD's*, 193 at p. 194-195

An analysis of actual practices in each of the respective jurisdictions was then performed, followed by a comparison of actual practices in these jurisdictions to the law. Finally, comparisons between the jurisdictions, directed towards identifying their degree of compliance with appropriate regulatory regimes were performed.

The Grounded Theory Method

The Grounded Theory Method was used to conduct the study, based upon the method's ability to integrate various forms of qualitative data and offer a structured method through which interview and observational data may be analyzed and interpreted. Since this study involved contact with individuals vested in the issue at hand, in their naturalistic environment, this was an ideal method through which to conduct a study of this nature. Glaser and Strauss developed the Grounded Theory Method in 1967.³⁷⁷ Due to its focus on giving structure and extracting theory from data that is inherently unstructured, and then extracting theory from the data, this method is inductive to its very core. The strength of the Grounded Theory Method (GTM) lies in the fact that the theory that it yields simply makes sense.³⁷⁸ That is "the reader will have immediate recognition that this theory, derived from a given social situation, is about real people or objects to which they can relate".³⁷⁹ The strength of the GTM lies largely in the practical way that it records and organizes data regarding human social interactions.³⁸⁰ Key to the

³⁷⁷ Glaser, B. *Theoretical sensitivity* (Sociology Press, 1978); Glaser, B. *Basics of grounded theory analysis: emergence versus forcing*. (Sociology Press, 1992); Glaser, B. and Strauss, A. *Discovery of grounded theory*. (Aldine Press, 1967); Strauss, A. *Qualitative analysis for social scientists*. (University of Cambridge Press, 1987)

³⁷⁸ Stern, P. On solid ground: Essential properties for growing grounded theory. From Bryant, A. and Charmaz, K. *The Sage Handbook of Grounded theory*, (Sage Publications, 2008) at p. 11-20

³⁷⁹ Ibid, p. 114

³⁸⁰ Seaman, J. Adopting a grounded theory approach to cultural-historical research: Conflicting methodologies or complementary methods. (2008) 7(1), *International Journal of Qualitative Methods*, 1

pragmatic, clear and structured approach associated with the GTM is its ability to derive theory from emerging social patterns that are present in the data, while capturing their essence in a way that clearly explains the relationships between key variables.³⁸¹ Prior to the advent of the GTM, research generally required that one develop well structured categories before data were actually collected, which often confined research to areas in which enough was known to make clear predictions regarding the possible outcomes of a given study. Grounded Theory on the other hand, provided a means of exploring social phenomenon in situations where little was known, therefore establishing an inductive means of developing such categories.³⁸² That is, rather than test a specific hypothesis, the method is emergent in that the aim is to delineate the basic social processes present in the data in order to facilitate a greater understanding the situation that is the topic of inquiry.³⁸³ In essence Glaser and Strauss defined grounded theory as theory derived from data that has been systematically gathered and analyzed through a structured research process.³⁸⁴ In the case of this thesis, and the lack of empirical research characterizing the social constructs under consideration, the GTM offered an ideal method through which to conduct such a study.

The Grounded Theory Method offers a very flexible method through which to perform research. While the method does prescribe a basic structure, the approach to the method is fluid in that its founders stress an approach that is appropriate to a specific research question, and thus, the method may differ slightly from researcher to researcher

at p. 8-11

³⁸¹ Glaser, B. Conceptualization: On theory and theorizing using grounded theory. (2002) 2, *International Journal of Qualitative Methods*, 23 at p. 27-30

³⁸² Kell, U. The development of categories: Different approaches in grounded theory. From Bryant, A. and Charmaz, K. *The Sage Handbook of Grounded theory*, (Sage Publications, 2008)

³⁸³ Glaser, B. and Strauss, A. *Discovery of grounded theory*. (Aldine Press, 1967) at p. 60-69

³⁸⁴ Ibid at p. 5-8

or problem to problem.³⁸⁵ Glaser, in his pragmatic way, referred to the central theme of the method, “pattern naming”, in his characterization of the way that social processes were considered within the context of the GTM.³⁸⁶ The basic steps of the model include data-collection, note-taking, coding, memoing, sorting and writing.³⁸⁷ Data, in the context of the Grounded Theory Method come from virtually any source according to Glaser, although social scientists often focus on interview data due to its facilitation of direct observation.³⁸⁸ In the context of this study, the data was comprised of interviews, demographic and data forms, and observations made during interviews.³⁸⁹ In fact, the data was collected, notes taken, coding and memoing were performed simultaneously. The method relies on a purposive form of theoretical sampling that strives to identify different properties inherent to a phenomenon in a way that increases the diversity of a sample.

During the process of the interviews, for instance, notes were taken. The text of the interview, sentence-by-sentence, was then compared using the continuous comparative method, and was coded thematically, with a mind towards placing data into one or more categories. Generally this involved a core or overriding category and one or more subcategories. A category was coded for until the themes in the data began to repeat themselves, which is referred to as theoretical saturation. Once this occurred, the other

³⁸⁵ Bryant, A. and Charmaz, K. Grounded theory in historical perspective. From Bryant, A. & Charmaz, K. *The Sage Handbook of Grounded theory*, (Sage Publications, 2008)

³⁸⁶ Glaser, B. Conceptualization: On theory and theorizing using grounded theory. (2002) 2, *International Journal of Qualitative Methods*, 23 at p. 35-38

³⁸⁷ Strauss, A. *Qualitative analysis for social scientists*. (University of Cambridge Press, 1987)

³⁸⁸ Glaser, B. Doing formal theory. From Bryant, A. & Charmaz, K. *The Sage Handbook of Grounded theory*, Sage Publications, London, 2008.

³⁸⁹ Observations were limited due to ethical considerations associated with ethical clearance gained to perform the study. Thus, these observations were related directly to the participant’s actions during the interview.

categories evident in the data were coded until each reached a point of theoretical saturation. Memoing, as previously mentioned, was undertaken concurrently, and involved the recording of notes that reflect upon the relationship between categories or hypothesis regarding them. It is important to note that subsequent participants' data was coded with a mind towards the previous participant; thus, theoretical sampling sought to add diversity to the data set with the goal of exhausting common themes in the data.

The final step of the process involved sorting. During this process, memos regarding the categories were sorted to the extent that they relate (or do not relate). During sorting memos were sorted based upon their relationship to the core category that was central to the phenomenon being investigated. Essentially, it is during sorting that the themes present in the data become theory (or that which theory emerges from).³⁹⁰

In the context of this study, the Grounded Theory Method was used to investigate the relationship between undocumented migrants and the healthcare system in their respective countries, and then to compare the categorical data between the two countries. This required that interviews were performed sequentially, but in an unstructured manner, dependent upon the nature of the data. That is, when an individual participant was interviewed, the data was then analyzed to determine its content, in order to drive theoretical sampling to the extent that the data represents the core category and any other categories to the maximum extent possible. This process occurred until theoretical saturation occurred across the categories. The major limitation of this process was

³⁹⁰ The inductive nature of analysis in the GTM hinges on the notion that the theory present in the data emerges through the process described in the text above. While Glaser had been very firm in a 'looser' style of analysis, Strauss later stressed the need for the use of well-structured technique in order to ensure that data was processed in a thorough manner. Strauss, A. *Qualitative analysis for social scientists*. (University of Cambridge Press, 1987)

geographical, which did not facilitate alternating between jurisdictions regularly due to travel related limitations. This required, in essence, that a second layer of sorting occur, once data from both jurisdictions was available. The actual data for the study are presented in chapters 6 and 7, and will shed light on the categories present in the data and the relationships amongst them.

Setting

During the development of the study consideration was given to several means of collecting data regarding undocumented migrant's experiences. Initial planning included accessing National Health Service facilities in the UK, during which physicians and other health care workers would have been included in the sample. Due to the nature of the study and the desired population, it was not possible to access NHS facilities or the associated healthcare workers. This greatly limited the range of choices available for the conduct of the study, and limited the ability to access healthcare workers directly. As an alternative to NHS facilities, NGOs were identified as somewhat analogous to NHS healthcare facilities due to the range of services offered within them. While the focus of sampling within the NGOs was on caseworkers, several physicians who serve roles within NGOs were included in both the UK and US samples. The use of NGOs provided a diverse sample of individuals with extensive experiences working with undocumented African migrants living with HIV/AIDS.

The study utilized a survey and interview to gain information from NGOs that were regularly approached by migrants seeking assistance regarding healthcare related services. These NGOs were those who, at least in part, focus on gaining healthcare for undocumented African migrants living with HIV/AIDS. Data was collected from

individuals in these organizations working primarily in case management or service coordination roles. The inclusion of caseworkers provided a wider, although less direct approach, through which to gain a representation of the experiences of many migrants.

The United States offered a special challenge due to the many entry points into the system due to the privatized system of healthcare. Perhaps even more so than the UK, data collection from workers in non-governmental organizations provided a broader representation of the means through which services are accessed. The non-governmental agencies in the US context included non-profit organizations and organizations that provide health and social services to undocumented migrants. Although federally funded, migrant health clinics are administered by private organizations that offer medical and social services to migrant families regardless of their immigration status.

Sample

The sampling plan for the UK phase of the study was performed until thematic saturation occurred. That is, when no new themes were present in the interviews, they were complete. Therefore, there was no set number of participants who were to be interviewed, due to the nature of the Grounded Theory Approach. Non-Governmental Organizations that offered services to undocumented migrants were approached regarding data collection. In the UK context, this followed an approach that focused on the agency's headquarters in order to gain policy level information. Additionally, the operational or service providing entities of the organization were approached in order to gain information regarding the day-to-day efforts to gain health related services for individuals. The majority of large non-governmental organizations in the UK are located in major cities. Alternatively, the service providing entities within these agencies are

located across the country and in small to medium sized cities where there are concentrations potential clients.

Table-1 denotes the characteristics of non-governmental agencies included in the sample. The table details the regions included in the study. These were selected based primarily upon the availability of organizations that met the criteria for the study. While agencies from the Midlands and the Northwest were included in the sample, several limitations dictated the composition of the sample. The London metropolitan area, as the largest municipality in the UK, includes the headquarters of many organizations. This combination of factors resulted in a greater representation for this region in the sample. Additional large metropolitan areas in the Northwest of England were included, however, there were limited numbers of agencies available in these cities. Sampling in these areas was further complicated by the relatively low levels of African migrants in the northwest of England, and the concurrent lack of agencies in these cities that provide for their needs. Finally, it was essential to include smaller communities in the study; thus, attempts were made to enroll organizations in the Midlands.

Table-1 also provides a reflection on the services offered in each of the agencies. Participants from each of the agencies were asked to list the services that they offered. The nomenclature selected by each of these individuals varied in their description of similar services. In order to standardize these classifications, services were grouped under standardized labels that serve to provide for the possibility of comparison. This portion of the data reflects that several classifications of agencies were present in the sample. The agencies included provided data reflecting on the major constructs of interest in this study including: 1) Agencies that provide legal or immigration related assistance; 3) Agencies

that provide social services or support; 3) Agencies that provide medical care assistance and coordination; 4) Agencies that provide services that provide counseling services; and 5) Agencies that provide HIV/STD related services. Finally, several agencies that provide assistance to individuals in immigration detention were included. Sampling of these agencies proceeded systematically until theoretical saturation was achieved.

Table-1: Participating Agencies in UK

<u>Agency Description</u>	<u>Agency Location</u>	<u>Primary Population Served</u>	<u>Agency Activities</u>
UK-SE-1	Large City in the Southeast of England	1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS	1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling. 7. HIV and STD testing.
UK-SE-2	Large City in the Southeast of England	African populations	1. HIV and STD prevention services. 2. Case management services. 3. Legal and immigration assistance. 4. Individual counseling.
UK-SE-3	Large City in the Southeast of England	1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS. 3. Each of the above are in the context of the evangelical church community in the city.	1. Coordination of social care needs. This includes childcare, social care and educational assistance. 2. Home care and maintenance assistance. 3. Assistance with daily needs such as food, shopping and transportation. 4. The provision of educational materials. 5. HIV and STD prevention services. 6. Legal and immigration

UK-SE-4	Large City in the Southeast of England	People within and outside of the UK with difficulty accessing medical care.	<p>assistance.</p> <ol style="list-style-type: none"> 1. Public advocacy. 2. Political campaigns supporting groups at risk related to their lack of access to medical care. 3. Legal counseling. 4. Case management services (UK only). 5. Education regarding methods through which to gain healthcare access.
UK-SE-5	Large City in the Southeast of England	People being held inside of or those who have been released from immigration detention.	<ol style="list-style-type: none"> 1. Public advocacy. 2. Political campaigns supporting groups at risk related to their lack of access to medical care. 3. Legal counseling. 4. The documentation of medical conditions to provide support for asylum applications. 5. The provision of medical consultation and support to those being held in immigration detention.
UK-SE-6	Large City in the Southeast of England	Asylum seekers and undocumented migrants with health needs.	
UK-SE-7	Large City in the Southeast of England	HIV positive individuals with immigration concerns including those in detention.	<ol style="list-style-type: none"> 1. Specialist consultation regarding HIV/AIDS care for people being held in immigration detention and for immigrants with such needs. 2. Public advocacy. 3. Political campaigns.
UK-SE-8	Large City in the Southeast of England	Immigrant populations who lack access to the NHS.	<ol style="list-style-type: none"> 1. Direct medical care. 2. Case management services. 3. Referral and coordination of immigration related legal services.
UK-Midlands-1	Medium Sized City in the Midlands of England	<ol style="list-style-type: none"> 1. People living with HIV/AIDS 2. Populations at risk of contracting 	<ol style="list-style-type: none"> 1. Individual and community educational Services. 2. The provision of educational materials.

		HIV/AIDS	<ul style="list-style-type: none"> 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling. 7. HIV and STD testing.
UK-Midlands-2	Small City in the Midlands of England	<ul style="list-style-type: none"> 1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS 	<ul style="list-style-type: none"> 1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling. 7. HIV and STD testing.
UK-Midlands-3	Medium Sized City in the Midlands of England	People at risk of or who have been infected with sexually transmitted diseases.	<ul style="list-style-type: none"> 1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Individual counseling. 5. HIV and STD testing.
UK-Midlands-4	Large City in the Midlands of England	<ul style="list-style-type: none"> 1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS 	<ul style="list-style-type: none"> 1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling. 7. HIV and STD testing.
UK-Northwest-1	Large City in the Northwest of England	People living with HIV/AIDS	<ul style="list-style-type: none"> 1. Individual and community educational Services. 2. The provision of educational materials. 3. Case management services. 4. Legal and immigration assistance. 5. Individual counseling. 6. Massage, Acupuncture and

UK-Northwest-2	Large City in the Northwest of England	1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS	physiotherapy. 7. Home maintenance and gardening assistance. 1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling.
UK-Northwest-3	Large City in the Northwest of England	People living with HIV/AIDS	1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling. 7. Massage, Acupuncture and physiotherapy. 8. The provision of meals at the agency and in the homes of those unable to care for themselves. 9. The provision of home care assistance.
UK-Northwest-4	Large City in the Northwest of England	1. People living with HIV/AIDS 2. Populations at risk of contracting HIV/AIDS	1. Individual and community educational Services. 2. The provision of educational materials. 3. HIV and STD prevention services. 4. Case management services. 5. Legal and immigration assistance. 6. Individual counseling.

During the US phase of the study, the following sampling approach was undertaken. The US was different from the UK, in part, due to the vast geography of the

country and differences in the distribution of undocumented migrants. The majority of individuals entering the US find themselves working in agriculture, and thus, the agencies that serve these individuals tend to be in rural areas. In a manner similar to the UK, the major headquarters tend to be in the large cities, which necessitated extensive travel.

Table-2 provides a representation of the agencies included in the US phase of the study. The sample in the US context differed from the UK phase of the study in several respects. The US phase required that a higher proportion of agencies that provide services specifically to African people were included. This was due in large part to the lower proportion of African immigrants in the US. This resulted in a lack of experience on the part of many US agencies, who declined to participate based upon this factor. The US sample was evenly distributed across three large east coast cities. The UK phase required that the majority of organizations included in the sample be in one major city, however, in the US the presence of more large cities facilitated a broader approach to sampling. Attempts were made to locate agencies that met the sampling criteria for the study. Unfortunately, the lack of African persons in these communities, and the concurrent lack of need for agencies that provide assistance to these individuals were problematic. While there were some difficulties in enrolling agencies within the UK, this was not a significant problem in the US. The primary problem in the US context was to identify agencies that fit the design of the thesis, especially in the context of having provided services to African migrants.

Participants from each of the agencies were asked to list the services that they offered. The nomenclature selected by each of these individuals varied in their description of similar services. In order to standardize these classifications, services were

grouped under standardized labels that serve to provide for the possibility of comparison. The major difference between the US and UK phase of the sample is the presence of more agencies that provide comprehensive medical care to underserved and migrant populations. This reflects the fact that the lack of universal coverage in the US results in higher numbers of people who lack access to medical care. Table-2 reflects that several classifications of agencies were present in the sample. The agencies included provided data reflecting on the major constructs of interest in this study including: 1) agencies that provide social care and medical coordination services; 2) Agencies that provide direct medical care; 3) Agencies that provide legal or administrative assistance with immigration issues; 4) Agencies that offer HIV/STD care and prevention; 5) Agencies that provide counseling services and 6) Agencies that provide care to individuals in immigration detention centers. The agencies were selected in such a way as to facilitate theoretical saturation. That is, agencies were selected and the interview transcripts analyzed until there were no new themes present in the data. This was accomplished with the mix of agencies reflected in this section.

Table-2: Participating Agencies in the US

<u>Agency Description</u>	<u>Agency Location</u>	<u>Primary Population Served</u>	<u>Agency Activities</u>
US-Northeast-1	Large City Northeastern US.	African migrants	1. Case management and social service coordination. 2. Legal counseling and assistance with immigration issues. 3. Individual counseling. 4. Educational offerings regarding the process of establishing a sustainable way of life in the US.
US-Northeast-2	Large City	African migrants	1. Case management and social

	Northeastern US.		service coordination. 2. Legal counseling and assistance with immigration issues. 3. Individual counseling. 4. Educational offerings regarding the process of establishing a sustainable way of life in the US.
US-Northeast-3	Large City Northeastern US.	African migrants	1. Legal counseling and assistance with immigration issues. 2. Individual counseling. 3. Educational offerings regarding the process of establishing a sustainable way of life in the US. 4. Referral for medical care in cases of severe need.
US-Northeast-4	Large City Northeastern US.	Persons who lack access to medical care.	1. The provision of primary medical care services. 2. The provision of HIV related care and associated treatments. 3. HIV/AIDS related case management services. 4. Counseling services.
US-Northeast-5	Large City Northeastern US.	Migrant workers.	1. The provision of primary medical care services. 2. Case management services. 3. Counseling services.
US-Northeast-6	Large City Northeastern US.	Individuals in immigration detention facilities.	1. Legal counseling and assistance with immigration issues. 2. Assistance in gaining needed medical, psychological and social services.
US-Middle Atlantic-1	Large City Mid-Atlantic US	African migrants	1. Legal counseling and assistance with immigration issues. 2. Individual counseling. 3. Educational offerings regarding the process of establishing a sustainable way of life in the US. 4. The provision of food and housing assistance.

US-Middle Atlantic-2	Large City Mid-Atlantic US	African migrants	<p>5. Limited medical care and pharmacy related assistance.</p> <ol style="list-style-type: none"> 1. Legal counseling and assistance with immigration issues. 2. Individual counseling. 3. Educational offerings regarding the process of establishing a sustainable way of life in the US. 4. The provision of food and housing assistance. 5. The provision of financial assistance and grants in cases of dire need.
US-Middle Atlantic-3	Large City Mid-Atlantic US	Persons who lack access to medical care.	<ol style="list-style-type: none"> 1. The provision of primary medical care services. 2. The provision of HIV related care and associated treatments. 3. HIV/AIDS related case management services. 4. Counseling services.
US-Middle Atlantic-4	Large City Mid-Atlantic US	African migrants	<ol style="list-style-type: none"> 1. Legal counseling and assistance with immigration and social care issues. 2. Medical and social case management services. 2. Educational offerings regarding the process of establishing a sustainable way of life in the US. 3. The provision of food assistance. 5. The provision of financial assistance and grants in cases of dire need.
US-Middle Atlantic-5	Large City Mid-Atlantic US	Persons who lack access to medical care.	<ol style="list-style-type: none"> 1. The provision of primary medical care services. 2. The provision of HIV related care and associated treatments. 3. HIV/AIDS related case management services. 4. Counseling services.
US-Southeast-1	Large City Southeastern US	People living with HIV/AIDS	<ol style="list-style-type: none"> 1. The provision of HIV/AIDS related case management and social services.

US-Southeast-2	Large City Southeastern US	Migrant workers.	2. Educational offerings regarding life with HIV/AIDS 1. The provision of primary medical care services. 2. Case management services. 3. Counseling services.
US-Southeast-3	Large City Southeastern US	Persons who lack access to medical care including those with HIV/AIDS related medical care needs.	1. The provision of primary medical care services. 2. The provision of HIV related care and associated treatments. 3. HIV/AIDS related case management services. 4. Counseling services.
US-Southeast-4	Large City Southeastern US	African migrants	1. Legal counseling and assistance with immigration and social care issues. 2. Medical and social case management services. 3. Counseling services. 4. The provision of financial assistance and grants in cases of dire need
US-Southeast-5	Large City Southeastern US	Individuals in immigration detention facilities.	1. Legal counseling and assistance with immigration issues. 2. Assistance in gaining needed medical, psychological and social services.

Protection of Human Subjects

Clearance for performing the study was gained from the University Non-Clinical Research Ethics Committee in February of 2008. All data collection was completed in accordance with the Data Protection Act 1998 (UK). Access to the health related information of individuals is very sensitive within the UK and US. The collection and handling of this type of data in the US context is governed by the Health Information Privacy and Portability Act (2003). This study, however, did not require access to either the clients of healthcare facilities or their health related information. Instead, it focused

on common practices within these organizations and the practices of the individuals who seek care within them.

During the UK phase of the study, data collection occurred outside of healthcare facilities, and thus, did not require the additional levels of clearance that would be required within the National Health Service. Instead, the project was referred to the Law Department Departmental Ethics Officer for approval under the University of Leicester Human Subjects Research Ethics protocol. The US phase of the study, in a similar manner, involved interface with non-governmental organizations. Both phases of the study, had a core effort aimed at the protection of anonymity, in order to prevent any individual or agency from being exposed to undue scrutiny due to their efforts on behalf of individuals with questionable legal status. Thus, no individual or agency was identified by name in the printed and/or publicly accessible components of the study.

Informed consent

Initially, individual NGOs were contacted via e-mail. A copy of the information sheet contained in Appendix C was included with an invitation to participate. Those agencies that referred specific individuals were considered for inclusion in the study. Individual persons employed by the agencies who work in an appropriate area were then contacted with regards to their willingness to participate. They too were provided the information sheet. If they agreed to participate, they were provided with the informed consent document. Informed consent was obtained from each participant prior to data collection. The informed consent document detailed the guarantee of anonymity of participants, and the parameters governing their participation in the study. These included, but were not limited to voluntary participation and the right to withdraw, without

consequences at any time. Additionally, data was largely reported as group data and thus was not attributable to any individual or organization. The rationale for these measures was associated with the possible fear on the part of participants related to the possibility of involvement with immigration or law enforcement officials due to participation in the study.

Confidentiality and Data Protection

The guarantee of confidentiality was paramount to the performance of the study. All data was handled in compliance with the Data Protection Act of 1998. The hallmark of this aspect of the study was the overriding need to avoid labeling of interview transcripts and study materials so that none of the data may be associated with a particular participant. The following procedures will be used to ensure confidentiality.

1. A coded list, for use solely by the researcher, was used in order to track agencies and to match the qualitative questionnaires with specific sites where interviews were being conducted. Completed surveys and interviews were stored in such a way that they were matched by code numbers, however, after data collection was complete, questionnaires and interview transcripts were stored separately from any document that indicated that actual site from which data was gained.
2. Data collection instruments were labeled using a number, which was used to cross reference the questionnaire to the list of agencies. The list of agencies denoted the name of the agency and its' location. Again, after data collection, this information was stored separately to avoid an agency from being identified.

3. No data collection instrument was labeled with the name of any person or agency that might allow one to attribute data to any particular entity. Again, the list was stored separately in a locked cabinet in the researchers office.
4. During the writing up of the research, only the country, and region was used to refer to the site from which data was obtained. No reference, at any time, attributed answers to any individual.

Instrumentation

The study methodology was based upon both survey and interview techniques. The demographic survey for non-governmental organizations is contained in Appendix A. It was an instrument that facilitated the comparison of aspects of the non-governmental organizations and associated personnel included in the sample. Interviews were performed after the completion of the survey. The interview for the non-governmental organizations is contained in Appendix B. The interview script included in the appendix reflects the baseline interview for the study. Throughout the application of the Grounded Theory Method, as theoretical saturation occurred in various areas of the data, the interview was adjusted in order to more thoroughly address topics which had been touched on, but were not manifested to the degree that theoretical saturation had occurred. This very mechanism negated the need for extensive piloting of the interview, due to the evolving nature of data in the Grounded Theory Method.

Research Protocol

The research protocol for the study was as follows. Individual agencies were contacted, and request made to coordinate interviews with appropriate individuals. Although agency structure may differ, officials that had expertise and knowledge

regarding client administration were sought for the sample. In the case of Non-governmental organizations, officials who had actively worked in areas involving the allocation of health services to their clients were sought for the sample. The informed consent document was then be forwarded by Fax or through mailing. The agency was not contacted further until the informed consent document was completed and returned. Following the completion of the survey, arrangements were made for the taped telephonic interview. This was completed during taping, and the tapes later transcribed. The interview was taped using a digital tape recorder. Prior to taping, the participant were reminded of this, and asked to refrain from identifying any person, place or organization that may have identified the participant or their agency. The interview was then conducted, and then transcribed.

Data Analysis

Data gained from the interviews were recorded and were immediately transcribed, prior to the initiation of the coding process. Each participant's data was coded in this manner prior to proceeding to the next participant. The transcribed versions of the interviews were then coded. Thematic coding was used initially in order to categorize statements made on the part of participants. Initial coding was recorded within the margin of the typewritten transcripts of the interviews. This aspect of the coding process allowed for the identification of anchors within the data that served to identify key points. These themes were then be categorized in order to build a picture of practices, as they existed. Following the initial stage of coding, which provided a relatively crude set of often loosely related theses, concepts were developed based upon interrelated themes identified during initial coding. This involved the grouping of themes identified from initial coding

resulting in the development of well-developed concepts. This process continued across successive participants, with continuous comparison of the conceptually developed data. These comparisons involved the comparison of concepts in order to develop categories of data that were used to develop the theory that arose from the study. Data from the UK and US phases of the study were coded as if each comprised separate research studies. Chapters 6 and 7 present the data, and further explain the relationship between the categories present within the data, and the theoretical model, which was derived from them.

Limitations

No study can provide an absolutely comprehensive view of a particular phenomenon. In the case of this study, there were several clear limitations that related primarily to the methodology and the scope of the project. These limitations are common to studies using qualitative techniques such as the Grounded theory Method. Some limitations of the study are as follows:

1. The study was limited to several discrete geographic areas of the US and UK. The external validity of the study was limited due to the scope of the project.
2. The sample size of the study was highly limited, thus, the external validity is limited by the small sample size.
3. The purposive sampling technique inherent to the study provided an additional limitation to the external validity of the study.
4. The inability to directly interface with undocumented migrants was a limitation of the study. The study, instead, focused on the experiences of workers who have broad experiences in dealing with the limitations experienced by undocumented migrants. In

this manner, a wider representation of the patterns of experiences seen amongst undocumented migrants was gained than would have been possible in interviews of a limited number of actual undocumented migrants.

Conclusion

The purpose of this chapter was to provide a clear reflection of the research methodology and approach to this project. Although the scope of the empirical element of the study was limited, it provided a cogent reflection of the nature of healthcare access in this population. The key to this phase of the study was the eventual comparison of the data to the actual law in the respective jurisdictions. Thus providing a reflection of the legal phenomenon associated with this population and the actual law.

Chapter 6 – Undocumented Migrant’s Access to Healthcare in actual Practice: An Empirical Examination within the UK.

In this chapter, the results of the empirical data related to Non-Governmental Organizations within the UK are presented. These data were collected during the period that spanned Autumn 2007 through Summer 2008, during four trips to the UK during which the researcher visited various cities. This chapter will provide a presentation of the data with integrated analysis. The purpose of this chapter is to present the empirical data according to the aims presented in the previous chapter. These include: (1) Examining cases where health services are gained and determine the most common modalities wherein African migrants living with HIV/AIDS gain access to health services, and; (2) Making a determination of the concordance between current regulatory instruments and actual practices in the UK and US regarding undocumented African migrants living with HIV/AIDS endeavors to gain health services. Data will be presented thematically, during the continuous comparative analysis guided by the Grounded Theory Method.³⁹¹ This is followed by a presentation of the theoretical model developed from the data. Analysis will be integrated throughout the chapter.

Data Collection

Interviews in the UK context were performed at various NGOs during visits to the country. The continuous comparative nature of the Grounded Theory Method required that each interview be immediately transcribed, and then analyzed line by line in order to establish the presence of themes in the data. Arising themes were used in order to guide

³⁹¹ The continuous comparative approach characteristic of the Grounded Theory Method identifies themes as they arise in the data. These themes are continually compared to subsequent data, and are refined throughout the research process resulting in themes that represent the basic social processes present within the data.

further data collection to the degree that thematic saturation occurred after data, which reflected the totality of the phenomenon of undocumented migrants seeking HIV care could be established. Data elicited from the interviews was transcribed, analyzed, coded, and thematically categorized in order to identify theoretical concepts. Throughout data collection, themes and categories present in the data were compared to all previous data collected for the study to fully characterize the presence of themes and concepts and to identify relationships between these factors. This process guided data collection with subsequent participants. Data collection continued until theoretical saturation had occurred, which became evident when new themes in the data ceased to emerge.

The UK phase of data collection was challenging, primarily due to the researchers lack of practical familiarity with the health and social care systems within the UK. The process of enrolling participants was accomplished without great difficulty, due to individual agency willingness to participate in a project of the nature represented by this thesis. The primary difficulty associated with data collection occurred when the issue of detention centers and their effect on healthcare access began to emerge in the data, since this element of the data was not foreseen, and required the identification and enrollment of participants with knowledge of such centers. Several participants, who fit the inclusion criteria for the study, were identified and included in the sample. This completed the data collection process and resulted in theoretical saturation.

Results

The results of the UK phase of the study will be presented according to themes that arose from the data during continuous comparative analysis. These themes will be presented according to gerunds, which is a common practice when using the Grounded

Theory Method.³⁹² These represent the Basic Social Processes experienced by undocumented immigrants as they establish their lives in the UK and strive for all of their needs to be met. These processes will be considered in the context of the law and human rights principles. Five major thematic categories arose from the data during analysis. They included: a) Striving to gain the resources necessary for survival; b) Working to gain asylum through the initial application and the appeals process; c) Seeking access to needed health services; d) Struggling to maintain access to health and social services after failure during the appeals process; e) Maintaining hope and seeking the resources necessary for survival in the face of deportation. Each of these themes and the data accompanying them will be presented followed by a presentation of the theoretical framework, which explains the relationship between the constructs that arose from the data.

Striving to gain the resources necessary for survival

Throughout data collection, a common theme appeared to underlie each of the basic social processes that arose from the data. The findings indicated that undocumented African migrants from economically underdeveloped countries are characterized by a lack of resources at the time of immigration to the UK. This major theme within the data was characterized by three subthemes, which included: 1) Gaining employment within the UK; 2) Working to secure adequate housing; and 3) Working to gain assistance from government funded social services agencies. It must be stated that throughout data

³⁹² Gerunds represent the action noun form of a particular verb, which is based upon the addition of the suffix 'ing'. In the context of the grounded theory method, these will represent the Basic Social Processes that will form the basis for the theoretical model that arises from the data. Strauss, A. *Qualitative analysis for social scientists*. (University of Cambridge Press, 1987)

collection, the participants lacked extensive experience with individuals who would have been considered illegal entrants to the UK. Thus, the reflections of the participants pertained primarily to individuals who had initially entered the country under legal circumstances (eg as asylum seekers), and who went on to fail in their asylum application.

Gaining employment within the UK.

Employment, or some means of earning a living wage was a primary concern expressed by the vast majority of the participants at the NGOs included in the sample. Participants commonly cited aspects of the initial drive of newly arrived African migrants to gain employment. A recurring theme throughout the study was an emphasis on temporary legal status associated with the pending asylum application or appeal. A later section will address the period of time that follows the loss of legal status. A common theme was the overwhelming drive on the part of participants to gain employment. A major portion of this aspect of the study was directed towards communicating the degree to which all other endeavors were secondary to the maintenance of employment. The following statement demonstrates the focus on employment.

You are asking about many processes. A lot of this is administrative. These things are secondary to this population. These are hard working people. They have families to care for. After all, most have come here for opportunity, to work, you know. And when they get here they will do anything to work. My experience, if you please, is that they won't stop unless they are so ill that they simply can't physically work.

African Services Case Manager, 10 years experience

The notion that work is a priority to newly immigrated Africans is important since it communicates information related to the social norms of this population. Statements reflecting upon gender-based norms regarding employment amongst African families were frequently cited. The key element of this portion of this data related to African men, and the degree to which they forwent almost all other activities in order to work. Women, however, were generally perceived to work hard, but according to the social norms of this group tended to spend more time at home or with children, and thus had more time to engage in activities which are associated with health or general welfare of the family. The following statement, which was provided by an employee at a large NGO that provides a broad array of social services within the HIV positive migrant community, reflected upon the issue of gender.

I was one of these guys. I mean, when I came, I was educated, but there were not jobs for an educated immigrant. I worked 70 or 80 hours weekly doing all manner of things. They were all poor jobs, nothing to be proud of. I never went in to the GP, even if I was very ill, that is who we are. The women work equally as hard, but usually in the home and maybe something else part time. So yes, the women do all of these things you ask about. The men, however, they just don't come in, they can't.

African Services Case Manager, 10 years experience

While the participants cited extensive efforts towards gaining employment, they also cited difficulties associated with employment in African migrants. There was a consensus amongst a majority of the participants who reflected upon: 1) Difficulties experienced by African immigrants when considering securing initial legal work and; 2)

Difficulties experienced by Africans with employers and overall poor working conditions.

Concerns regarding initial employment related directly to the need for proper documentation (a work permit) prior to initiating in employment. The participants agreed that this was complicated by the African migrant's need for subsistence during the initial process. One participant demonstrated this through the statement "No they cannot work, not legally" (interviewer "do they work"), "of course they work (laughs)". Instances where employers were known to have hired these individuals prior to their having received proper work documents were commonly cited. The following statement reflects on the degree to which undocumented migrants are able to maintain employment.

You certainly can't put them on the payroll, but yes they work. They must. Small businesses generally hire them and pay them in a way that allows the employer to avoid the tax.

Case Worker, 5 years experience with African clients

The final element of the data related to the working conditions experienced by African immigrants. The majority of participants cited instances where individuals were treated unfairly in the workplace due to their lack of recourse. This was associated primarily with the economic reality of the individual migrants, and the degree to which their need to survive required that they endure significant hardship in the workplace. The following statement reflects the economic realities which undocumented migrants face.

They hire a bloke who can't legally work quite yet, and yes, they take full advantage. What are these people to do? They tell us that they are treated badly, even after they gain leave to work, but they have to make a living, and the jobs

that they can obtain are limited. I think we all know that the sort of people who hire laborers aren't always kind.

Case Worker, 20 years combined experience in case management for people with HIV/AIDS and as an advocate for same, 5 years experience with African clients.

The following statement further demonstrates the prioritization of employment over health related concerns.

I had a guy come see me last week. He is HIV positive, actually weak from the medicines. His employer strikes him regularly for mistakes. He can't get another job though, so what does he do. I'll tell you what he does, he apologizes in order to keep his family fed.

Consultant Physician, 14 years of experience in the care of clients with HIV/AIDS.

The need to maintain employment in order to gain necessary resources such as food, shelter and the necessities of life is a very basic need. The participants in the study were asked to reflect upon the needs of undocumented African migrants living with HIV/AIDS, and thus, concerns regarding healthcare were expected to be the primary concern on the part of this population. In the context of healthcare, however, the immediacy of human needs must be considered. The profound concerns regarding the need for employment, and thus, the ability to provide for one's basic needs, appeared throughout the study as a more prominent theme than issues related to healthcare. In a sense, the need to earn funds sufficient to gain basic needs is fundamental to maintaining health.

In the context of legal status, the quest for employment required the ability to work in the UK. Given that most Africans enter the UK with some form of legal status (See Chapter 3), it is clear that the majority would be able to gain some form of legal employment upon their initial arrival. In the case that legal status is lost, however, employment becomes a considerably greater challenge, and thus, becomes an overwhelming focus of individual undocumented migrants. When considering the health and legal challenges to maintaining long-term employment amongst HIV infected undocumented migrants, a particularly dire situation appears to arise.

Working to secure adequate housing.

Efforts to gain housing comprised an important aspect of the concept represented by the process of striving to gain the resources necessary for survival. The need for housing was frequently cited by the participants with theoretical saturation occurring very early in the process. There was a general consensus that while the housing needs of African migrants were met, there were issues associated with the nature and type of housing that they were able to obtain.

You are focusing, I know, on issues related to health, but in this area, things are difficult. *(de-identified location)* is not a traditional area for Africans to settle.

You are from the South right, I mean, I think you would surmise that they aren't always so welcome, so housing can be a difficult proposition at times. They certainly manage, but they don't get their pick of flat to be sure.

Case manager, 7 years experience, with mixed clientele that is approximately 50% African.

Housing related concerns were further demonstrated in the following statement.

They don't have the resources to rent a nice flat. So it's public housing for the lot of them. You walked past many of these units when you came in. I am sure you have seen better, but these are the best that (*de-identified location*) has to offer (laughs). They are often crowded into a very small flat, 3,4, 5 maybe more children as well.

Social Worker, 10 years experience with African clientele

The issue of housing was uniform considering the differences in geographic region represented in the study. That is, while there are challenges, most individuals are able to obtain a form of minimally adequate housing. The relationship between the issue of housing and health is clear, since shelter is such a basic human need. The key to this element of the data is the fact that, uniformly, the participants agreed to the fact that African immigrants, even those with HIV prioritized issues such as housing above their disease and healthcare related needs. The following statement illustrates the prioritization of housing over other common concerns.

Shelter is a human need, right. I mean to say, how can someone worry about their ART when they haven't a warm bed to lie in? So we really have to work to help people establish a home of some sort and their other basic needs before we can even talk with them regarding their disease.

Consultant physician with 20 years experience in HIV/AIDS care

The aforementioned statements by the study participants reflected on the important role that shelter plays in the context of basic human needs. That is, shelter is vital for survival, and thus, is vital in maintaining one's health. The data reflecting upon housing relates housing to health in a vital context. For instance, through the realization

that one who is homeless may not focus on taking one's medications or engaging in an overall healthy lifestyle. The ability to gain housing requires that one secure employment to pay rent or through public assistance programs. The issue of public assistance in the context of housing demonstrates another circumstance, besides healthcare, under which undocumented migrants depend upon governmental assistance to gain resources. This too, is profoundly affected by the loss of legal status.

Working to gain assistance from government funded social services agencies.

The final aspect of the data related to African migrants' efforts to gain the resources necessary for survival is related to the broad range of social services that are often necessary for individuals that come from such impoverished and socially challenged backgrounds. While participants universally cited this aspect of the data, it must be stated that the participants came from NGOs whose primary focus was to assist individuals in gaining assistance regarding the immigration and HIV/AIDS related challenges. Thus, the participants would have contributed a great deal of their time towards assisting individuals in gaining these services. There was a near unanimous agreement within the data that indicated that, regardless of immigration or disease status, most social care mechanisms were available to both documented and undocumented African migrants, which is illustrated by the following statement.

There is so much that we can't get our clientele, but we have become expert at identifying resources that they simply need to live. Whether we're speaking of assistance with their children, food or educational needs, we can generally offer a great deal of help. Healthcare is another issue, but these other things are far easier.

Social Worker, 6 years experience with African clientele

In fact, the participants appeared to communicate extensive pride regarding their abilities in this area, as demonstrated by the following statement.

I am proud to say that this is where we can offer help. There are services that we ourselves offer. Anything from housekeeping, meal preparation, physiotherapy, and these, they are funded by the social care trust. Then the government has its usual range of social services. Now I can't truthfully say that we can do everything, and (*de-identified location*) is a tough place to make it, but we can really help people along. For goodness sake, they can even come here and watch tele all day if they like!

Manager and Case Worker, 16 years experience, 7 years experience with African clientele

The area of social care was one that was characterized by relatively broad access to services during an individual undocumented African migrant's entry to the country. This pattern of access to government assistance was associated largely with the initial asylum application, much in the same way that access to healthcare is associated with this period. This was clearly the area where non-governmental and governmental organizations alike were able to offer a broad array of services. Overall, the drive to gain employment, housing and governmental assistance were consistent with the assertions of Maslow regarding the prioritization that occurs within the human context whereby individuals prioritize items of necessity such as food and shelter ahead of items with less immediate ramifications.³⁹³

³⁹³ Maslow, A. H. (1943). A theory of human motivation. *Psychology Review*, 50(4), 370-396.

While the prioritization of these needs is predictable based upon theoretical frameworks such as that proposed by Maslow, the relationship between law and human rights in instances involving necessities such as food and shelter are inherently troublesome. That is, most undocumented African migrants in the UK have come from countries where the human rights record of the government is questionable (See Chapter 2). They inevitably faced similar challenges in their home countries, and arrived in the UK with access to basic social services programs due to their initial legal status. Upon exhaustion of their appeals, however, many lose access to these basic services and thus, find themselves with considerable needs. Inevitably, many undocumented migrants find themselves suffering from patterns of need and oppression similar to that which they experienced in their home countries. The result is a situation where they find themselves at threat of deportation from a country where they could not survive, to a country where their ability to survive was questionable in the first place. While no specific law prevents this action on the part of the government, it raises serious human rights concerns associated with individual migrants' inability to maintain an adequate standard of living.

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Working to gain asylum through the initial application and the appeals process.

Throughout the study the participants communicated the fact that the vast majority of undocumented migrants began their lives in the UK with some form of legal authorization to remain in the country. Thus, while they enter the country lawfully, for instance on a travel visa, it is essential that they establish the grounds to legally remain within the country on a more permanent basis. This of course requires that they navigate

³⁹⁴ See Article 25 of the Universal Declaration of Human Rights, which ensures an adequate standard of living to maintain health and wellbeing.

the system to the degree that they receive leave to remain in the country by the Home Office. This can be an extremely stressful process given the requirements associated with the process, and the concurrent need to establish a household and means of subsistence in the country. The sub-themes contained in this section of the data include: 1) Navigating the initial asylum process; 2) Navigating the appeals process; and 3) Seeking hope and security after the failure to gain legal status on appeal. The basic social process represented by the need to gain asylum for newly immigrated Africans was the single most frequently cited factor during the study, and truly represents the overwhelming concern cited by the participants. This statement is supported by the fact that participants universally referred to this as one of the most crucial aspects of the phenomenon of Africans newly arrived to the country. It must be noted, as well, that this statement was not only mentioned, but was intensively discussed by each of the participants. This was due at least in part to the fact that this factor is intertwined with so many factors associated with the lives African immigrants.

Navigating the initial asylum process

All of the participants agreed that Africans were entering the UK initially with some form of legal status. This is an important distinction, given the nature of migrants who lack legal status in many other countries. The following statement reflects concerns related to asylum status.

I remember years ago, before all of the limits on immigration were so strictly enforced, when people, when they gained asylum at very high rates. Not all people, mind you, but many Africans. After all, I think Africa is a place where we sowed our share of sin, yes. Anyways, today, the rules have changed. In my

experience, even in the most terrible cases, people are turned down. It is almost a part of the process. And we wonder sometimes why it is that they protest, that their lives are so wrapped around the idea of asylum. What is the alternative for these poor people?

Case Worker with 7 years experience serving 50% African clientele.

Difficulties associated with completing all of the steps within the asylum process were frequently cited as well. Fear of government authorities involved in the asylum process were frequently cited by the participants. The most common factors limiting individuals difficulties in navigating this process were 1) lack of familiarity with the system; 2) Fear regarding becoming involved with government officials; and 3) Lack of adequate legal representation of participants. All of the factors cited by the participants fell into these categories. The following statement reflects upon the nature of data related to African immigrants' lack of familiarity with the system.

Can you imagine, with all of the complexity that one of the most substantially complex systems in the world can bring to bear, the Home Office really fails to make things easy. Now Africans, the ones we deal with, they are generally educated people unlike many other immigrant groups. But the process is very difficult, and requires so many steps. It can become difficult for people who are so unfamiliar with the country to deal with.

Manager and Case Worker, 16 Years Experience, 6 years experience with African clientele.

The following statement further clarified the role of the foreign nature of the asylum system.

Of course it is difficult, and with the cuts that we've seen, what do they cut. It's just not possible for us to help everyone. We employ several people who help people with the process, but we know, we know that for everyone we help, there are five no one helps, who try to take care on their own, and Bob's your uncle, they fail. No surprise, right?

Women's Services Case Manager, works exclusively with Africans, 3 years experience.

The following statement reflected that that fear regarding interaction with government officials is problematic.

The last guy I visited with was from the DRC ³⁹⁵, wrong tribe, you know. He was picked up by government troops, he was 15 at the time. Anyways, I am documenting his scars for his appeal, they don't feel that he is eligible, wasn't abused enough. His flesh was whipped off of his back literally, and he has terrible PTSD, but it is some business about the group who he fought with, as if he had a choice. And now, just getting him through the process is terrifying for him. I mean, look what happened to him the last time he interacted with government.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS.

This statement further reflects the fears of many African immigrants regarding contact with government officials.

Remember though, that their focus nowadays seems different. I am not saying that they mistreat people, but I am saying that the bureaucrats in this area have an

³⁹⁵ Democratic Republic of the Congo

imperative to decrease the rate of the granting of status. There is a mood in the country against immigration, immigrants, that seems to have worsened since the establishment of EU membership for many of the eastern European countries. The Africans and even some West Asians understand this, they know that they are largely unwelcomed, and in kind, they avoid the government, even when they should get their applications completed.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS.

The final issue compounding the challenges associated with the initial asylum application focused on difficulties with gaining legal representation. The following passage provided a reflection of this issue.

You used to be able to go into any solicitor's office, and there were solicitors who did this sort of work. The government subsidized their work, I think. But now it is not available. It is the government really; they just don't allocate money to aid people in gaining legal help. Not like before. So many of the people in our area either give up, or just continue to live illegally until someone discovers them, or they get really sick.

Case Worker, 16 years experience with African clientele

The challenges associated with the asylum process were often perceived by the participants to be a key factor in African immigrant's inability to gain asylum, and are reflected in the following passage.

We are able to offer legal services on a limited basis. The Home Office rejects almost all cases these days. When one is rejected, they either give up and try to

disappear into the population or they appeal. With so many limits to gaining the assistance of a good solicitor, and given the fact that an average person could never do this on their own, this is a real problem. In my opinion, the presence of a good solicitor, one who is astute in immigration matters is the difference between failure and success. All these people have is in this country, for many, failure means death on their return home.

African Services Case manager, 10 years of experience.

The asylum process is a central component of the basic social processes, and like the variables in the previous section, are seen as essential to survival on the part of the study's participants. The participants did not reflect extensively on the relationship between the initial application and healthcare, but did reflect upon the potential harm associated with the return to one's home country, especially when this return could potentially result in harm. This return, as well, would result in the return to a system with sparse healthcare resources. All told, the factors detailed in this section reflect the focus that undocumented African migrants have on gaining asylum, and detail this quest as one related to ensuring their very safety. These fears have important implications related to the potential harm associated with deportation. The next section reflects upon the routine nature of denial of asylum application in the majority of cases that involve Africans.

Navigating the appeals process

The routine nature of asylum application denials was an important component of the data contained in the previous section. This, of course, requires that individuals make appeals if they are to remain in the country. This aspect of the data fell into several well-

defined categories, which included: 1) Challenges associated with the appeals process; and 2) The life altering nature of the pending appeal.

The data reflecting upon the challenges associated with the appeals process was very similar in that it reflected largely upon the need of individuals to gain assistance, usually from a solicitor skilled in immigration matters in order to assist them. This in itself was a significant challenge for these individuals, as evidenced by the following phrase, which was representative of this element of the data.

It is never as simple as you would think. I don't believe that the average guy from Africa can really comprehend the kinds of issues that one has to include in a potentially successful appeal. The average person has a pretty uniform set of feelings regarding their appeal. They seem to dwell on the terrible nature of their home country, which isn't necessarily grounds for appeal. They really require, absolutely, a solicitor to frame their thoughts, their reasons, and the reason that they are somehow unique in this process.

Manager and Case Worker, 16 Years Experience, 6 years experience with African clientele.

The following passage further reflects on these challenges.

They all have an extraordinary story. They just didn't get on a train to England. They certainly didn't leave their countries because everything was fine and dandy. The key is gaining someone who can frame their story properly and show the Home Office the reasons that they are unique with respect to their likelihood of harm in their former country.

General Practitioner, 17 years experience, serves large African clientele, also involved with an NGO catering to their care.

While the appeal is challenging, the data reflected heavily on the life altering nature of the process, and the overwhelming nature of the pending appeal. Participants described the appeal process in many ways that indicate the degree to which the process induces fear and stress. These included phrases such as: “Life ruling”; “A source of constant worry”; “A persistent source of agony”; and “ the major fear in their lives”. The following phrase provides an accurate overall reflection regarding this theme.

Status is everything, absolutely everything to the women I care for. The appeal is like awaiting a death sentence. Not only for themselves but for their children. It means new life, or the end of that life and return to a country where they have nothing. For many of my clients, they don’t even have family in their home countries. Can you imagine knowing that you were going to lose the ability to care for your children, lose your home, your safety.

Case Worker, 16 years experience with African clientele

For many, the appeals process is the final step prior to deportation. This too offers one the ability to examine the extent to which negotiating this process has a direct relationship to safety concerns on the part of the individual undocumented migrants. As the final step in the process prior to deportation, the appeal is of vital importance to individual undocumented African migrants, as it represents the final step in their loss of safety. While the participants did not reflect directly on the appeal as it relates to healthcare, it must be stated that the filing of the appeal serves to maintain access to

health services. The following section discusses perhaps the final basic social process observed in this population prior to their removal for deportation.

Seeking hope and security after the failure to gain legal status on appeal.

The data included in this section focused on several key social processes that were cited frequently by the participants. These included 1) Hoping for the continued ability to remain within the country; 2) Striving to maintain access to the necessities of life; and 3) Working to comply with government regulations.

The participants had a near universal reflection regarding the finality of one having failed to gain leave to remain in the country after their failure on appeal of their initial denial of asylum status. From the time that an individual failed on appeal, the participants reflected upon the general compliance of undocumented African migrants with the Home Office requirement for weekly meetings, despite the likelihood that these very meetings often become the mechanism for a person's deportation.

My clients, they tend to strictly comply, they are good people, and I think they truly want to obey the law. So yes, they comply, attend each of these meetings really. This is truly surprising since the person could literally be removed within hours of one of these meetings. (interviewer "Just like that?"). Oh yes, they don't have a concrete idea of when they will be taken, so yes, 'just like that' as you say. I have seen it many times.

Women's Services Case Manager, works exclusively with Africans, 3 years experience

Despite the fact that these individuals are to be removed from the country in the near future, they maintain some degree of hope, despite their realization that they are so

likely to be removed. The following passage reflects upon the role of hope amongst undocumented African migrants.

My clients are generally from groups that have been persecuted. Not only have they departed their home country, in general, their entire families have fled and are dispersed all over Europe in various capacities. So if they return home, they are likely to find themselves alone. They have an astounding degree of hope. They just wish that something would change, that the law would somehow offer them mercy.

Case Worker, 12 years experience in HIV/AIDS care, 7 years experience working with African clientele

The results indicated that migrant's drive to survive despite their precarious immigration status was central to their experience in the UK. That is, while they have a realization that they are likely to be deported, and could be at any time, they must survive. This was reflected primarily in statements that illustrated the degree to which undocumented African migrant's lives changed little while they awaited removal. The following passage reflects upon the role of pending deportation.

No, actually, they don't receive any special help or respite as they await deportation. They must live, and so they continue to struggle, to work. They really continue as in the past even though they appear to know that they may be sent home at any time. They just don't give up, they are people of great faith.

Women's Services Case Manager, works exclusively with Africans, 3 years experience.

Perhaps the most surprising element of this theme was the fact that these individuals are generally perceived by the participants to be highly compliant with existing immigration law. That is, while one might predict that they would attempt to depart when their location became known by the Home Office, they do not. Instead, the majority continued to attempt to appeal for leave to remain through the established immigration system. The following statement by one of the participants reflects upon the finality associated with a pending deportation order.

I am often amazed by the fact that they don't attempt to move on more often.

There is a general finality associated with what will likely happen, and I think that they realize that they will be found out eventually if they attempt to move to another region. The majority of my clients tend to develop plans to move to another third country. Perhaps the States, Spain or another European country.

Consultant Physician, 20 years experience in HIV/AIDS care.

The attempt to maintain legal status is a key principle involved in the basic social processes that underlie to experiences of undocumented African migrants. While this element of the data will be discussed with greater detail later in this thesis, it is important to consider that the loss of legal status is the very point at which undocumented African migrants lose access to many necessities of life from a legal point of view. This too is the very point at which significant human rights concerns begin to surface. For example, the Article 25 stipulations of the Universal Declaration of Human Rights are seldom observed after this point in time.

Seeking access to needed health services

While the basic aim of this project was to determine the pattern of healthcare access amongst undocumented migrants, the UK context offered an important challenge. This was related to the fact that, within the UK, very few Africans will have entered the country illegally. As previously detailed in this thesis, the initial entry to the UK on the part of most Africans was legal. The fact that these individuals possess some form of legal status (ie a visitors or student visa or a pending asylum application) allows them access to some health and social services at the time of entry. Individuals initial access to legally health services became one of the crucial basic social processes discovered within the data, as it is the initial ability to access this system that influences later efforts to maintain access to medical care.

During this section, the efforts of persons who initially entered with some form of legal status, but later lose legal status based upon failure to gain asylum will be explored. Further complicating the issue is the fact that, for the newly arrived, challenges during the process of gaining health services was evident within the data. During the analysis of this element of the data several sub-themes arose: 1) Failing to secure care due to socio-cultural factors; 2) Seeking initial access to care through the general practitioner and 3) Seeking HIV specific care via the consultants. Before exploring the data that characterized the two major categories within this theme, it is important to explore the overall context of the theme. All told, the participants universally cited the fact that the newly arrived, particularly those who are HIV positive, lack the knowledge to properly access the healthcare system. This is an important point, since most of these individuals

are eligible for care. The following statement characterizes the obstacles faced by many undocumented African Migrants.

I think they, the most important obstacle in gaining care, which I think is different from the other EU countries and maybe even the USA is lack of information. The main problem in the UK is that if someone comes here, maybe as an asylum seeker or as a student they may or may not be eligible for free care. The main obstacle as I see it is lack of information you know. You see many of the people who come here from the African nations are unaware of what is available due to the countries that they come from, and the fact that they are often used to that way of life, and often don't like to draw attention to themselves.

Case Worker, self identified as living with HIV, 21 years experience in advocacy and social care

The following passage provides another example of the obstacles to gaining care.

As you know, I am African. We arrive and we don't always feel very welcome. Furthermore, the system is complicated. We also come from countries in which one does not place themselves in a position to be noticed, by government officials you know. It is very difficult at first, even when they are ill, to gain the information that they need to seek care. Where to go? What am I eligible for? Will it cause me trouble if I seek care?

African Services Case manager, 10 years of experience

The following passage reflects on the notion that 'health tourism' plays a role in the decision to immigrate.

That is an excellent question, and many people here in England believe this is true. I will tell you that they come here for safety, work, a new life. When they arrive, they really don't have a good idea of what services are offered, and I see, at least at first, apathy towards these services. Even when they are needed, we see that they are often not accessed due to a simple lack of knowing. They just don't know what they are eligible for, or even what is available. We work to educate them, but we just don't get to everyone.

Consultant Physician, 16 years experience in HIV/AIDS care

Sociocultural factors have the potential to greatly influence the likelihood that one might seek health services. This section reflects upon factors specific to the African population that reflect upon the possibility that cultural factors, in addition to systemic factors, may decrease the likelihood that one will seek care. Additionally, the participants reflected upon the lack of knowledge regarding the social and healthcare systems in the UK on the part of migrants. The combination of the cultural characteristics of African migrants and their lack of knowledge regarding the UK are prominent variables when one considers their ability to gain health services. While this does not have a bearing on the law, it does offer insight regarding other barriers to seeking healthcare. Additionally, this element of the data offers some justification for community education projects directed towards improving migrant's awareness of service availability.

Failing to secure care due to socio-cultural factors

The initial thrust of this study involved a search for institutional and governmental limitations. The data, however, yielded the presence of significant factors that likely play a role in establishing de facto limitations to care seeking behaviors amongst African

migrants. Many participants identified the presence of cultural trends within the African community that result in the stigmatization of those who are HIV positive. Thus, these individuals often avoid accessing care, HIV testing services and even treatment, a trend that is reflected in the following passage.

For instance, if they are ill or have HIV, they may not know if they are eligible for care or where they might gain care if they are eligible. On top of that, they are bound by things like stigma. Although people know that they have been exposed to HIV most people don't want to test because of the stigma attached to HIV. They don't want to know. You see in Africa it might bring shame on them with their families and here, they might end up feeling as if they were undesirable.

General Practitioner, 17 years experience, serves large African clientele, also involved with an NGO catering to their care

The following passage further characterizes the effect of stigma on health seeking behaviors.

Well, I came from Zaire in the 1980s with my best friend. I had no one else. And when we were here, she got ill. She was very sick, about three or four months after we arrived. And she....she....it still makes me very sad, but things were different then. I think what is not different was her shame. She had gotten the disease from her boyfriend several years ago. People don't want other people to know, I mean, you're dirty right? So she always avoided the topic, even to the point that she did not seek care. So she waited, and waited, and by the time she went to the GP, well there were limited treatments then, and she died. After she

died I was alone. And I worked, and had children, attended my church. I looked for a chance to help with this problem, and I volunteered here.

Women's Services Case Manager, works exclusively with Africans, 3 years experience.

The issue of socio-cultural limitation associated with stigma can reach extremes for instance, in the case of cultural and religious beliefs, which is reflected in the following passage.

Some churches were deceiving people to stop taking their medications in the African community. They were telling people that they were sick because they had sinned. You know, they were cursed? They were telling them that they were healed, because they repented from the sin that have them HIV, and they were not, so they died. These we call born again churches, evangelical. One pastor, he was pastor of the Kenyan church here, he was telling people that they we healed and they were not healed, he was the worst of them. He told them that the Holy Spirit had healed them. He said to show their faith they must stop taking medication, or it was a sin. And then they, so may of them, they just died. I found this a part of my work that was very important, educating, because they just did not know.

Case Worker, 16 years experience with African clientele

Despite the limitations presented by a lack of knowledge regarding the means through which they could gain assistance, and the effects of culturally based stigma, individuals were generally seen to have sought care during the period that they were eligible. Stigma does, however, represent an important socio-cultural factor that the data

indicated can limit the health seeking behaviors of undocumented migrants. While this factor is not directly related to the legal and human rights based underpinnings of the thesis, it is an important variable that represents an extra-governmental limitation to accessing healthcare and HIV screening services. The unique nature of the undocumented African population relates directly to its societal and religious norms, which influence Africans due to their identification with their community of origin. While it is not a focus of this thesis, stigma is an important component of the study that warrants further study in the future. This section amplifies the commentary offered during the previous section in that it indicates the profound effect of culture on health seeking behaviors. This element of the data indicates that even in cases where services might be available, cultural variables may influence individuals to avoid gaining healthcare. In the following sections, individual African migrants' attempts to gain care will be detailed.

Seeking initial access to care through the general practitioner

The normal access point to the healthcare system within the UK is the general practitioner. In the care of Africans newly arrived to the country, they gain official access to a general practitioner once that have filed for asylum or established legal status within the country. This represents a significant basic social process in the context of the current study. The relationship between the general practitioner and the individual who has failed to gain legal status will be discussed later in this chapter. The issues surrounding initial attempts to access the healthcare system reached theoretical saturation very early during data collection, and are reflected in the following passage.

Most of these people come from countries where there is war, violence, persecution. They can't go back, and so they apply for asylum. After their

application and during the period where they are awaiting the initial decision and the inevitable appeal, they have access. That access will last until they fail on appeal. This unfortunately is becoming more and more common.

Consultant Physician, 32 years experience

The following statement further illustrates this point.

Once they have status, the Africans seeking asylum, those who aren't from a second EU nation, can be assigned a GP. I guess status isn't a great way of saying this. I think the way to approach this is to say that once they have made application for asylum, they are eligible, and they remain so through the period when their case is being either considered or commonly these days, while the denial is under appeal. It seems that they deny most Africans anymore.

African Services Case manager, 18 years of experience

However simple that this process appears, there are non-systemic barriers, as reflected upon in the following passage.

At some point they are all eligible for care within NHS. Look, you just can't walk here from Africa, right. It's not like the states where a bloke can just pop up on the border. They come on various visas or as refugees and all seem to get a period of time when they can access services. It is interesting to me, in my work that this does not always happen. (interviewer "Please Explain?") Well, they have other priorities, right. They must work, eat, find somewhere to live, take care of their families. Everything is a challenge to this group, nothing is easy.

Consultant Physician, 20 years experience in HIV/AIDS care.

Finally, the GP, while representing the access point to care is not the primary setting for care when considering the African migrant who is in fact HIV positive.

The GPs are a wonderful lot really, but they offer basic medical care services. Our clients tend to present to them expecting HIV specific treatment. This is not available at the GP clinic level, and they must receive referral to the GU medicine clinics. This extra step can be a problem for many of our African clients. It is difficult for them to take time from work to do this, so we don't see many men taking advantage of their ability to get into the GUM clinic.

Manager and Case Worker, 16 Years Experience, 6 years experience with African clientele

This section reflected the process of entering care in the UK, where GPs act as the 'gate keepers' to the healthcare system. It must be noted that this section of the data reflects upon individual's experiences prior to their having lost their legal status. Thus, this element is an illustration of the legal manner through which undocumented migrant can seek care within the current system. While the reflections of the participants regarding GP care were positive, they reflect upon the need for referral to consultants in order to gain HIV specific treatment. The need for referral too, intersects with fears on the part of migrants regarding lost work, again reflecting the profound effect of both survival related concerns and cultural factors in the quest for healthcare.

Seeking HIV specific care via the consultants

Those who present to the general practitioner with HIV or those who are subsequently diagnosed receive referral to the genitourinary medicine clinic. This is the normal site for the provision of HIV related care, and the sole location where

antiretroviral therapies can be prescribed. The participants often cited elements of the care afforded to those with legal status, with theoretical saturation having occurred early in the process. While this was not a vital portion of the data related to the studies stated aims, it comprises a crucial point in the basic social processes represented by the data, and is reflected upon in the following passage.

Let me tell you though, explain to you, so that you understand the way that one gains care for HIV in the UK. One cannot really get HIV treatment, especially medicine from the GP. You can only access it from the hospital, the GUM clinic to be specific. This is the sole site at which they can gain this form of care, which is a considerable problem. You see, the GPs tend not to check eligibility, but the hospitals where these clinics are situated are a different story. They are far more likely to check. During the time that people have application pending, this is generally not a problem.

Case Worker, self identified as living with HIV, 21 years experience in advocacy and social care

The majority of participants discussed access in the case of the genitourinary medicine clinics in the context of the failed asylum application, and often referred to the inevitability of the failed application. Access to the genitourinary medicine clinics was an area where many of the participants voiced frustration, which is reflected in the following passage from the data.

I am an HIV consultant physician, so this is of particular concern to me. Of course I am speaking to you in my capacity with (*Agency de-identified*)³⁹⁶ and we are also very concerned with this. The GUM clinic is the proper location for the care

³⁹⁶ Name of organization removed to maintain anonymity.

of people with the disease, obviously. I form long and very close relationships with my patients, as so many cease to see the GP. There is just so little that the GP can do for them. So here I am, with an ethical and some would argue legal responsibility to my patient, who I suddenly can't see.

Consultant Physician, 20 years experience in HIV/AIDS care

The major underlying theme of this section was the trend whereby care was initially available, and later unavailable as changes in immigration status occur. This element of the data is discussed in later sections, however, it appears that many of the inconsistencies in the enforcement of regulations stems from the presence of these frustrations.

Struggling to maintain access to health and social services after failure during the appeals process.

The previous section related to the fact that the vast majority of individuals entering from African countries initially are able to legally access health related services. The concept represented in this section is central to this thesis, in that it addresses the vital element represented by the majority of Africans who lack legal authorization to remain in the country. This element of the data comprised the basic social process that precedes the one detailed in this section. The failure of individuals to gain asylum after initial application and upon appeal is catastrophic in the lives of Africans living with HIV/AIDS. This is particularly true in cases where they come from nations where poverty and violence are realities of daily life. This section is central to this thesis in that it directly illustrates the challenges faced by those who lose their illegal status and find themselves undocumented migrants. During the analysis of this element within the data, the following subthemes arose. They were: 1) Gaining basic health services through the

general practitioner, 2) Working to maintain HIV specific services through the consultant, and 3) Accessing care the accident emergency department when all other options have been exhausted. During this section, each of these elements of the data will be addressed in depth in order to fully explore the areas where undocumented migrants can and cannot gain access to health related services.

One element of the data that was nearly universal reflected upon the perception on the part of the participants that undocumented African migrants experience limitations to their access to healthcare. That is, while the majority of participants spoke freely regarding the limitations to healthcare access placed upon undocumented migrants, there was a pervasive feeling communicated by the participants that this was a relatively recent development within the NHS, and is reflected in the following passage.

So it really started from there with our providing training, talking with people, support and advocacy work and campaigning. Over the last two years our work has really centered about access to healthcare. As you know, the NHS has put into place vast limits to gaining services. I would say that this has been unique to the UK. Until 2004 or so no one in the UK would have considered denying service to an individual. (Interviewer “Unique?”) Oh yes, now remember, in the US, once could put together some money and go in for an appointment at a fee for service clinic. It is our position that the UK is very unique in that we have a single tiered system, a monopoly if you will. There is nowhere else to go. We suddenly found as part of our work getting people into care. For the first time, around 2005, we began having people who were unable to gain care. So we began to alter our mission, and, and campaign on these issues as this was clearly a growing problem.

Case Worker, 16 years experience with African clientele

The relatively recent nature of this trend is further illustrated in the following.

There were always rules, laws against the ineligible receiving care. I think that this is not a new development. What is new are the controls that we have experienced over the past few years, they have actually begun to turn people away. This is a real adjustment for people who work in the system. These are people, their patients, their neighbors. Turning them away is very foreign for people who work in the NHS. It just wasn't something that we did in the past.

Consultant Physician, 32 years experience

It must be stated that the data was expected to reflect upon a very broad loss of healthcare services once one lost their legal status within the country. This was a fascinating element of the data, particularly in the context of undocumented African migrants with HIV/AIDS, since this population would tend to require services at multiple levels including the GP and consultant based specialty clinics. In the following sections, issues referring to healthcare access to these categories of care will be addressed separately, due to profound differences in healthcare access in each of them. The following sections will present the data detailed under each of the aforementioned themes and associated analysis.

Gaining basic health services through the general practitioner

Perhaps the most interesting aspect of the data was the participant's reflections regarding the level of access to GP clinics experienced by individuals who had lost their legal status through refusal of their asylum applications. The participants who cited this process within their interviews were nearly unanimous regarding their perception that the

vast majority of their clients continued to have access to GP based care. Interestingly, the recurring theme in this element of the data was based upon close relationships formed between GPs and their patients along with their concurrent refusal to cease providing them care based upon this relationship was commonly reflected upon, as it is in the following passage.

In terms of healthcare, most GPs in the clinics, they tend to put a blind eye to these issues, and they, the GPs that is, continue to offer them care. I will give you a scenario, maybe something like you see in the USA. You have been looking after this patient and they were an asylum seeker, and you cared for them. And after this five years somehow they have failed to gain asylum. And you know, you see, that you now can't offer them care, but you also know that there is no real link between the GP clinic, or even the GM clinic and the home office, so what do you do? Do you just stop giving them the care, or do you continue to help this person that was your patient. So, as I said, many of the doctors just look the other way. And the Home Office, for them to actually take the time to come forward and tell you that this person is not eligible for care, it just doesn't happen.

Consultant Physician, 14 years experience in HIV/AIDS care

Further, the participants voiced the existence of a phenomenon wherein officials within the GP clinics failed to check a patient's immigration status either purposefully or through negligence, as reflected upon in the following passage.

It often takes time for the GP clinic to catch up with the Home Office decisions about someone's case once it is disposed of. So their entitlements can be a problem. So if someone comes here, without papers, like many do in the USA, it

would be very difficult for the GP to register an individual. But here in most cases, people come here, and at least apply for the asylum, which gets them into the system. Once you are in the system, and a GP has registered you, then it becomes a lot easier for the GP clinic to give them care. You see, they are in the system. Really, this makes it so that they can look the other way.

General Practitioner, 17 years experience, serves large African clientele, also involved with an NGO catering to their care

The following passage further illustrates the connection between GP access and immigration status in the context of the participant's widely held perception that GPs tend to purposefully avoid checking the immigration status of their patients.

I'll be honest, they tell me that they know and they don't check (interviewer "they know?). They are caring for this African family, and they know, they know they are newly arrived, and they know, that most cases seem to be denied, and 4, 5, 6 years elapses. In many neighborhoods, here in (*location de-identified*) for instance, this is just the way it is. They know, and they don't check, because they don't want to deal with it.

African Services Case manager, 18 years of experience

These reflections were voiced by participants in smaller cities as well.

You walked up here, right, I mean, you see all of the African people around here. (interviewer "Yes, many African accents") And you know of course that the majority of application seem to get turned down. The GP around the corner, he is west Asian, I think from Bangladesh, and he came her not so long ago himself. I have worked with him, and I can tell you, that we now have many asylum seekers

here in (*location de-identified*), and as many that have been denied and are awaiting final word on their deportation. Many are overstayers on purpose, students you know. But he cares for them. How could he turn them away.

Case Worker, 7 years experience, 50% of clientele is African

The widespread ability of undocumented African migrants to gain access to GP services reflected upon a significant degree of healthcare access. While this represents a form of access to care, the focus of this project was on individuals from Africa who were also afflicted with HIV/AIDS. During data collection, the participants reflected intensely on the issue of GP versus consultant access and the factors that differentiated these levels of care. The participants who addressed the issue of access to GPs frequently addressed this issue. There was near unanimous agreement between these participants that, while the GPs continued to offer access, they were not able to directly address HIV disease specific care, as reflected in the following passage.

I have two points of view I suppose. One as a consultant, and one as an official with the (*agency de-identified*).³⁹⁷ I suppose they are not all too different. As a consultant, I am able to offer the full range of testing and antirets to my patients. I can properly follow their disease progression in every way. The GPs in this area of (*area de-identified*) are a wonderful bunch of people, and they want to do what is right, but they are severely limited. They do not have the ability to track CD4 counts, Viral Loads, and certainly don't have access to antirets.

Consultant Physician, 20 years experience in HIV/AIDS care

In fact, this was a widely held perception of the participants from a variety of areas.

³⁹⁷ Name of organization removed to maintain anonymity.

Here in (*location de identified*), the GPs are wonderful, and they do their best in most cases. They can't offer care related to HIV or AIDS. This is a very small town, and the other medical services are limited though, and nowadays they are beginning to check.

Case Worker, 12 years experience in HIV/AIDS care, 7 years experience working with African clientele

Participants in other regions of England held this perception as well as well.

Here in (*location de-identified*) we have a wonderful healthcare network, and yes, the GPs are generally assisting people even after they lose status. We care for people with HIV, however, so they are of limited utility or no utility really. I mean, they can't give them HIV medications, and the GM clinics are now becoming more difficult to get into by the day.

Case Worker, self identified as living with HIV, 21 years experience in advocacy and social care

The overall reflection according to the data was that, while access to GPs was widely available to undocumented African immigrants, there were emerging limits to their access to care in the specialist based healthcare settings where consultants practice. Access to GPs, while important, is not the most essential form of care in the case of HIV positive individuals. Thus, the overall reflection of the participants communicated the notion that while undocumented African immigrants had access to GP level care, the limitations related to access to consultant care represented a severe functional deprivation of healthcare access. The next section will specifically address the data related to HIV specific healthcare settings.

Working to maintain HIV specific services through the consultant

While access to care at the level of the GP is possible in most of the cases encountered during data collection, there were substantially different challenges seen when one considers the impact of migration status on the ability of the undocumented to gain the care of consultants. The preceding chapters were focused primarily upon the case of individuals who had some form of initial legal status (e.g. a pending asylum application or student visa). The data reflecting the challenges associated with gaining access to consultant care, as it is in the following passage, revealed an interesting trend.

Oh yes, you see, as I said they just can't be registered. So then, if they have HIV then they can't get into the GP and can't be referred to the GM clinic. So, the hospital is not a place where they can get in. It is preferable to be in the system, and most are. Even if you have been on a student visa, you will have gotten into the system, so really, I would say that the vast majority of people have come here with some form of legal status, even if it is only brief. We have dealt with maybe one or two cases where people had no papers whatsoever, and no real means to gain them. These are very challenging cases since we have many difficulties getting them service. What they normally do, when they come with papers. They file papers with the Home Office. But often, they want to normalize they may provide some documents to the home office. Initially, they are given a letter that documents that they are beginning the process of application for asylum. Once we have this letter, you see, we can begin the process of getting them into a better situation. If we can get them to this point, it would be very surprising if we could not get them services. Again, it is key to get them into the system somehow. In

my experiences, getting them into the system once, even if they are later found ineligible is a key factor in getting them the things that they need.

African Services Case manager, 18 years of experience

The data reflected that this problem is due to the case of many individuals who do not access the system during the time that they have legal status, for whatever reason, and lack any connection to the healthcare system. The participants often reflected upon the lack of previous interface with the healthcare system:

We see this routinely. Individuals who come in with an active appeal often enter care and are seen in the GM clinic. This lot has good access and are often not found out when they lose access, at least under normal conditions. When we see people who never accessed this system, getting them in is very difficult here in London, if not impossible. There is unbelievable pressure on these clinics.

Case Worker, 12 years experience in HIV/AIDS care, 7 years experience working with African clientele

There were additional differences seen with regards to access to consultant-based clinics (e.g. GM clinics) when one considers facilities that are not within major metropolitan areas. The cases of smaller communities illustrated what appeared to be a difference regarding access with a trend towards indicating the possibility of differences in access to services for undocumented African migrants. Three organizations were visited within these small municipalities. The data from these agencies indicated that there was a perception on the part of the participants that indicated that the GM clinics that serve these regions had not initiated exclusions of undocumented migrants. Further, the data indicated that this phenomenon was due primarily due to a lack of extensive

contact with such individuals to the degree that one might expect in the larger cities. The following statement reflects upon this phenomenon.

You must understand that this is relatively new to us. (*location de-identified*) is a smaller town and our experiences with immigration are limited. We are not seen as a community with a lot of immigrants, or Africans for that matter. As you know, there are many, but we are not London. To date, we have done well keeping our clients in care, and the clinic, at the hospital, the staff have continued to care for most of them.

Case Worker, 16 years experience with African clientele

The following statement further reflects upon this aspect of the data.

We haven't had the kind of problems that we are seeing in the larger cities yet. I think in part due to the lower HIV caseload, in part due to lower numbers of foreigners. Now of course, we have immigrants and many people with HIV or even AIDS. Our numbers are manageable compared to places like London, or even Birmingham where large numbers of immigrants are living. We are seeing more of them, but still, a pittance compared to the larger cities.

African Services Case manager, 10 years of experience

The majority of the data for the study reflected upon the larger cities. During visits to larger cities a trend that included the gradual institution of limitations was evident in the data. These limitations were focused on progressively increased rates of administrators checking the immigration status of the current caseload for various GM clinics. This included eligibility checks in two general cases. The first were checks based

upon regular attendance at scheduled clinic visits. The second were associated with acute hospitalizations, and resultant eligibility checks.

The primary instance wherein eligibility checks are occurring is in connection with acute hospitalizations. While these participants agreed that they had not seen eligibility checks being performed during regularly scheduled visits, they agreed that hospitalization represented a special case, as reflected in the following statement.

What happens unfortunately is that the GM clinic looks the other way, a lot like the GPs. People can go there and get medications, and other treatments. As long as they stay well, that is good. They continue to come in, get treatment, get the things that they need. The real problem comes when they get sick. You see, the care in the clinic is easier to provide regardless of someone's status. The real problem comes when they have to be placed in hospital, you know, for a severe illness. Once someone is placed in hospital, financial officials then begin the process of determining eligibility. As you know, we have laws that require visitors, among others to pay. When they begin to search for this information, the person is generally identified as being illegal, a failed asylum seeker or whatever. The difficult part is, that while they had been very ill, by virtue of the hospitalization, they are suddenly well enough to be deported. This is very difficult, in that the treatment set the stage for the deportation. It is often tragic that it progresses this way.

African Services Case manager, 10 years of experience

The primary concern, as communicated by the participants who cited this element of the data, was related to the large financial burden of these acute hospitalizations

coupled with the less personal nature of hospitalization. While there is cost associated with GM clinic visits, clinic staff possessed an emotional, professional and ethical investment in their patient population. The hospital staff, however, dealt with far higher numbers of patients, and are less likely to take individual concerns into context when they make the decision to identify ineligible persons, as reflected upon below.

I do not agree with it, but I certainly understand. The hospitals here in (location de-identified) have constant budget problems. They are now billing people for care as well, and the Africans simply can't pay, they can't. The hospital administration has a vested interest, right, in order to decrease the burden to care for the ineligible, to take care of their other patients. Theoretically, the GM clinic is to do the same, but I have seen this as a great difficulty. How does a physician turn away their patient?

Consultant Physician, 20 years experience in HIV/AIDS care

The following statement offers another example of this phenomenon.

How do I as a physician cease to care for my patient? How? I have had many instances though, where I admit them to hospital due to illness, usually and ARC³⁹⁸. I care for them, and they improve. At some point, often unknown to me, they are found ineligible and these notations are made within the system. They invariably return to see me, and are turned away, as they are now ineligible. In our clinic, we generally don't check, but once someone is ineligible, they simply can't get care unless there is an emergency.

³⁹⁸ Aids Related Complex or ARC refers to AIDS defining illnesses that occur late in the disease process.

Consultant Physician, 32 years experience

The least concrete form of service limitation to undocumented African immigrants living with HIV/AIDS occurs in the case of the GM clinics based within regional hospital facilities. This section does not detail the individual who begins with legal status. Instead it focuses on the individual who entered care in one of these facilities while they were legal, and then subsequently lost their legal status. The participants focused on vague instances where they have seen this form of service denial, as in the following statement, but were quick to state that they had not seen this commonly as of the time that data collection was performed.

I personally have not seen cases like this locally, but I am hearing of them (interviewer “please explain?” (*location de-identified*) is large city, obviously and colleagues of mine are beginning to see this. (Interviewer “This?”) Yes, they are beginning to check within some clinics but not uniformly, I have many clients without status and who have failed on appeal who are doing well. There is a fear though, based upon sporadic denials, that this will happen.

African Services Case manager, 18 years of experience

Another participant, a physician had a more personal reflection upon the situation within the GM clinics.

The GUM clinics though are associated with the hospitals, so they are having terrific problems. You know, administrators are not in a position to worry about things like ethics. They are driven by budgets and the need to help the people whose care they are charged with, so it is not in their interest to care for more people than they might already have in the system.

Case Worker, 20 years combined experience as an activist and social care provider for people living with HIV/AIDS.

The following statement, too, was illustrative of this pattern.

I have not seen this widely, not in my clients. I have had only a single case where someone went to clinic and was found to be ineligible. This became a problem for this person, as he became ill after his medicine ran out. He was hospitalized, survived and was later deported. I really don't know why he was found out, but they are checking at times. I would guess that this will become more common.

Case Worker, 16 years experience with African clientele

The pattern of access to care within the GM clinics was highly inconsistent when considering undocumented African migrant's ability to consistently access services. The data focused on several vital topics that will be addressed on a point-by-point manner:

1. There is wide agreement on the part of participants that their clients are not eligible to receive care at the GM clinics once they have failed on appeal of negative asylum decisions.
2. The GM clinics, regardless of size, have been seen to inconsistently enforce the prohibition on providing care to the undocumented. Factors such as healthcare worker unwillingness to deny care to their previously legal clients were cited repeatedly.
3. GM clinics in smaller municipalities tended to be cited as the least likely to deny services within their GM clinics. The participants cited, primarily, their lack of contact with large numbers of undocumented African migrants.
4. There are cases wherein undocumented African migrants who previously enjoyed access to GM clinics having lost their access after losing their asylum claims on appeal.

A prime factor in such cases tended to be associated with hospitalization during acute illness, which resulted in administrators performing eligibility checks.

Accessing care the accident emergency department when all other options have been exhausted

The final form of healthcare access available to individual undocumented African migrants is associated with the accident emergency departments within the country. The data in this area focuses on several important areas. Participants often reflected upon the availability of care through the accident emergency department. Further, the participants cited the inadequacy of care related to visits to the accident emergency department. This element of the data is important, in that it reflects upon the nature of care available within this setting and reflects upon the characteristics of this setting.

The participants who reflected upon this element of the data were invariably attempting to provide the interviewer with information regarding the broad range of services available once an individual had lost the ability to attend the GM clinic. During this element of the data, the participants who cited this element of the data agreed that, in many cases, participants were able to access some degree of care through the accident emergency department. The following statements reflect upon this element of the data. “There is always the A&E department. One can’t simply go there for routine care, but in the case of a severe illness, they may gain care in the A&E.” “The A&E is likely to turn them away, but they will at minimum ensure that something terrible is not going on. If there is not, though, they are likely to be turned away, and will get a bill for their trouble.” “It is a level of access, the A&E. No, they can’t provide routine care. They are there in order to preserve life in major illnesses.”

Finally, participants reflected upon the lack of appropriate services in the accident emergency department setting. This element of the data reflects upon the functional lack of access to appropriate services. That is, all access to care is not equivalent, as one of the participants reflects upon below.

I have brought people to A&E, and in those cases, where they are very ill; they are admitted to hospital and receive high-level care. They invariably improve and are then discharged. Incidentally, often after having been reported to the Home Office. In other cases, though, my clients present, and are not very ill and thus receive nothing.

Case Worker, 7 years experience, 50% of clientele is African

The following statement further reflects upon issues related to care in the Accident and Emergency setting.

There is care available through A&E, to be sure, but it is life-preserving care. Yes, many people, out of desperation attempt to gain care in the A&E, but they simply don't provide the proper care (interviewer "the proper care?") they can't give the proper medicines, or even referral for them, since the person is ineligible. There is very little that they actually provide.

General Practitioner, 17 years experience, serves large African clientele, also involved with an NGO catering to their care

The final statement provided by an official with a medical rights agency provided an apt summation of the data in this section.

It all makes me very angry. It's all a useless mess. Yes, people come here sometimes to gain services. But largely this is not true. We've worked out here

that it costs 30 pounds to see a GP but 150 to see someone in A&E. Yet, we are driving people to A&E, where diseases like TB and HIV are not identified, as A&E is not set up to diagnose such problems. Rather, they are set up to address life-threatening illness. It makes no sense, it doesn't save money, it doesn't preserve resources, it doesn't make people go home. It only serves to pander to people's sense of injustice. The thought that people are doing this to us is always a convenient approach for political people.

Consultant Physician, 32 years experience

While the accident and emergency department was cited as an access point for care, the participants detailed its limited utility by illustrating the limitations of this care setting. That is, while life-preserving care was available, the department cannot offer follow up care or HIV specific care. These departments are unlikely to provide the degree of care required for long-term survival with HIV/AIDS. This element of the data is important, as it represents the futility of seeking care outside of the GM clinics in the UK. The availability of HIV treatments is isolated exclusively to this setting in the UK, and thus, no other setting is able to provide this level of care. The data in earlier sections reflected upon the inability of individuals to gain HIV specific care in the GP clinics. This section details this trend within the accident emergency departments. When one considers the emerging pattern of service denial within the GM clinics, it appears quite unlikely that an individual living with HIV/AIDS will enjoy the ability to gain adequate care. This will certainly result in the eventual degradation of their health, and eventually,

the development of the complications of advanced AIDS. Again, this too is inconsistent with basic human rights principles.³⁹⁹

Maintaining hope and seeking the resources necessary for survival in the face of deportation.

The final basic social process that was identified within the data was associated with the failure of these persons to gain leave to remain legally within the UK. This process generally occurred after extensive appeals. While this is the final phase of the process, it is vital in that it details the struggles associated with life while awaiting deportation. This period is unique given the individuals lack of official access to governmentally provided resources, and their former ability to access these. During the analysis of this component of the data the following sub-themes arose: 1) Interacting with immigration officials as required; 2) Maintaining hope through a connection with the community within the UK; and 3) Striving to maintain health and well being in the face of rapidly dwindling resources. The following statement from the data reflects well upon the period that follows loss on appeal.

So for these people, once their legal status is lost, after appeals are exhausted, it is only a matter of time until they are ineligible. And of course buying the medications is out of the question, especially at the cost that they would have to pay. After all, if they have jobs, they pay poorly and care could cost 500-600 pounds monthly at minimum, when the medications are considered alone, much less laboratory following and the like.

African Services Case manager, 10 years of experience

Interacting with immigration officials as required

³⁹⁹ See Article 25 of the Universal Declaration of Human Rights.

It is important to consider the profound effect of one failing to gain legal status. The data reflected almost universally, that this was followed by a period during which individual undocumented African migrants began to wait for their eventual deportation, and during which they suffered a great deal of anxiety. The data reflected an extensive sense that the prospect of being deported was a worst-case scenario for Africans faced with an involuntary return to their country of origin. The following passage demonstrated the meaning of this to many Africans.

Can you imagine? You escape from a country where war, violence, corruption and starvation are the norm, and find yourself in a place where a man can make a proper living. Not to mention the fact that you have some degree of safety. You do as you are told, file all of the required papers, and then you are sent back.

Manager and Case Worker, 16 Years Experience, 6 years experience with African clientele

The following statement further illustrates the meaning of deportation to Africans.

So many of our clients have fled with their entire family, who are now spread all over Europe. Often, deportation means returning to a country where you have no family, no home, no safety. I can't think of anything more inhumane.

African Services Case manager, 10 years of experience

Finally, the following statement further demonstrates the meaning of deportation to these individuals.

They have always been disappointed, so this is another in a long line of disappointments. The sad truth is that for many, this means death. A return to a place where they cannot gain treatment, much less establish a household or even

secure proper food. I don't know what the solution is, but certainly to act so inhumanely is not the way to do things.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS

The realization that they would likely be deported was reflected upon often. In the UK, individuals who are to be deported are required to maintain weekly appointments with Home Office officials and can be deported with little notice incident to these visits. Many of the participants reflected upon the trend that indicated the vast majority both complying with these requirements and maintaining the hope that they would somehow be allowed to remain in the country.

I deal with this daily. Our clients, many of them, have failed to gain status through initial application through a very long review process, and at that point, they are assigned a worker with whom they visit and update regarding their week-to-week status. This is of course for the purpose of the bureaucrat's wishes to deport them. They are an odd lot, these Africans. Despite our counsel, they are convinced, often through prayer, that they will gain leave to remain, very odd indeed given the reality of it all.

Case Worker, 16 years experience with African clientele

The following statement further demonstrates the effect of pending deportation.

The fact that they could, at virtually a moments notice, be sent home is amazing to me. It is as simple as the Home Office arranging a flight. It tends to take longer than the days when Eastern Europeans were deported, but very similar. Somehow they don't grasp the situation. I mean, they understand, but they somehow hope

that something will happen that will allow them to stay. This generally does not happen.

Consultant Physician, 20 years experience in HIV/AIDS care.

The near certainty of deportation accompanied by such feelings of hope is an interesting commentary on the psyche of undocumented African migrants. The fear of deportation is supported by the profound likelihood that most undocumented migrants will most certainly be deported. This offers a startling illustration of the desperation of undocumented African migrants, who are faced with deportation to their former countries, where despite their healthcare limitations in the UK, certainly offer the prospect of more dire conditions. The next section offers reflections upon another closely related element of the data.

Maintaining hope through a connection with the community within the UK

The near certainty of deportation in the majority of cases and frequent visits with government and Home Office officials would seem to indicate that most individuals would greatly alter their lifestyle. This element of the data was reflected upon frequently. The participants associated African's sense of community and focus on interacting extensively within their own community as a way in which Africans maintained a positive outlook regarding the possibility of a beneficial outcome. Further, participants cited previous experiences as the main factor driving this process. That is, the process of deportation was greatly prolonged in the past, whereas the interval between failure of appeal and deportation was perceived to be progressively shortening over time, as reflected upon in the following passage.

I suppose the past is the best teacher here. A fellow could wait years prior to deportation in the past. What was different was the fact that they continued to receive many services for which they were ineligible. They tended to turn towards their own community to avoid drawing attention to themselves. This often went on for many years. We now see this, but it is rapidly changing due to the rapidity of deportation.

Case Worker, 16 years experience with African clientele

The following passage further illustrates this pattern.

I think it is natural that they try to take on a low profile and focus their interactions in their own community. London is a place where this is very common, especially given the large African population. Yes, they tend to live amongst themselves, but I see this more often at the point that they lose their fight for status. In the past, one could disappear into a community like this. Now, the Home Office imperative to move people out quickly is changing that rapidly.

Case Worker, 20 years combined experience as an activist and social care provider for people living with HIV/AIDS.

While the social process representing this section is important to this component of the data, it reflected upon an important outcome associated with the denial of the asylum application. This represented an evolving element of the social process due to changes in the immigration system that are gradually decreasing the time span from loss on appeal to deportation. The result, likely, would be alterations to this element of the social process, and the accompanying reality that one cannot simply just ‘blend into the woodwork’.

Striving to maintain health and well being in the face of rapidly dwindling resources

The period of time that follows the denial of the appeal of the undocumented African migrants is one characterized by extensive needs for services. This portion of the data reflects specifically on those individuals who find themselves without access to medical services. These individuals, additionally, generally suffer a lack of social services. The added burden reflected by HIV/AIDS, in these cases further complicated the issue, especially given the life threatening nature of their inability to gain medical services. The data reflects that during this period tended to focus on non-governmental agencies as a medium for gaining assistance with their many challenges, as is reflected in the following passage.

This is a large proportion of what we do. As you may realize (*location de-identified*) is not a place where there were lots of Africans. Our clientele was originally gay, male and white. We are now employing two caseworkers who work solely with Africans in the position that you describe. We offer them extensive support, but we cannot give medical care, which is their greatest need.

Manager and Case Worker, 16 Years Experience, 6 years experience with African clientele.

The extensive service needs of Africans who have lost their quest for legal status was a common theme throughout the thesis, while reflecting upon the fact that the assistance offered by these organizations provided only for non-medical needs. The following passage further reflects upon this.

We offer them much of what they need. We offer food, housekeeping, childcare, social worker support, even legal advice. We cannot offer medical care. Their

greatest need is their medicine, which we cannot offer either. Because of this, our support fails to extend life, rally, makes it more comfortable though, and helps the children.

Women's Services Case Manager, works exclusively with Africans, 3 years experience.

This period of profound need offers a keen insight into the plight of undocumented migrants in the UK. Basic human rights declarations such as the Universal Declaration on Human Rights establish the right of every individual to maintain a standard of living adequate for health and. The data in this section reflected upon the dire need of these individuals and the inability of NGOs to provide comprehensive services to undocumented African migrants. This data is consistent with that related to healthcare in that the NGOs too, cite their inability to provide HIV therapies. When one considers the fact that the accident emergency departments offer care only under emergent circumstances, an interesting pattern arises. While some medical care, GP care for instance, is provided; HIV specific care is the sole purview of the GM clinics. NGOs conversely, lack the ability to provide access to HIV medicines. Thus, the system almost guarantees that individuals will experience a gradual loss of immune function, and eventual life threatening illness, at which time they will receive accident emergency and hospital based care. Upon discharge, however, they will again be lost to care, and will most certainly repeat this cycle despite the efforts of the NGOs to prevent this.

Immigration detention and access to medical care.

During data collection, several of the early participants described conditions within the country's immigration detention centers. While they provided some

reflections, which invariably included limitations to medical care access, they were hearsay, and thus, did not reflect their own experiences. This necessitated that, with great difficulty, data be collected from individuals who had worked within the immigration detention system. All told, 3 participants with direct knowledge of the detention centers were interviewed. This portion of the sample addressed other portions of the data, but sufficiently addressed the data regarding the detention centers to the degree that theoretical saturation was achieved.

These participants reflected upon a general availability of basic medical services with a concurrent lack of services related specifically to HIV/AIDS. They represented a strong sense of concern related to the effects of the lack of appropriate therapies for these individuals, as reflected in the following passage.

Some come to the camps with medication given them by the GM clinics when it became apparent that they would be detained and deported. The remainder does not have medications or run out soon after they have arrived. In either case, the results are normally the same.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS

Another participant who was a physician experienced in the care of Africans in immigration detention reflected similarly.

Most people will have a period, sometimes days, sometimes weeks when their medications aren't available. As you know, these treatments can be very expensive and in the case of these detainees, they are helpless. That is, they cannot publicly complain, thus they have to bear the situation and wait.

Consultant Physician, 20 years experience in HIV/AIDS care

The participants reflected upon the results of limited therapies and therapeutic interruptions the immigration detention centers.

The problem as you know is ART resistance, which can occur, in mere days. I think that this is a major concern, especially given resistance patterns in Africa where they will soon find themselves. You see, in Africa they can not generally receive testing for resistance, much less get medicines at a reasonable price. What we see then is a situation where their immune systems cannot cope, The lapse in medications becomes the thing that speed the end of their lives.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS.

The individuals interviewed regarding their direct experiences with immigration detention reflected actual doctor-patient interactions as well, which further reflected upon the lack of access to medical care within these facilities.

He was very ill, again, had TB, HIV very ill. He was not allowed to speak to me for days, and finally I was able to examine him. His response?: “finally, I might receive help, I might get to live”. This was terrifying, as he had not been provided care.

Consultant Physician with 32 years of experience in caring for a variety of patients including those with HIV/AIDS.

The participants who provided data regarding immigration detention voiced frustration with the setting represented by immigration detention due to the limitations that they place on one's ability to practice.

So, what do you do with someone with HIV who is going out on a plane tomorrow? What is his duty, as a physician there, given that he does not have the power to stop the removal, and in truth he may never see them again, likely won't.

Consultant Physician, 20 years experience in HIV/AIDS care

In total, the data regarding immigration detention reflects upon an environment in which it is difficult to administer HIV specific care. Further, the participants reflected upon limitations to care provided in these settings, particularly regarding non-acute diseases such as HIV.

The Theoretical Model

The issue of health access amongst undocumented African Migrants was considerably more complex than was first foreseen. Data collection, thus, progressed in such a way that issues highly related to healthcare, migration and survival were encompassed within the data. The purpose of this section is to present to theoretical model which arose from the data during the course of the analysis. The model, in essence, provides a reflection upon the relationship between the various major themes present within the data.

The theoretical model for the study is presented in graphic form in Figure-1. The primary structure of the graphic representation of the theory is related to the relationship between health services, survival related endeavors and the efforts of migrants to continue their ability to dwell within the UK. Initially, data collection focused on issues related directly to healthcare; however, the participants that related to survival related issues provided extensive information. Simply put, there was a clear focus on the part of newly arrived Africans on survival. This required that they focus intently securing the

resources necessary to sustain their lives within the UK. The element of survival pervaded every aspect of other elements of the data. Even at times when health related aspects were considered, the participants tended to refocus their interviews on the profound socioeconomic challenges experienced by Africans newly arrived in the country.

The drive to maintain the resources necessary for survival was closely paralleled by issues related to immigration law, and the ability of these individuals to remain in the UK. This was a central social process in that the ability to remain in the UK was analogous to the survival related social processes detailed in the previous paragraph. While the interviews focused heavily upon health related constructs, there was an overwhelming and pervasive focus on the asylum process within the UK. This element of the theoretical model focuses on the prevalent form of immigration by Africans. That is, most enter and apply for asylum, followed by appeals based upon the initial denial of the asylum application. The result is an initial period of limited legal status followed by the loss of legal status. African migrants, due to the geographic separation of the British Isles, were not perceived by the participants to enter the country illegally.

The parallel representations of survival issues and issues related to ones ability to remain in the UK reflect the degree to which these constructs are closely related to every element of undocumented of HIV positive African migrants' ability to maintain their access to health related services. This is an essential aspect of the model, since healthcare was not the primary goal of African migrants. This element of the theoretical model is logical since healthcare is dependent upon survival in a general sense. Further access to healthcare in the UK context would require one's continued presence in the country.

These elements of the data are central to the model and are the primary factors impacting the behaviors of the participants.

The healthcare seeking elements of the model fall between the aforementioned concepts related to survival and immigration related processes. While one might posit that health related concerns would be absolutely central to the day-to-day activities that HIV positive undocumented African migrants engage in, this was not the case. The data did reflect heavily upon the individual efforts of African migrants directed towards gaining health related services. There was a clear demarcation between the ability and lack of ability to gain health related services. The broken line at the point represents this demarcation when one loses their final appeal, and fails in their quest to gain legal status.

The theoretical model reflects upon the process of gaining healthcare prior to the loss of legal status in a very simple and concise manner. In fact, the data reflected upon the very broad access to care enjoyed by individual Africans during the period that their asylum applications were pending. While care was available, it is important to note that the data reflected heavily upon factors related to the limited likelihood that one would seek the services to which they were entitled. These factors were closely related to the social implications of having been infected with HIV. This was largely related to the stigma associated with HIV disease. While this was a limiting factor, the data reflected broad availability of care from GPs, and from consultants within the GU Medicine clinics. This element of the model reflects the degree to which individuals experience comprehensive access to health related services.

The loss on appeal of the initial asylum application denial is a significant event that was heavily reflected upon within the data. The broken line in the model represents

this event. It is this broken line, the point of loss of services and legal access to care, which is essentially established by law. For instance, if the law were to change offering less service to those pending asylum proceedings, the line would move forward considerably (thus invoking the negative events of the model far earlier in the process). Several processes related to the access of African migrants to health services occur at this point. It is essential to focus at this point on the relationship between some access to health services and functional access to health services. The theoretical model reflects heavily upon this. Individual undocumented African migrants, even after their loss of temporary legal status, continued to enjoy almost universal access to care at the GP level. While access to GP care represented some level of access to health services, the GP cannot provide specialized services to those infected with HIV. Additionally, individuals who found themselves suffering life threatening illness were able to gain care through the Accident Emergency Department. This too represents a limited form of care, since emergent care does not provide for continuing care even for those suffering HIV related complications.

The issue of access to consultants within the GU medicine clinics was the major area identified within the data that would constitute a limitation of access to care. These limitations were not, however, uniform throughout the regions included in the sample. The major mechanism for service limitation is one related are the interactions between law, administrative process and technology. Simply put, there was broad agreement on the part of the participants which indicated that there are major limitations to the ability of individuals to gain services within GU medicine clinics rested upon their ability to remain undetected in an administrative sense.

Factors that were perceived to increase the likelihood of detection were related to events such as acute illnesses that required hospitalization. Acute illness invariably resulted in the administrative determination of ineligibility. Additionally, the size of the municipality where the particular clinic was located played a role as well. Large cities with a very high volume within their GU medicine clinics were more likely to perform eligibility checks, while smaller regions, such as those in the Midlands were more likely to continue to provide care. This element of the data also reflected upon the fact that many of the doctors and nurses within these clinics had profound ethical problems with limiting care to people who they previously cared for. This reflects upon the complicated nature of service denial, in that healthcare workers ethical codes are generally counter to this practice.

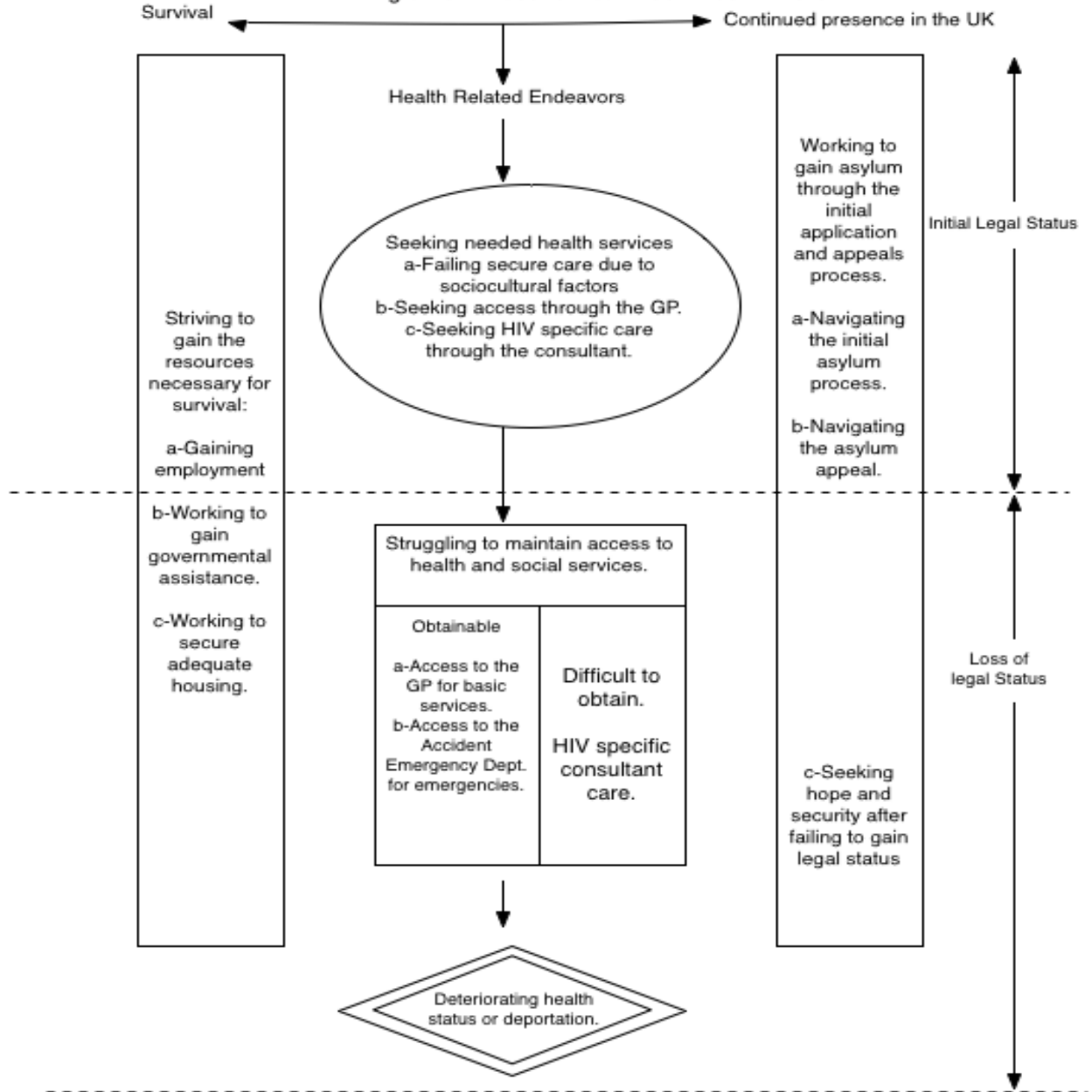
The theoretical model accounts for the continued interaction between the individuals survival related needs, quest for immigration status and their health related needs. It culminates with a final step referred to as deteriorating health status or deportation. Each of these events is inevitable to a degree, given the dual progression inherent to the immigration system and to improperly treated HIV disease. This is the key element related to basic human rights models, such as the Universal Declaration for Human Rights, since this is the very point that this declaration seeks to prevent.⁴⁰⁰ The data and the theoretical framework reflect the fact that eventually undocumented African migrants' lack of status will be discovered by health authorities, either through a status check due to hospitalization or a routine check by an administrator. This aspect of the data does reflect a pattern of access within the system, and a lack of enforcement of

⁴⁰⁰ United Nations (1948). Universal Declaration of Human Rights. Resolution 217 A (III)

patient billing provisions, that represents functional access to services for many undocumented migrants. This will result in the termination of antiretroviral therapy, followed by the inevitable degradation of the individual's immune system. The latter possibility, deportation will result minimally in the interruption of therapy or possibly cessation of therapy altogether. This depends upon the availability of appropriate therapy after the individual's arrival in their home country. Both of these possibilities; loss of service and deportation, are likely to result in worsening of the individual's HIV and eventual loss of immune competence.

While this theoretical model is an initial attempt to define the relationship between variables involved in undocumented African migrants' attempts to gain healthcare services, this is an initial foray into this topic. Additional explorations of the variables defined in this document are necessary to fully define the relationship between these variables in a more quantitative way. This model does, however, provide a comprehensive examination of the variables that influence the experience of health seeking behaviors in this population. It further provides a holistic reflection upon an individual's experiences within the UK as they relate to the legal processes that newly arrived African migrants are subjected to.

Figure-1: Theoretical Model for Undocumented African Migrants Access to Health services in the UK



Conclusion

The data reflected upon a holistic representation of the interaction between the basic social processes underlying African migrants' efforts to gain healthcare services. This included a reflection upon other prominent factors related to the establishment of a safe and productive life and the ability of individuals to remain within the UK. The data reflects extensively upon the aims of the empirical phase of this thesis. The first aim sought to determine the patterns of access of African migrants living with HIV/AIDS to health services in the UK. The data reflected heavily upon the ability of migrants to enter the medical care system during their asylum. The data delineated the clear ability of migrants to gain care through GP based clinics, and a more limited ability to gain care through the GU Medicine clinics specific to their HIV disease. The data, as well, identified an emerging pattern of service denial after loss on immigration appeal, which often resulted in a discontinuation of medical therapies. The second aim sought to cases where health services are gained and determine the most common modalities wherein African migrants living with HIV/AIDS gain access to health services. The data reflected heavily upon this, and also delineated circumstances where this element of care became more difficult to access. Following loss of the asylum applications on appeal, many continued to receive care. Events such as hospitalization, however, often resulted in administrators withdrawing their eligibility, with subsequent cessation of care. The final aim sought to determine the concordance between current regulatory instruments and actual practices in the UK regarding undocumented African migrants living with HIV/AIDS endeavors to gain health services. The data reflecting upon this element of the data presented a widespread pattern through which individuals were gaining care. There

were, however, clear limits to this ability associated with lack of full legal recognition. The results of this examination are notable in that they have demonstrated a more concise timeline related to the interaction between the asylum process and access to health related services. In fact, the results reflect that African migrants maintain a degree of access to health services both during the period that they possess legal access to services and after the failure of their asylum claim. The difficulty lies in their ability to maintain access to HIV specific services through access to care in the GM clinics. The chapters that follow will provide a more in depth analysis of the factors that contribute to this pattern and the degree to which these are similar to, or different from the pattern of access seen in the US.

Chapter 7– Undocumented Migrant’s Access to Healthcare in actual Practice: An Empirical Examination within the US.

In this chapter, the results of the empirical data related to Non-Governmental Organizations within the US will be presented. The data will then be presented based upon the over riding themes that arose during analysis. The aim of this chapter is to address the overall research aims for the thesis, which include: (1) Examining cases where health services are gained and determine the most common modalities wherein African migrants living with HIV/AIDS gain access to health services, and; (2) Making a determination of the concordance between current regulatory instruments and actual practices in the UK and US regarding undocumented African migrants living with HIV/AIDS endeavors to gain health services. The chapter will conclude with a presentation of the theoretical model that was developed during the analysis of the data.

Data Collection

The US phase of data collection offered several substantial challenges when compared to the UK phase of the study. The first was related directly to the demographics of communities within the US, and the selection of newly immigrated Africans as the primary population of interest for the study. During the UK phase of the study, this population was more broadly available in various geographic regions. Thus, most if not all organizations had some degree of experience in addressing the needs of this population. This resulted in the availability of both small and large sized communities in which to perform data collection. While it was desirable to identify smaller communities within the US where Africans dwell in sufficient numbers, and to the degree to which organizations had interacted with them extensively, this was not possible. The majority of smaller communities had a far greater breadth of experience with Mexican, Central and

South American Immigrants. Thus, the US phase of data collection occurred within The Northeastern US, The Middle Atlantic Region, and the Southeastern US.

The second major challenge within the US context is related again to geography. During the UK phase of the study, it was possible to sample several organizations within each of several regions. Due to the resources associated with this study, and the large distances between communities included in the study, it was not possible to include multiple municipalities within each of the regions. It is the case that this reflects the geographic disbursement of communities within the US and UK and differences in ones ability to travel reasonably through these areas utilizing mass transit.

Results

The results of the study will be presented first according to the major themes that arose from the data during continuous comparative analysis. These themes will be presented according to gerunds, which is a common practice when using the Grounded Theory Method.⁴⁰¹ These represent the basic social processes experienced by undocumented immigrants as they establish their lives in the US and strive for all of their needs to be met. During analysis of the data 6 major themes arose from the data contained in the interviews. These were: 1) Striving to gain the resources necessary for survival; 2) Working to gain legal immigration status; 3) Avoiding detection by immigration authorities; 4) Identifying appropriate healthcare resources; 5) Navigating the complexity and cost of the healthcare system; and 6) Making do with available

⁴⁰¹ Gerunds represent the action-noun form of a particular verb, which is based upon the addition of the suffix 'ing'. Strauss, A. *Qualitative analysis for social scientists*. (University of Cambridge Press, 1987)

resources while striving for legal status. Each of these themes and the data accompanying them will be presented followed by a presentation of the theoretical framework that explains the relationship between the themes that arose from the data.

Differentiation of the African Migrant Population in the US

During data collection, the participants reflected extensively on the differences between African and Latin American migrants. This distinction was specific to the US context, since the vast majority of migrants within the US are not African. The UK conversely, had a more diverse population of migrants. The characteristics of the legal and social systems within the US were a primary factor influencing the data regarding African people newly arrived to the country. The primary distinctions made by the participants were those that made comparisons between African migrants and the far larger population represented by Mexican and Latin American migrants. During the analysis of data under this 3 sub-themes used to differentiate African from Latin American or Mexican Migrants arose. The subthemes which arose in this element of the data were: 1) Differences regarding their intent to establish permanent residence in the US; 2) Demographic differences related to family composition in the US context and; 3) Differences related to the educational backgrounds of African migrants. In the context of this study, it is important to draw these distinctions, as they have an important relationship to the overall experiences of undocumented migrants.

Differences regarding their intent to establish permanent residence in the US

The notion that the intent of Africans to establish permanent residence in the US differed from that of Mexican and Latin American migrants was common. In fact, this component of the data was theoretically saturated early in data collection, although even

without direct questioning these themes continued to arise repeatedly throughout data collection. Participants communicated a strong feeling that while many Mexican and Latin American immigrants intended to return to their countries of origin, for instance in the case of seasonal labor, most Africans intended to establish permanent residence in the US. The following statement demonstrates the juxtaposition of Latin American and African migrants.

We deal with a lot of Mexicans, really more than we can count. They are different in many ways. I would say the biggest difference has to do with their level of need. They just don't need or want much at all, but they live differently than our African clients. These Mexicans, they usually go home, or at least go back and forth. Now the Africans; they'll do just about anything to stay here. I don't blame them, I mean look; they've given up their homes and everything. They have nowhere else to go.

Manager and Case Worker, 15 years in HIV/AIDS Care, 11 years solely with Africans

The following statement further illustrates this element of the data.

I help people get housing on a daily basis. The differences I see in this area are striking. These Latin guys, they want a place where they can put 10 or 12 young men in a single apartment. You know, just a place to take meals and rest when you're not working. The Africans, they are very needy, very difficult to work with. You could be dealing with a whole family, babies to grand parents. Now they, they want a place, you know, where you would live with a family,

something a lot more permanent. They are looking to really establish lives, not just make money.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

The following statement illustrates the differences between African and Latin American migrants with regards to their intent to establish permanent domicile.

The Africans who we work with are wonderful people. They want very much to establish lives here in the US permanently. This is unique to this population, since we really don't see a lot of single African men working seasonally. Now this is the norm with our Mexican, Central and South American clients. These folks are generally looking to make a living. Maybe after a few visits they'll decide to stay here, but not generally. The Africans stories are heart wrenching. I mean, they come from poverty like the Mexicans, but most of them also have experiences with war, rape, violence, and absolute starvation. They have a far more profound drive to remain, while the Mexicans, they come, they go, it's an awful lot easier for them to come back.

Case Worker, 25 years experience, 10 years with African clientele

This section reflects the profound differences between African migrants and the predominant migrant groups in the US who are largely of Latin American origin. The data provides an important differentiation in that African migrants were seen by the participants to be fleeing unbearable circumstances, with no intent of returning to their home countries in the future. In the context of US immigration, this is very different from their Latin American counterparts given the frequent return of Latin Americans to their home countries. This differentiation provides an important indication of the human rights

ramifications of African migration to the US, since it appears to indicate that it is not solely economic.

Demographic differences related to family composition in the US context

The previous section makes several references to family composition as well. While some Mexican and Latin American families migrate as a complete family unit, it is more commonly reported that men from this community migrate and remit funds to their families in their countries of origin they. Africans on the other hand are more widely seen living with their families I the US, which is demonstrated by the following statement.

These Mexicans are little more than boys, young guys just coming to work here in the states. I would say that their reason for coming is purely economic. They are willing to take on risk to make money and support their families back home. The Africans have clearly come for economic reasons, but due to war and fear of persecution have severed ties with their home. They come here, family in tow, looking for a new life. For them, the stakes are higher. Yes many of them are illegal, and they take on this risk of deportation for their whole family. Difference is, the level of fear. I mean, look at the situation they'll be deported to compared to the Mexicans. Mexico has its problems, but lets face it, places like the Congo are terrifying, particularly if you come from the wrong tribe.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The following statement further illustrates Mexican and Central American's family situation after immigration.

We have caseworkers for all of the people we deal with. Our organization works with everyone, I mean, all of the various migrant groups, of which the Mexicans

and Central Americans are the largest. I have one caseworker that works with this group. They are primarily young and male, so their health needs are limited. I have 3 caseworkers with our African families, because they are just that, multigenerational families.

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

The data in this section builds on that from the previous section by further delineating this population. That is, they tend to be seen as migrating in a family unit rather than simply coming to the US in order to secure employment. This too speaks to the finality of the decision to migrate, in the case of Africans, as they seem to establish a situation where return to their former country could be difficult due to the lack of well-established family in their previous country.

Differences related to the educational backgrounds of African migrants

The final element of the data that reflected upon the differences between African and Mexican or Latin American populations, was the notion that these populations differed greatly with regards to their educational preparation. Participants commonly reflected upon their impression that the African immigrants possess higher levels of education than their Mexican and Latin American counterparts, as demonstrated by the following statement.

The Africans I care for are educated people. Really highly trained. I even have a few patients who were physicians in Africa. They find themselves destitute here in the US and unable to work due to their status, so they work in menial jobs. The Mexicans I see generally don't even have a basic level of education. Really nothing beyond elementary school by US standards.

Program Manager, church based HIV treatment program.

Educational differences are further demonstrated in the following statement.

The Africans I deal with speak English, are educated and very motivated to try and fit in. They simply lack resources and the legal status necessary to gain it. The Latin people we see generally don't possess an education, nor do they speak the language. In this respect, I find the Africans easier to deal with from the viewpoint of settling permanently in this country.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The final issue presented in this section differentiates the African migrant population even more profoundly, since a high percentage are well educated people who likely had a higher social standing in their countries of origin, and who must then find themselves in a markedly lower social standing in the US. This offers a stark contrast to Latin American migrants who are largely laborers and agricultural workers in their former countries.

Analysis of data reflecting upon the differentiation of the African Population.

The US data was unique compared to the UK data in that it included significant reflections upon the nature of immigration to the US. That is, it made a strong case for the differentiation of Mexican and Latin American migrants from those who come from Africa. The data makes a strong case supporting the notion that most of the immigration to the US is based upon economic influences. The participants were clear, however, that these economic variables played a lesser role in the case of Africans. This differentiation spanned variables such as intent to remain in the US, differences in family composition and differences in educational backgrounds of most African migrants.

While many of the Mexican and Latin American migrants come to the US as seasonal workers, often without their families, the data reflected the contrary in the case of African migrants. That is, the participants related the strife associated with many Africans' country of origin as a major factor motivating their desire to remain in the US. Further, the data reflected on the presence of complete families within the African community. These multigenerational families have more complex challenges as compared to their Mexican and Latin American counterparts who are largely young and male. Further, a major factor differentiating these populations is the presence of high numbers of well-educated persons in the African community, as compared to Mexicans and Latin Americans who come primarily from the 'peasant farmer' class in their native countries. Thus, the data makes a strong case against purely economic migration on the part of Africans, instead indicating that their primary difference from other migrant groups in the US lies in the state of their countries of origin and the profound likelihood of human rights abuses should they return.

The relationship between the unique nature of the African immigrant population and the legal system is notable. Since Africans tend to seek permanent residence, they are more likely to attempt to navigate the naturalization system, rather than simply work in the country for a period of time as is often seen in the Latin American migrant population. Further, the differences in family composition also increase the likelihood that African migrants will attempt to access social and health related services. In cases where these services are not provided for undocumented migrants under the law, this population may well find themselves lacking in essential services. Finally, the trend towards higher levels of education amongst Africans in the US (as compared to Latin

Americans) increases the likelihood that they will seek professional positions of high visibility compared to the simple labor (eg farm labor) sought by their Latin American counterparts. These factors indicate a greater likelihood that undocumented African migrants will interface more frequently with government agencies.

Striving to gain the resources necessary for survival

The factors detailed in the aforementioned sections serve to set a stage for the examination of the basic social processes underling the motivation of African migrants and their efforts to gain access to health services. Since the study focused specifically on those living with HIV/AIDS, one might surmise that each should possess an overwhelming drive to gain such services. This section was surprising in that, while all of the participants were able to speak to the challenges which confront African people with HIV/AIDS, a high proportion of participants also reported that they questioned the degree to which health care was a primary concern despite the known HIV/AIDS status of many of their clients. There was a pervasive undertone in the data that indicated that the participants felt that issues related to gaining the resources requisite for survival, more so than access to healthcare, governed the efforts of the individuals for whom the participants provided care. The following statement demonstrates the prioritization of basic necessities, over health services.

I realize you're looking at health access. Obviously, that is what we do, I mean, that's what it says on the door anyways. In truth, our efforts, primarily in the area of case management are invariably focused on providing support not only to the patients who we care for, but also for their families. Look, it is hard, very hard, to tell someone to go to doctors appointments, obtain meds, take care of themselves,

when they don't have money. You need money for rent, food, transportation, clothing. These folks aren't generally able to get state help, so what's left. I'll tell you what we see, we see people trying to survive.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

The following statement from a healthcare organization further illustrates the prioritization of basic survival necessities over health related needs.

Antiretroviral meds are very difficult to take. We can get people the medications. It is not easy, but we manage. What can we do about their need for resources? Simply put, can you imagine taking these meds without any food to eat, or following complicated regimens while your working 14 hour days to pay rent, attempting to care for your kids with little or no help. The people we care for have so much to worry about, that health concerns are often the last thing on their minds until it is too late.

Physician, Infectious Diseases Consultant with 14 years of experience

Organizations whose work lies primarily in the area of social care had similar reflections, as demonstrated by the following statement.

They really aren't eligible for any help when they lack legal status. In many cases, we can't even do much when they have promising asylum applications. Yes they want to take care of themselves. In many cases this would require them to do so out of pocket. When you're balancing your need to eat, have shelter and care for your kids against these meds, it is never a question. They put off the health related aspects of their general condition and take care of the here and now. I can't say I

would do differently, even though I know it would likely result in severe illness or death.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

This final statement further illustrates the degree to which the prioritization of basic survival necessities plays a role in the daily lives of undocumented African migrants.

I spend my days helping people find shelter, food, helping them get their kids into school, this takes about 80% of my time. These are things that I can do. It's not easy, but I can do it. Healthcare is essential. I think it is a human right, but the government doesn't agree. My ability to help people with HIV or AIDS get care is limited in a major league way. Because of this, I often end up referring people who are deathly ill to the hospital where they can't be turned away. I really hate this, but I must help these families in the best way I can. They appreciate this, and since staying alive is their number one priority, they don't seem to have a problem with it.

Program Manager, church based HIV treatment program.

This section was composed in such a way as to provide a reflection of the focus of undocumented migrants of African origins in the US on survival. The data, unexpectedly, provided extensive reflections differentiating this population from the largest migrant population in the US (Mexican or Latin American). This data served to first delineate the unique nature of this population, in order to demonstrate their unique needs compared to other populations. This element of the data was not meant to downgrade the importance

of healthcare for this population. Instead, it is presented in order to demonstrate the relative value of healthcare to this population in relation to their other life challenges.

The data reflecting upon issues of survival focused on several subthemes that arose from the data during analysis. These included the following: 1) Working to maximize earnings; 2) Establishing a household or living space; and 3) Building an infrastructure for long-term financial viability. These elements of the data reflect upon several cultural variables that appeared to be unique to Africans who were newly immigrated to the US. That is, their drive not only to survive but also to establish long term financial viability is an important element within the data. One of the major factors that were apparent throughout this section was that, despite current immigration initiatives, the participants reported few if any difficulties associated with locating and maintaining employment.

Working to maximize earnings

The issue of employment and earning was an important aspect of the data. The relative ease with which individuals within the African community were able to gain employment was an important variable. While the majority of Africans were able to gain employment, their positions tended to provide low wages. Rather than make do with lower salary as a limiting factor, the African migrants referred to by the participants tended to secure multiple positions in order to maximize their earnings, which is demonstrated by the following statement.

These are amazing people really. While many Americans won't maintain a single job, most of these guys hold down 2 of 3 jobs. I mean, HIV or not, were talking 60-70 hours a week on average. They are forward thinking in that their focus is on

establishing a better life, period. They give of themselves in incredible ways, all for the sake of a better life for their families.

Case Worker, serving African Clientele for 7 years.

The following statement further illustrates the work ethic seen in African migrants.

I am awed by the work that these people do. Many with untreated HIV. They work 80-hour weeks cleaning hotels rooms, washing windows, doing construction site labor. Their key is their spirit and lack of complaints. While so many Americans complain, these Africans can't believe that they have such great opportunities to earn a living. They will do most anything, even risk their health, to make a good living and care for their family.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

This section reflected upon the profound focus on earnings amongst undocumented African migrants. In part, this provides a reflection regarding the ease with which one who lacks legal status can gain employment within the US. Given the well-described health needs of persons living with HIV/AIDS, the drive to maximize earnings is not likely to result in better health practices or increase the frequency with which these individuals might attempt to gain healthcare.

Establishing a household or living space

The establishment of a household arose as one of the sub-themes regarding African's endeavors to survive in the US. The majority of the participants reflected upon this element of the data. This data was interesting, since most of the participants outlined the scenario by which many Africans, unable to get public housing, did their best to manage adequate households. This was generally accomplished through low cost

housing. African's housing related experiences focus on low-income housing sources, as demonstrated by the following statement.

I've seen 12 to 14 people in a small apartment. By our standards this is amazing, but to these African's the chance to maximize their earnings, to save money, is their priority. Yes, housing and shelter are important to everybody, but their priorities tend to be a little more forward thinking than ours.

Case Worker, serving African Clientele for 7 years

The following statement further reflects on African's experiences regarding housing.

I think the key word is adequate housing. They generally end up in small houses or apartments that are safe, but with no frills. You would probably consider these substandard. It is a big part of their culture, you know, making do with what they have and working for more. Family is there priority.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

This section too, reflects upon the immediate needs of undocumented African migrants, and is likely a portion of the reason for these individuals having so highly prioritized earnings. That said, these basic drives are consistent with the propositions of Maslow regarding the hierarchy of needs and the way in which individuals have been shown to prioritize their expenditure of resources.⁴⁰²

Building an infrastructure for long-term financial viability

The final subtheme that reflected upon elements of survival within the US addressed directly the issue of forward thinking strategies and priorities on the part of African migrants. The main component of this element of the data reflected upon

⁴⁰² Maslow, A. H. "A theory of human motivation." (1943) 50(4), Psychology Review, 370 at p. 374

African's drive to defer satisfaction in a material sense in order to save in order to facilitate a more prosperous future, which is reflected upon in the following statement.

They really don't work for the kinds of things that a lot of American families work for. I mean; they are working to forward the position of their families, you know, working towards the 'American dream'. They are not working to buy things, move into a nicer place, or buy a fancy car. They are saving for education, a business, to get ahead.

Program Manager, church based HIV treatment program

The following statement further reflects upon African's tendency to defer gratification while they establish themselves in the country.

Most ride the bus, even if they can afford a car, live in a small place even if they could move up. They are very focused and hard working people. They just have such a drive, to make a better life. It makes me sad sometimes because they often don't take very good care of themselves.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The data in this section reflected upon the necessities of life, and the degree to which securing essentials is a priority. This does not in any way degrade the health related aspects of their challenges, but instead serves to confirm the need for people to establish the basis for survival at its most basic level. It is notable that Africans are forward thinking in their efforts to establish a viable life in the US. These efforts, in turn, increase the likelihood that African families will fall under the scrutiny of the authorities. This element raises important questions regarding human rights issues in the context of individuals living with a life threatening chronic disease such as HIV/AIDS. The data in

this section calls into question the degree to which undocumented African Migrants can access these vitally needed resources.

Working to gain legal immigration status

The drive to gain legal status within the US was central to the basic social processes present in the data. Throughout the conduct of the study, the occurrence of this theme was universal, manifesting in all of the interviews. While it occurred in all of the interviews, the theme became theoretically saturated during the midway through the interviews. During analysis of this category within the data three subcategories arose. These included: 1) Attempting to establish grounds for asylum; 2) Working to navigate the administrative requirements of the system; and 3) Seeking to establish a legitimate lifestyle in the US.

Attempting to establish grounds for asylum

One of the key elements of the data, which was communicated universally, was the notion that Africans living in the US who lacked legal status needed to establish grounds through which they might establish an effective case for asylum. The organizations that participated in the study communicated some general notions regarding this process. This included the pervasive viewpoint that individual Africans who lack asylum status, as are those who come from countries that are not designated by the State Department as nations where asylum is automatically granted. Thus, these individuals must provide evidence of some other extraordinary circumstances that would serve to justify the leave to remain in the US, as reflected upon in the following statement.

If they have come to see us, they generally never met the criteria for asylum upon arrival. To be honest, a high number of our clients are people who oversaw

student visas and subsequently brought their families in. Their families are, in turn, overstaying visas granted for the purpose of visitation. So what we do, essentially, is start from the beginning, and attempt to delineate where they have come from and under what circumstances. The idea that we can retrospectively assist individuals in this situation is possible, but very very difficult in today's environment.

Case Worker, 25 years experience, 10 years with African clientele

According to the participants in the study, the addition of HIV disease to this equation represents a significant factor but is not the sole grounds for gaining asylum. The following passage is reflective of this element of the data.

Common sense would tell you that you just can't go shipping people back to the third world who are sick. HIV is a serious problem, but they really don't factor it into the equation. The key is establishing the presence of some form of inevitable persecution, danger or human rights wrong if they are returned to their country of origin. So here they are trying to stay healthy, and HIV is the biggest thing in their lives, but they must place the fact that they'll quickly die of HIV when they return secondary to the fact that some other ill will befall them.

Physician, Infectious Diseases Consultant with 14 years of experience

The following statement further reflects upon the prioritization of establishing one's self within the US over health related issues.

I sit for hours interviewing people and families who have already established pretty respectable lives here to try and establish that there is a reason that they shouldn't be deported. This is not easy, since we must produce some real proof

that they would come to harm in some way if this were to happen. The issue of HIV is purely secondary unless they are on their deathbed. If they are, it is possible to get them some treatment in the hospital, after which they improve, and are right back where they started.

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

The need to establish grounds for remaining in the country was cited as an area of profound frustration to many of the participants, as illustrated by the following statement.

When I initially have meetings with clients it is clear that they simply can't be returned to the places that they come from. It is absolutely certain. That is not enough though, poverty, HIV, war, all of these things are bad, but they are run of the mill problems in the African context. We spend months searching for more, as if there is somehow a greater justification. It is an absurd process, absolutely absurd.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The difficulty associated with establishing grounds for asylum is one that clearly introduces substantial stress and fear of deportation to undocumented African families. These difficulties are directly related to the manner through which asylum is granted in the US (See Chapter-2). That is, the State Department determines a country for which asylum is available, resulting in relatively low probability that individuals from other countries can apply for and receive asylum. Otherwise individuals find themselves unable to gain leave to remain in the country legally. Further, the data reflects the dire circumstances of possible deportation given the dangerous nature of many African's

home countries. This in itself may indicate the presence of a significant human rights based concern.

Working to navigate the administrative requirements of the system

While establishing the grounds for gaining asylum is a challenge, participant's also reported unanimously that pervasive fear regarding the act of filing an initial application, and then appealing said application after it has been denied, is an almost overwhelming problem for most African immigrants. According to the data gained from the participants, this phenomenon is driven primarily by a combination of lack of familiarity with the US legal system on the part of individual migrants coupled with their inability to gain legal services. The following statement demonstrates the notion that cultural factors play a significant role in individual willingness to navigate the administrative system in the US.

You must remember that these people come from countries where government officials are very scary and corrupt people. They come to the states jubilant to start new lives, enjoy new opportunity, and here they are now, being asked to trust government officials. I think that the fear of being deported is quite enough, but when you superimpose their old fears that are based upon experiences in their own countries, it becomes clear while even getting them to participate in this process is so difficult.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

The process was commonly cited as a significant by many of the participants.

I have a law degree and a couple of experienced paralegals working for me. I think we have something like 50 years of combined experience. With all of that,

the process is a full time job for us. It is very confusing. The people who are my clients, they are educated, but not in the ways of this country. The process overwhelms them, and many perceive that the process itself draws negative attention to them.

Legal Aid Program Director, 17 years working with undocumented migrants.

The fact that so many African migrants have been able to obtain work and establish their lives in the US was another common theme. This was seen as a factor limiting their motivation to participate in the administrative process, since legal status is not an absolute requirement to gain employment within the US, as reflected upon below.

I think that a large part of the problem is the fact that many of these folks are doing well until they are found out. Until that time, they are earning a living and taking care of their families. How do you convince someone who is doing so well to take this chance? Even if it might result in their being able to gain treatment for their disease. It is clear to me that their fear of HIV is far less than their fear of returning home.

General Practice Physician in NGO based clinic, 22 years experience

The administrative barriers represented by the asylum procedures in the US are a significant concern to the newly arrived. Additionally, African migrants were seen to come from countries where governmental interaction could result in one's drawing negative attention. This is a significant cultural variable associated with this population's interactions with the government.

Seeking to establish a legitimate lifestyle in the US.

The final phase of this basic social process is the capitulation on the part of the undocumented migrant that their efforts to establish a legitimate lifestyle becomes the driving force behind their attempt to gain legal immigration status, as reflected upon in the following statement.

Like I said before, they aren't just here to earn money, they want new lives. They strive for normality through establishing an education, careers, a household, a family. Problem is, these families grow, and when they do, the kids go to school. This begins a pattern where they file taxes, enroll kids in school and other programs. This doesn't include the need for healthcare. In the case of HIV, they just can't afford it. Legitimacy becomes a sort of problem for them.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

The following statement further illustrates African migrant's constant efforts towards attaining legitimacy.

Of course they want to establish a normal lifestyle. They want legitimacy, don't they? But they can never be legitimate until they enter the system. This requires that they work to gain legal status. For Africans this most often means working to gain some form of asylum. You can't live here long enough to establish a household, pay the tax, buy cars and the like and not begin to make a significant footprint that will eventually be noticed.

Program Manager for NGO that provides services to African Migrant populations, 19 years experience

Their need for medical services is further intertwined with the establishment of a legitimate presence in the country, due to limits placed upon the availability of insurance to people who lack legal status, as demonstrated in the following statement.

HIV can lay dormant for so long. Many of these people have established fairly normal lives by the time they get sick. It is my experience that they are drawn towards gaining legal status the more normal their lives become, and the more the realization that they will one day be ill and in need of care becomes evident to them.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The drive to gain legal status is an important component of the basic social processes that undocumented African immigrants undergo upon their arrival to the US. While many, early in the process appear to seek anonymity, the drive to establish legitimate lives leads them to seek legal status more aggressively. This appears to be mediated by their engagement in actions that effectively normalize their lives, but in the end, result in progressively higher levels of interaction with the government. The establishment of status as a legal alien is seldom achieved by most undocumented migrants. The end result, save for cases where they are detained unexpectedly, appears to be one in which individuals attempt to establish grounds for asylum, which is the first step towards gaining legal domicile in the US. The rule of law in the US greatly diminishes the ability of undocumented African migrants to the US to establish legal domicile.

Avoiding detection by immigration authorities

The preceding section detailed the efforts of undocumented African Migrants to gain legal status in the US. It was noted throughout the study that while this was a prevailing theme, many of the participants stated that one of the primary social processes observed amongst undocumented African immigrants was their effort to avoid attracting the attention of immigration authorities. During data analysis the following subthemes emerged from the data. They were: 1) Avoiding contact with immigration officials; and 2) Being influenced by perceived stigma.

There were indications of this phenomenon presented in the preceding section; however, elements of the previous section might seem contradictory. This is particularly true in the section that indicated that as individuals establish legitimacy in their lives, they often appear to display higher levels of motivation towards negotiating the immigration control system within the country. This important distinction is clarified in this section through the prevailing themes associated with the data regarding undocumented African immigrant's fear of the authorities.

Avoiding contact with immigration officials

The participants who made assertions regarding this element of the data made two important distinctions regarding the efforts of undocumented African persons to avoid detection by the authorities. The first element of the data indicated that soon after immigrating or losing legal status, undocumented migrants are more likely to avoid contact with immigration officials in order to avoid detection. The second theme, cited by the participants, was associated with fears on the part of individuals related to their HIV positive status.

Many of the participants viewed the avoidance of detection as a behavior that is characteristic of one who has more recently immigrated or lost their legal status. Statements from the participants who cited this factor during their interviews are included in the following section. The following statement is highly indicative of the general nature of the data reflecting efforts to avoid detection.

I think the key point in the process is when they lose their legal status. With most of the African people who I have worked with, this happened when they overstayed a travel of student visa. From the point that they do this I see them working very hard to just melt into the woodwork. They really avoid calling attention to themselves. As time passes, and they establish lives, this becomes impossible, and I think that they are more likely to begin to engage with the system.

Legal Aid Program Director, 17 years working with undocumented migrants.

Efforts to avoid detection were present throughout the data, as illustrated below.

I think that at first, they are terrified. They are used to systems where outsiders are not common, and I think they project this on our system. So yes, they'll do just about anything including go without medical care to avoid being found out. As well, it is human nature to relax after a while. They clearly begin to relax as they interact more with other people and groups in society and begin to move towards initiating the naturalization process.

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

The following statement further reflects upon efforts to avoid detection.

The newly arrived and or newly illegal Africans grossly overestimate the ability of the government to identify and deport them. I am not sure why this is, but they clearly begin to understand this fact over time, and develop a sort of apathy to the system. Later in life they seem to embrace the system when they have the resources to put together a respectable asylum package.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

This section established that undocumented African migrants maintain a significant fear of being identified, despite their efforts to gain legitimacy. This reflects the ability of undocumented migrants to ‘blend in’ to the US context and maintain relatively normal lives despite their lack of legal status. For instance, they work, pay taxes and strive to establish a legitimate lifestyle. While the data indicated that the fear of deportation was profound, there appeared to be an underlying theme that indicated the likelihood that individuals could well remain in the country for long periods of time without being discovered.

Being influenced by perceived stigma

Stigma or the perception that one is being stigmatized due to their HIV positive status is an important influence in the context of a broad array of basic social processes. The second theme present in this element of the data was less universal but was cited by the participants. This element of the data indicated the presence of perceived stigma as a factor that influences individual decisions regarding their decision to avoid detection. The following statements provide examples of the effects of stigma.

You have to realize that until recently, HIV was grounds to be denied entry into the country. So you take this population who are HIV positive, and oh by the way are black Africans, and illegal. The fact that they perceive stigma is no stretch, let's be serious.

Manager and Case Worker, 15 years in HIV/AIDS Care, 11 years solely with Africans

The following statement is indicative of participant's reflections regarding perceived stigma.

I think when you look at stigmatization, from a social point of view, black people have had it pretty tough in this country. Illegal immigrants are right there besides them. When you look at disease, I can't imagine any disease that society views in such a stigmatizing manner as they do HIV. When you combine these factors, you get my clients. I think that this brings to light the degree to which their fear of discovery is well founded.

Program Manager, church based HIV treatment program. 7 years experience

This statement nicely summarizes the perception of stigma and its effect of African migrants.

What is stigma to you? Stares, glaring, an unkind word. These people come from Africa. In places like Rwanda, Darfur, the Congo, stigma is death. It is imperative that we view this as a component of the reason for granting these people asylum in our country, not as a reason to hunt them down.

Physician, Infectious Diseases Consultant with 14 years of experience

The basic social process represented by undocumented African migrants' attempts to void detection by immigration officials is not an unexpected finding. This is compounded by cultural variables and accompanying fears associated with HIV related stigma. Stigma is an issue that arose in both the UK and US data and reflects a significant non-government variable that negatively influences the likelihood that one will seek care. As in the UK, the strong morays seen within the African community play a significant role in influencing individual behavior. The effects of the fear of discovery and perceived stigma serve to magnify the desire to avoid contact with others within the community and with the authorities. This result is a predictable one in this population, as is the element of the data that indicates that over time, this effect wanes. Familiarity with the system and an emerging cultural viewpoint may well play a role in this social process.

Identifying appropriate healthcare resources

Prior to undertaking the US phase of the study, it was hypothesized that gaining of health resources would have been the highest priority need on the part of individual undocumented African migrants who were living with HIV or AIDS. While healthcare is a priority issue to these individuals, there was a clear prioritization based upon their need to survive in and maintain the ability to remain within the country. These elements of the data are detailed in the preceding sections. During the interviews, there were very rich observations provided by the participants, which reflected on multiple aspects of the health seeking efforts of individuals who were lacking healthcare. The first theme to arise was a logical one, since the participants found it necessary first, to clarify the ways in which individuals came to realize that they were in fact HIV positive. This element of the data became evident during the very earliest interviews, with theoretical saturation

occurring early during the interviews. Additional participants did, however, expand on these concepts as well. During this phase of the data analysis several subthemes reflecting upon the search for appropriate healthcare services and factors that influenced this process arose from the data. These were: 1) Realization of the need for healthcare based upon individual knowledge of HIV status; 2) Delaying healthcare access attempts due to fear and stigma related to HIV; 3) Seeking healthcare due to major illness; and 4) Seeking healthcare due to previous knowledge of HIV serostatus

Realization of the need for healthcare based upon individual knowledge of HIV status.

This portion of the data is related to the dynamics surrounding the time that people became aware of their HIV positive status, and the degree to which this influenced their perception of need for health related services. The perception of need is a key antecedent to the engagement in actions designed to facilitate the identification of resources. The following statements serve to differentiate individuals who immigrate with known HIV status versus those who have not yet been diagnosed.

We have a number of people who come in with known HIV positive status. Of course many of these concealed this status during the time when you were asked upon entry. Even people who were coming on vacation or to visit family needed to enter. Many of these cases were in people who were treated in their home countries, maybe half of the cases. These are the ones that are a mixed bag. I mean, they know they need treatment, and some really work at it initially, but the need to make it in this country gets the best of them. The other big group we see are the women. Most of them are diagnosed when they arrive. You know, with

childbirth they can get Medicaid; their kids are Americans right! Then the mandatory testing IDs them.

Social Worker, African Services Coordinator, 11 years experience caring for African migrants.

While many factors influence one's likelihood of seeking medical care, the following statement provides evidence that the time of diagnosis plays a role.

I see a good deal of variation I guess. Most of my patients are women. The men don't seem to come in until they are very sick, but these guys have such a strong focus on working. I see ladies 'right off the boat' frequently with empty medicine bottles requesting help. The second group that I tend to see are those who have likely been infected for years and who were diagnosed either after a routine women's exam or childbirth. These tend to have waited longer.

Case Manager, Migrant Health Center, 13 years.

This statement similarly illustrates this point.

These women come in mostly now days when they are diagnosed. You know, the one's who have been tested at the health department during their prenatal care. Some know, but are afraid to come in. They start to have problems. I see some who know that when they get thrush, skin infections, frequent colds, that there is something wrong. They've seen it back home in family and friends. They come in after being sick for years.

Physician, Infectious Diseases Consultant with 14 years of experience

The participants reflected primarily on younger populations who previously had few if any healthcare concerns. The realization that one has contracted HIV has profound

implications, in that previously healthy individuals find themselves in need of healthcare services. Further, they have little familiarity with the healthcare system or ways of gaining service within it. The cultural variables associated with this lack of familiarity compound the problem.

Delaying healthcare access attempts due to fear and stigma related to HIV

The fear of stigma plays a significant role, and was mentioned repeatedly by the participants. The fear of stigma represents a negative influence regarding the likelihood that one might access immigration services as well. Participants who cited the time and nature of diagnoses commonly cited stigma as a significant influence on individual behavior.

In their community, you know, among their own, this is really bad news. They tend to put it off for as long as possible. They seem to know they are sick, but sort of hope it will just go away. This group comes when it is very late in the disease process. Sometimes when it is too late.

Case Manager, Migrant Health Center, 13 years.

The following statement further illustrates African's delay in seeking care as related to the life situation of these individuals.

They have so many economic challenges. So a woman is diagnosed. She knows she will become ill. It is inevitable. But how can she bring this problem home, when medical care isn't available in a real way, and she knows that this will have to be taken care of out of pocket. This problem, HIV, it tends not to be as great a priority. Its understandable isn't it. Her children must eat, and she feels fine for now.

Program Manager, church based HIV treatment program. 7 years experience

The time of diagnosis was a persistent theme that appeared to influence, at least to an extent, the time that individuals might seek care. In general, those who realized that they were positive upon entry to the country, tended to seek care soon after their arrival. Those who were incidentally diagnosed after arrival were obviously delayed. The degree to which stigma influenced the time and nature of presentation is outside of the purview of this study, however, the participants made substantial statements that indicated that stigma remains a significant concern in this community. Given the presence of stigma in the earlier portions of the data, it appears that this is a profound cultural barrier to health seeking behaviors.

Seeking healthcare due to major illness

There are individuals who initially seek care secondary to acute life threatening illness. In these cases, people are generally seen initially in an emergency department setting, and are subsequently admitted to the hospital. The issue of access to care is very different in the US context when one is suffering severe acute illness, since the healthcare system is obligated to offer them care. Prior to detailing the general social processes associated with the search for appropriate healthcare services it is necessary to detail the process associated with the individual who seeks care in this manner. The phenomenon represented by one who becomes deathly ill due to an AIDS related illness was common amongst the participants. In many cases, this was cited as the means by which one initially became aware of and then sought healthcare related to HIV disease. This element of the data was separated from the preceding section because the act of becoming deathly

ill does not represent a purposive social process. It does, however, represent a significant event, particularly in the US context, as reflected upon in the following statement.

There are some who never really accessed healthcare, not ever. Their first introduction to our system is when they fall deathly ill, and are brought by friends or family to the emergency room. They then end up in an intensive care setting where they are subsequently diagnosed with an AIDS related illness.

General Practice Physician in NGO based clinic, 22 years experience

This participant went on to further detail the consequences of presentation incident to acute illness.

Oh yes, there is no question that, under these circumstances they have access to care. Absolutely no question! Access, yes, and then the bill comes. As you can imagine, someone living in poverty, weakened by hospitalization and then finds themselves \$200,000 in debt gets pretty down. The worst part, they don't have any access to follow up care, and often end up right back in the hospital.

Physician, Infectious Diseases Consultant with 20 years of experience

Another participant further expounded on presentation for care due to acute illness.

I have inherited many patients who are diagnosed at the time of their first AIDS related crisis. I am a Family Practitioner. These people need specialty care. I have no access to the medicines that they require, and the patients can't afford them. They receive specialty care in the hospital, care that they can never pay for, but will be responsible for, yet no follow up, no medicines, nothing. More often than not, they end up right back in the hospital because they can't get the medicines that they need.

General Practice Physician in NGO based clinic, 22 years experience

The fact that cases where undocumented African immigrants who lack access to healthcare sometimes present very late in the disease process should come as no surprise. The aforementioned themes present in the data do bespeak the reality that only emergent care is guaranteed, and thus, cases where people are discharged from the hospital without ongoing care or appropriate follow up are the norm in the case of this population. While this falls short of representing a purposively engaged in social process, it is extremely concerning given the lack of continuity represented by this form of medical care.

Seeking healthcare due to previous knowledge of HIV serostatus

The previous section reflected upon individuals who present for care due to an HIV associated illness. There are, however, significant numbers of Africans who present for HIV related treatment due to a previous knowledge of the disease or previous treatment experiences. For instance, individuals who were diagnosed while in Africa or another nation prior to arriving in the US. The experiences of these individuals, according to the participants in this study are extremely frustrating indeed, as reflected upon in the following passage.

I see people often, about to run out of meds and who require treatment. They know they have HIV and want to remain well. This is logical, right. So they begin to attempt to find help, and the best they can do is go to a doc in the box and pay out of pocket for a prescription that costs \$3,000 for the month. Sure they have access, but real access?

Manager and Case Worker, 15 years in HIV/AIDS Care, 11 years solely with Africans

The following statement further reflects upon the challenge represented by specialist care.

I have people who have saved to see the specialist. There are a few free clinics that actually help with referrals even though they are illegal. The visit is maybe \$300, and that doesn't include the meds. So they receive a prescription that would cost more than their monthly income for the whole family. It is very frustrating, no demoralizing, for these people. Can you imagine?

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

The data that arose from this subtheme reflects on a population who are aware of their HIV status, and simply unable to sustain the financial requirements of access to health services in the context of the US healthcare system.

Navigating the complexity and cost of the healthcare system.

Following the decision to seek healthcare, the newly immigrated often face a challenging situation. As the sole free market healthcare system in the world, the US system is extremely complex. This level of complexity presents a very confusing array of choices to individuals under normal circumstances. The data provided a representation of the basic social processes surrounding the search for healthcare resources on the part of undocumented migrants. During the analysis of this element of the data, the precise ways in which Africans tended to seek healthcare were examined. The following themes emerged from the data during this phase of the analysis. They were: 1) Seeking care within the traditional fee for service system; 2) Meeting the realization of cost associated with the system; 3) Attempting to gain assistance from state and federal agencies; and 4) Seeking care through non-governmental agencies which offer support to undocumented migrants. In the following sections, these components will be further explored. It must be

noted that many or even most individuals find appropriate services during this phase. The difficulty tends to occur when they attempt to identify the resources with which to pay for said services, a phenomenon discussed under the next major section of this chapter.

Seeking care within the traditional fee for service system

Because of their unfamiliarity with the healthcare system in the US, it is logical that Africans who are newly arrived to the country would seek healthcare in the areas where it is the most visible. In this case of the US, and most other countries, the most visible healthcare entities are clustered about large hospitals. Thus, this tends to be the site at which most undocumented African migrants first seek healthcare

It was notable that the participants reflect on the fact that so many individuals make the initial assumption that they might gain care in this area, as reflected upon below.

They are ill, and need help. It is only natural that they would go to the hospital.

When they show up, the nice receptionist up front, usually an elderly volunteer is kind enough to direct them to the emergency room, where they are very promptly checked in. At this point they are asked about insurance, and are required to sign documents that require them to take financial responsibility for their care. But hey, how bad could it be? They are then seen, prescribed meds and told to follow up with their doctor, which incidentally they don't have. They then find themselves with a bill that they can't pay, medicine they can't afford, and a primary care provider that they don't have.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

The frustration that was associated with the inability to gain care in the hospital setting was nearly universally present in the data. The following statement further expounds on this phenomenon.

They go to the hospital initially, but they present for a chronic disease, HIV, which requires chronic follow up. The emergency physicians don't really provide this, but they do their best. In my experience, they make this mistake once or twice, and then go only in cases of life threatening illness. The bill for these services horrifies them. These people come from countries where debtors can be imprisoned. So that's it, they avoid the hospital like the plague from that point on.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The other major factor related to difficulty in gaining hospital based care is the notion that the hospital does not possess the facilities to provide ongoing care to these individuals. Participants who cited the trend towards seeking care within the hospital emergency department often reflected upon this trend, as reflected in the following statement.

By the time we see them, they've met the realization that the hospital really isn't the place to get care unless they are dying. They just can't get the ongoing type of care that they require, so in the end, they end up seeking care elsewhere. This is a huge frustration for these people. They just reach a point where healthcare becomes less of a priority because it becomes a need that they can't meet.

Physician, Infectious Diseases Consultant with 14 years of experience

Meeting the realization of cost associated with the system

The next basic social process that arose from the data reflected upon the process of individuals realizing the profound costs of services within the US healthcare system. There were references to this theme made in the preceding section, in the context of the emergency department. This theme becomes more widespread in the data as other elements of the healthcare system are covered. The following statement reflects upon the cost related pitfalls common to the US system.

Everywhere they go there is someone asking them for money. These are hard working people, they want to pay. They simply lack the resources. This is at every level by the way, doctor's offices, primary care, specialists, and pharmacies. It is the sort of tired billing scheme that they have seen before in their countries, it certainly doesn't engender trust in the system.

Social worker, cultural liaison in NGO, working with newly migrated African clients

The following statement further reflects upon the fears induced by systemic cost.

They do pay to see doctors, but they often have huge misperceptions regarding the meaning of paying a doctor in our country. They somehow have the feeling that the care they receive will be more comprehensive than it really is. A consultation is a first visit. They will invariably require tests, treatments, other referrals. These are all extra. So when they go to an office, give blood, maybe get an x-ray, more bills come, all from a single visit.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

The data in this area also reflected upon the initial response of individual African's to this experience.

Yes, there is a period. A period when they almost give up. A number of experiences spur them on though. Someone else gets sick, maybe a friend, or they just, just worry themselves to the point that they want help. Problem is, that their experiences with these massive bills are terrifying, and tend to drive them elsewhere. But at that point, they know intuitively that there must be some other help available.

Manager and Case Worker, 15 years in HIV/AIDS Care, 11 years solely with Africans

The data in this section reflects upon the very real nature of the cost associated with the US healthcare system. Their inability to gain publicly funded services places undocumented migrants in the unenviable position of having to self-finance their health services. The data reflects on the degree to which fear regarding the cost of care represents a significant barrier.

Attempting to gain assistance from state and federal agencies

The next basic social process involved individual's attempts to gain assistance from is government. This too is a logical step for one to take while attempting to identify sources of health related assistance. In fact, many women have had state funded healthcare in the form of obstetric care provided under the Medicaid program, and have children who receive Medicaid funded healthcare as well. This element was prominent within the data, since this is a very confusing aspect of the system. The following statement illustrates some of the contradictions present in the system.

They become pregnant and get Medicaid. They have children who are American citizens, who also have Medicaid. So why would one think they were not eligible, were they not just eligible? So they apply and are denied based on their illegal status. This is very confusing to say the least.

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

The thought that one could be eligible under one circumstance, and then ineligible under another, was an important theme. The following statement reflects upon issues of eligibility issues in the context of HIV positive women.

I think the issue of lateral transmission prevention is the most interesting. They are provided antiretrovirals while they are pregnant, but after the baby, it ends. I mean, the baby is eligible, but momma is not. Of course they cry foul, I mean, how can someone go from being treated to not based on this.

General Practice Physician in NGO based clinic, 22 years experience

The previous statements provide illustrations that indicate that individuals frequently seek care from government agencies, and actually receive care under certain circumstances. In general however, in cases where childbirth is not an issue, people are generally denied government assistance.

They essentially find themselves referred to every state and federal agency by hospital case managers. The case managers mean well, really, they just aren't eligible for assistance under normal circumstances. There comes a time when they give up on gaining help from the bureaucrats. There is a lot of frustration amongst our clients and is frankly the thing that drives them to seek us out.

Case Worker, 25 years experience, 10 years with African clientele

The majority of the participants communicated the feeling that the government was unlikely to help this population identify healthcare resources. This is related to the government's unwillingness to offer assistance related to their immigration related difficulties as well.

Remember, this is the government that refuses to let them stay, and will likely be the instrument of their return to the dangerous countries from which they come. The last thing they want to do is to ask the government for help, but they are ill, and they lack resources. The government helps them at times, say in childbirth, or even emergencies, or so they perceive. In the end, they tend to give up on the state, I mean, who wants to raise the ire of the very organization that prefers to deport rather than work with you.

Legal Aid Program Director, 17 years working with undocumented migrants.

This section reflected upon the profound challenges faced by undocumented migrants who require care, but lack the insurance or funds necessary to gain these services. In desperation, HIV positive undocumented then seek to gain services from the government, which again, are not available under current law. The hopeless nature of the situation is demonstrated by the fact that they are faced with substantial bills even when they gain services under emergent circumstances. Their inability to gain governmental assistance further emphasizes their lack of options.

Seeking care through non-governmental agencies, which offer support to undocumented migrants

The final step in the process of identifying healthcare organizations that provide services to this population involves seeking care from various non-governmental social

care agencies. These organizations were generally identified through peer referral. That is, friends or acquaintances within the community who are similarly challenged tend to refer them to these agencies. The following statement represents one of the participant's reflections regarding this topic.

Well yes, I mean, they see each other struggling. They tend to pass the word amongst themselves. We never have the means to help everyone, but the fact that we help some people really has them coming to us in large numbers. We are the last stop in a sense.

Case Worker, 15 years in HIV/AIDS Care, 8 years with African clientele

Other participants further expounded on the tenuous feelings that this population has in relationship to governmental agencies.

The government says no. "No you can't stay, no we can't help". They tend to build a significant distrust of the government. Within communities, particularly the churches, we get massive numbers of referrals. It is only logical. I mean, they know we are safe; we're not about to cause them a bunch of problems.

Case Worker, 25 years experience, 10 years with African clientele

The nature of relationship that individuals cultivate with these organizations in order to gain needed help was important as well.

They tend to have to pick and choose among groups. One group may offer meals or food help. Another might provide limited primary care visits or grants for doctor's appointments. Another may help them to gain medications. They really become pros at working this portion of the system, since it is their last resort.

Manager and Case Worker, 15 years in HIV/AIDS Care, 11 years solely with Africans

The end result is generally represented by a situation where, after seeking assistance in many settings, they identify a group of agencies that can offer help in different areas. This tends to be the only safety net available to them. The identification of limited free services however provides an inconsistent stream of aid.

Of course their care, to an extent falls to groups like ours. But we have very limited resources, we help yes, but at the end of the day, we patch the holes. What they need is a way to gain funding, which isn't always easy, but they really need to land an insurance policy.

Case Worker, 10 years in HIV/AIDS Care, 3 years with African clientele

NGOs, as indicated by the data, provide significant services to undocumented migrants. The data indicates, however, that NGOs are able to provide limited services that tend to be specialized. This fractionated pattern of assistance appears to result in a high degree of complexity, which too acts as a barrier to gaining comprehensive services.

Making do with available resources and striving for legal status

The initial search for appropriate healthcare services on the part of undocumented African migrants can be a very frustrating experience. The previous section has delineated the basic social processes associated with this phase of the search for services on the part of this population. The identification of services, however, is a very small part of the problem. The previous section, in addition to identifying the basic social processes associated with the search for appropriate services, also detailed the process surrounding those who seek care secondary to a life threatening acute illness. During the current

section the basic social process that follows is detailed. This process is characterized by the individual making do with their current level of access to health related services while striving to gain legal status.

This includes those individuals who were hospitalized and subsequently stabilized and discharged into the community. The previous section, additionally, detailed components of the search for funding through its description of individuals quest for and subsequent failure to gain services from state or federal agencies. Based upon the data present in the interviews, this portion of the process was classified under the section wherein individuals were attempting to identify resources since it was seen as an almost universal phase that individuals experienced.

The point at which individuals meet the realization that there are limited resources through which they may gain care is key to the understanding of healthcare access amongst undocumented African migrants. This phase of the analysis was characterized by the emergence of several subthemes within the data. These were: 1) The realization of the limits of service availability; 2) Making due with access to non-governmental programs; and 3) Ceasing to engage in health seeking activities

This is followed by a final phase which reflects the early basic social processes in a circular manner and occurs when individuals meet the realization that obtaining legal status is the most direct means of gaining consistent access to health related services.

The realization of the limits of service availability

The realization that one simply lacks the resources to gain health related services is a very difficult one for undocumented African migrants. This is especially challenging since most will have identified the presence of appropriate services during the previous

phase. This stands in stark contrast to the countries from which many of these individuals come, since there is a dire lack of services in many of these countries. During this phase, individuals are forced to face the reality that they are unlikely to gain the care that they need in order to remain healthy, as reflected upon below.

This is a terribly difficult part of my job. They beg for help, they must have help, but we often reach the point where there isn't anything else that we can do. We do offer services, but they fall far short of what they need, particularly when your talking about medication and ongoing follow up in a purely medical setting. They very quickly seem to surrender to these thoughts. It is very sad.

Social worker, cultural liaison in NGO, working with newly migrated African clients

Many individuals are scornful regarding their lack of ability to gain help, and voice this while obtaining assistance within organizations that offer them care.

I know they don't mean it, but they often blame us. I hear it all the time. "I want help, you just can't let this happen to me", "How can they do this, there must be some way", "You could have done more". I really don't blame them, I mean, I think it is inhumane. I do what I can for everyone, it just never seems to work out in the current system.

Case Worker, serving African Clientele for 7 years.

Participants often expounded on the fact that the vast majority of individuals very quickly resolve themselves to the fact that they are unlikely to gain services.

Most of them understand the word 'no' very well. They are used to this. They very quickly resign themselves to this and move on. Just surviving is tough

enough. Yes, they'd prefer to have healthcare, but taking care of their families and living is a priority. So they just move on and put it off until later.

Physician, Infectious Diseases Consultant with 14 years of experience

This statement further emphasizes this point.

My impression is that they are just happy to be here. If they aren't sick yet from the disease, they are willing to put things off while they take care of other things.

You know, getting established here, setting up a household, saving money.

Case Manager, Migrant Health Center, 13 years.

This section provides a unique reflection of the plight of undocumented African migrants. Despite their efforts to gain assistance, they continue to focus on gaining the resources necessary to survive in the US. This is consistent with earlier portions of the data. This section is unique, in that it demonstrates a degree of willingness on the part of undocumented migrants to forego medical care while simply making a life in the US for their families. Given the dire nature of circumstances associated with untreated HIV, this is profound.

Making do with access to non-governmental programs.

Following the realization that that they are not likely to receive services, individuals tend to begin a process where they make do with the medical services that are available in their effort to maintain their health. Along with working to maximize those services that are available, there are two primary basic social processes that occur during this time in the lives of these individuals. First, there are those who continue to make due with limited access through programs, primarily of a non-governmental nature, and continue to strive to gain greater access through continued efforts to gain legal status.

The basic social process cited in the previous paragraph detailed those individuals who choose to maximize the services that are available in an effort to maximize their health under what are essentially unhealthy conditions.

They reach a point where they are aware of what they can manage. I mean, they get some help from us. When they get really sick they can go to the ER. They can manage some meds for acute treatment, you know, like colds or flu or whatever. Of course they would like to be on ART, to see a doctor regularly, but they have to ration this. They are acutely aware of incurring debt.

Case Worker, 11 years in HIV/AIDS Care, 10 years with African clientele

The following statement further illustrates the nature of these interactions.

I deal with this every day. I have a number of clients who can't get ART, or even meet with someone who could prescribe it. They tend to try to take care of themselves, live cleaner, eat well, avoid high-risk behaviors. Even with this, they constantly worry about getting really sick. When they do, they go to the ER because they don't require payment of front. They really can't pay either way, but they tend to avoid going to the ER too often. Only when they are really sick you know.

Program Manager, church based HIV treatment program. 7 years experience

Participants commonly cited the emergency department as the primary source of care for many of the undocumented African immigrants who otherwise lacked healthcare access, as reflected upon below.

They certainly have access, at least the people who I care for. They go to the ER, mostly when they're really sick. They can't get help with the HIV there unless

they are dying or something. So yes, they have access, just not to the right kind of care. The bills are almost a joke. They are never paid.

General Practice Physician in NGO based clinic, 22 years experience

The data in this section reflects the undocumented migrant's continued quest for services, which are available only through non-governmental programs, which fail to offer the full range of services required to treat HIV. While they find themselves relying on these services, these agencies cannot provide a full range of medical services. Thus, undocumented migrants find themselves relying on care administered in emergency departments, where cost is extremely expensive and focuses only on only the acute needs of patients, rather than the holistic treatment of their disease, as would occur in an HIV specific care setting.

Ceasing to engage in health seeking activities

The presence of individuals, who ceased to seek healthcare services in any form, was often cited by the participants. These individuals, due to their lack of success in multiple attempts to gain health services, simply cease to try. They tend to focus, at this point in their lives, on more essential activities such as earning additional wages.

Of course they give up. They spend so much time at first trying to get care, to get help. They struggle with everything, struggle to survive. They literally give up and go into denial in many cases. It is tough to blame them, I mean, they can't do anything about it so why focus on something that you just can't change.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

There was, in fact little variation in this theme within the data. The following statement, however, further defines the nature of statements that were present in this element of the data.

There is a definite time where people reach a point when they're just exhausted with the whole issue. They know that they are infected, and they know that one day the disease will likely take their lives. They're a lot more immediate concerns though, things that will happen today. Your landlord will throw you out onto the street if you don't pay rent. You will starve if you can't buy food. So many of our clients just try and quietly survive and hope for the best with respect to their health

Physician, Infectious Diseases Consultant with 20 years of experience

While the realization that one is not likely to gain therapy without assistance might seem hopeless, it actually serves to fuel a drive towards other elements of the basic social processes presented earlier in this chapter. During this phase, undocumented African immigrants living with HIV disease meet the realization that they are not likely to gain all of the services that they require without gaining legal status. Thus, they tend to refocus at this stage with regards to their need to gain legal status. In many cases, those who had waned with regards to their efforts to gain legal status now find themselves re-energized towards this end. This element of the data was not present in the early interviews, and emerged from the interviews as theoretical saturation regarding some of the more basic constructs was realized, and the interviews refined. All of this data was derived from interviews occurring in the latter stages of data collection.

I have watched many of them simply give up and try to blend into the background. They just get the feeling, it appears, that living quietly, working and living is a good option. This is until the reality of their needs hits them. Yes, most get some help from private organizations, churches and the like, but not all of the help that they require. This really seems to get them working on gaining their green cards in a huge way.

Case Manager, Migrant Health Center, 13 years.

This section provided an explanation for the actions of undocumented African immigrants who meet the realization that they will have needs far beyond the services that they could otherwise gain, as in the statement below.

Well yes, they come from countries where being noticed by government officials can land you in a world of hurt. So they do their best most of the time to avoid making trouble for themselves. Then they get ill, and begin to see the inevitability of their condition. This is when I see them really re-engage the system and attempt to gain legal status by any means that they can manage. As they say, necessity is the mother of invention.

Program Manager for NGO that provides services to African Migrant populations, 19 years experience.

It must be noted that while this applies to individuals with chronic HIV who become immuno-compromised at some point after their arrival to the US, this phase applies only to this population. Those who arrive in the country, and who are severely immuno-compromised tend to seek care consistent with the earlier phases of the basic social processes associated with the phenomenon delineated in this chapter.

It is the people who have felt very well, who didn't see an immediate need for care, who tend to put things off. I think that's human nature, isn't it? After all, many of the people we're talking about are young. I too thought I would live forever once. So yes, they get sick, and then they really begin to push for help, which almost always means a green card. The people who are unfortunate enough to get sick right after they get here, they tend to get right to the process.

Case Worker, 25 years experience, 10 years with African clientele

Data related to individuals in immigration detention.

During data collection there were inferences made in the early interviews as to the nature of healthcare services, and lack of comprehensive services for those held in immigration detention. While much of this chapter has focused on those who have managed to remain in the country, increasing numbers of individuals are being detained and deported. Thus, it was necessary to perform additional interviews in order to ensure that theoretical saturation was reached. These interviews were performed with participants who had extensive experiences offering care within immigration detention, and thus provided a reflection on the nature of healthcare access within the detention system. The following section details the degree to which services, once sought by individuals being held within the facilities, was provided. It must be stated that, while it was not anticipated that the phenomenon of healthcare services in detention would be included as a component of this thesis, it must be presented in order to delineate a full representation of the phenomenon being studied.

As previously stated, this theme became evident in persons who had dealt indirectly with the issues surrounding individuals in immigration detention. The following statement reflects the general nature of these statements.

I have had a lot of my clients end up in immigration detention. Whether through problems of a criminal nature or simply because they had exhausted all other avenues. My biggest problem with this was the fact that the few things I had managed to get for them really weren't continued, I know this from my visits. They did have access to acute care, sort of like in the ER, but not the ongoing care that they require.

Social Worker, African Services Coordinator, 11 years experience caring for African migrants.

The following statement further illustrates factors related to immigration detention.

I have only communicated with 2 or 3 people after they went to detention. It is my impression that they weren't able to get their meds in any form. In these cases I had gotten them some meds through the drug companies indigent program, but they couldn't bring these meds in, so that was it until they were shipped home.

General Practice Physician in NGO based clinic, 22 years experience

Additional interviews were conducted in order to ensure that theoretical saturation was reached regarding issues related to immigration detention. This involved interviews of two additional individuals with direct knowledge in the area of immigration detention in the US. It must be noted that these individuals were difficult to locate, however, the information that they communicated was very consistent and did not present any divergent themes. These participants' statements focused on two major underlying

themes, which related directly to the issue of healthcare access within immigration detention. The first related directly to the term of internment in one of these centers and associated unavailability of specialist or chronic forms of care. The second related to the broad availability of episodic (sometimes referred to as urgent) care.

Yes, they do have access to care, of course. The question is what kind of care.

You must remember that now days, many of these folks are very quickly deported. In these cases, they get care if something acute happens during their stay. In most cases nothing happens. In cases where there is an appeal and someone remains for longer periods of time, we tended to do our best, but this usually did not involve any form of specialty care. Even the HIV therapies were tough, because their expense could very quickly exhaust our budget. But yes we did our best.

Social worker, cultural liaison in NGO, working with newly migrated African clients.

When further questioned regarding the availability of antiretroviral medications, this participant expounded, stating that,

In most cases this did not happen, but we did have cases during my time at the facility when we were forced to obtain these meds, as I said, with prolonged detention. In most cases though, this was complicated. For instance, in many cases people had been on meds that we just didn't have on formulary, but we did our best.

Social worker, cultural liaison in NGO, working with newly migrated African clients

The need for hospitalization was also delineated as the one case when individuals were guaranteed specialty care.

Well, there were times when we had people admitted, and yes, the hospital physicians assumed their care and ensured that they received all of the care that was required under those circumstances. In these cases, we end up absorbing the cost of the stay, so they really don't tend to be shy regarding running up the bill (laughs). But yes, we would do our best to follow the recommendations of these folks as well.

Physician, Infectious Diseases Consultant with 14 years of experience

Finally, the broad availability of acute care, and the notion that the vast majority of detainees health needs were acute in nature was addressed in the following statement

Most of these people are here briefly, and we have an infirmary that is pretty well staffed. I would say that we could take care of 95% of their problems. Now, HIV or Cancer were out, but basic problems were seen to.

Program Manager, church based HIV treatment program. 7 years experience

The following statement further reflects upon the lack of chronic care and provision of primarily acute care services.

I killed myself to care for these people. I mean, they were really wonderful people, so yes, I did what I could. Any time limited disease, infections, basic things, I could handle. I could even take care of things like diabetes or high blood pressure, it was the high cost stuff like HIV that was the real problem in most of the cases that I dealt with.

General Practice Physician in NGO based clinic, 22 years experience

The overall reflections regarding the availability of care in the immigration detention centers was one in which acute and immediately urgent care was provided. Additionally, general chronic problems were easily addressed within detention. It was the high cost care that was the primary concern in most cases.

The Theoretical Model

A goal of this study was to delineate the degree to which HIV positive undocumented African migrants are able to access health services and then provide for a comparison between the US and UK systems using a legal framework. The US phase of the study was considerably more complex than the UK phase due to one primary factor. The lack of a well-defined structure within the healthcare system, as is seen in the NHS, rendered the task of identifying the sites where undocumented migrants were gaining access to health services very difficult. This was due largely to their profound difficulties in obtaining care. Data collection in the US addressed issues of healthcare, migration and survival. The purpose of this section is to present to theoretical model which arose from the data during the course of the analysis. The model, like the one in the previous chapter, provides a reflection upon the relationship between the various major themes present within the data.

The theoretical model for the US phase of the study is presented in graphic form in Figure-2. The structure of the graphic representation is meant to communicate the relationship between health services, survival related endeavors and the efforts of migrants to continue their ability to dwell within the US. Data collection focused on issues related directly to healthcare initially, however, participants provided significant information related to survival related issues. There was a clear focus by the participants

on the efforts of newly arrived Africans to establish lives in the US. Interestingly, most participants detailed the phenomenon whereby Africans arriving in the US were predominately on student or other visitors' visas, which invariably expired, rendering the individuals lacking in legal status. The purpose of this section is to describe the theoretical framework, and to explore the relationship between the elements that comprise it.

The theoretical model is formatted such that the central concept in the model relates to healthcare. The health related columns, which represent key elements of the experiences of newly migrated Africans, flank aspects of the model. The left column represents one of the foremost elements of the data, which related to the reflection on the part of the participants related to newly migrated African's focus on survival. In the context of the US environment, this portion of the data related to the individuals efforts to maximize their earnings, establish a household and build an infrastructure for long-term financial viability. The ability of African migrants who lack legal status to work extensively appeared unique to the US context. This is illustrated by the fact that the survival related endeavors of the African's appear not only to be focused on obtaining minimal resources, but also on establishing a solid financial basis upon which to base their lives in the country. This is unique, given the HIV positive status of the subjects of this study, prioritized their drive towards financial independence.

The right column is focused on the issue of African migrant's efforts to remain in the US. The unique element of the US system, as compared to that in the UK, is the relatively short period during which individuals in the US enjoy some form of limited legal status. This is reflected in the short interval between the broken lines delineating the

period during which individuals possess and do not possess some form of legal status. Mechanisms reflecting legal status included visas issued for the purpose of visitation and for study at US colleges and universities. In order for one to remain, it is necessary that they establish grounds to remain, which is extremely difficult in the US. This results in a situation wherein the individual African migrant strives to navigate the system working towards their goal of achieving legal status. Further, the interaction between these endeavors, and their goal of establishing long term financial viability combined in such a way that African migrant's strive to achieve a legitimate lifestyle. The caveat to this social process is the fact that in the vast majority of cases, individuals fail to gain legal status. The struggle to gain legal status often fails early in this process, however, individuals tend to remain in the country and continue to live and prosper within the US due to a lack of a highly organized system to facilitate deportation.

The health related activities of HIV positive undocumented African migrants in the US are characterized by the exhaustive search for resources. The structure of the US healthcare system was a primary factor influencing the health seeking behaviors of African migrants. That is, the free market nature of the healthcare system, lends itself to a poorly defined structure. This is particularly true when one lacks the financial or functional resources necessary to fund care. While it is quite possible for these individuals to gain steady employment, they are not the sort of jobs that provide sufficient pay or insurance resources with which to fund health services. The initial process detailed in the theoretical model reflected upon the initial realization on the part of the individual of their need for health services. This realization, however, is moderated by their fear of stigma associated with others' perception of their HIV status. The two

circumstances under which care is normally sought, was associated with a major HIV related illness and with the initial realization of the need for health services based upon knowledge of stable HIV disease. Major illness in the US context resulted in emergency department visitation and subsequent hospitalization. While this is an area where access to health services is available to all, the government does not provide for the cost of these services. Thus, cases where individuals suffer such an illness are characterized by significant financial costs.

During the next phase of the theoretical model, African migrants meet with the realization of the cost and complexity associated with the healthcare system. Still, they go on to attempt at first to gather the resources with which to gain healthcare services. To an extent, they are successful with limitations associated with the purchase of antiretroviral medications. The extreme cost associated with these essential medications is a significant limiting factor in African migrants' endeavors to gain comprehensive HIV related health services. The realization of these factors tends to lead individuals to seek services through governmental agencies, which is extremely difficult given the limitation placed on service provision to individuals with questionable legal status. In the end, individuals are left to seek the limited services available through non-governmental organizations that provide care to immigrants and people living with HIV or AIDS.

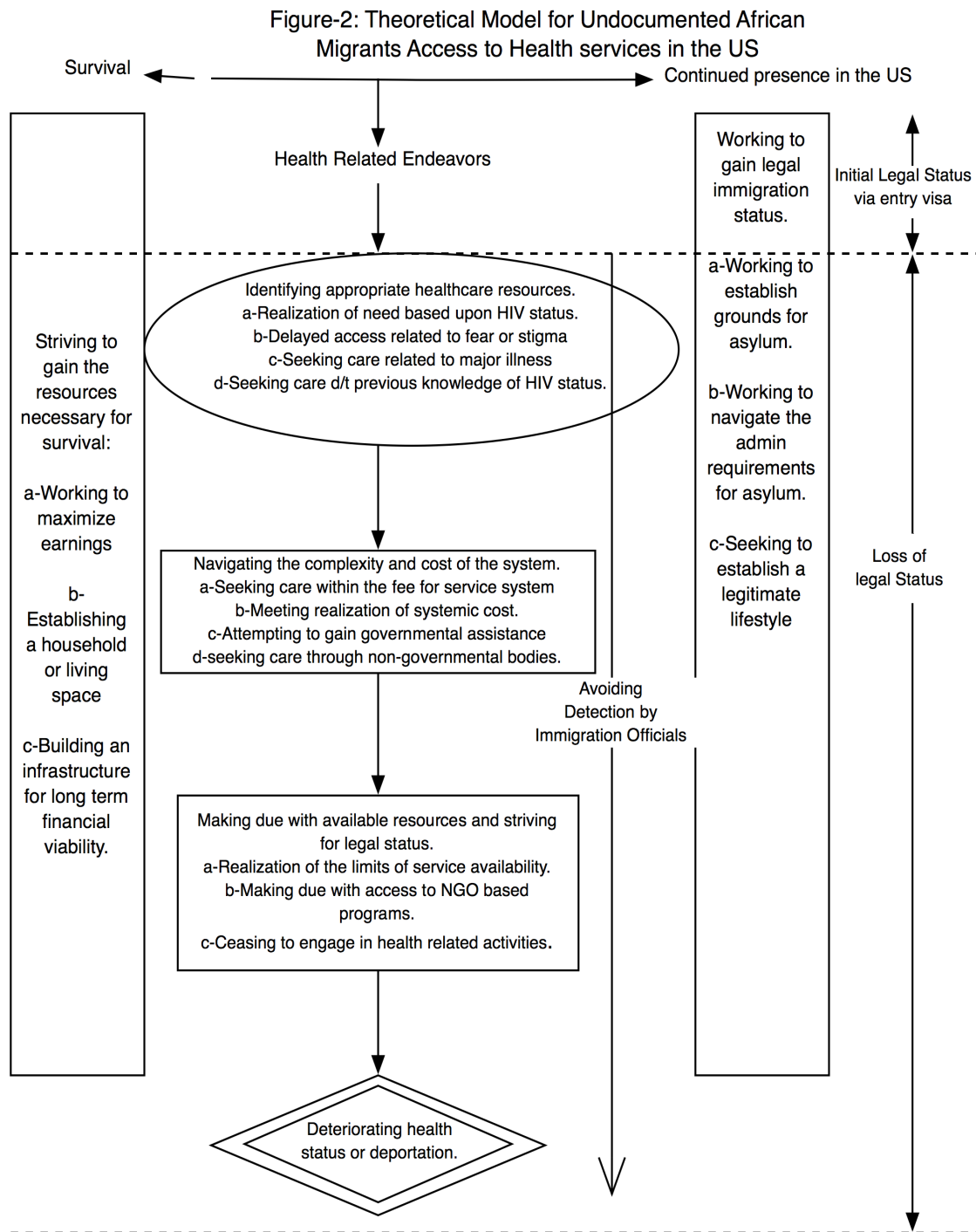
The final social process is represented by a sort of withdrawal on the part of the individual, which is based upon their realization of the limits to available resources and concurrent need to make due with access to NGO based programs that offer limited assistance. Care gained through NGOs, however limited, is often the best case, since individuals tend to engage in some level of care. The worse case scenario involves

complete withdrawal during which individuals cease to focus on health related endeavors altogether, instead focusing on issues of survival. The lack of treatment in HIV, of course, is a time limited process given the certainty of the immune system degradation associated with HIV/AIDS. Degrading health is a near certainty for many individuals. Additionally, while the participants did not report substantial numbers of cases where deportation had occurred, deportation is possible, and results in removal of the individual from modern healthcare resources.

The dotted line in the model represents the point at which service availability becomes a great difficulty. In the previous chapter, the UK based theoretical model established that the point at which service availability became impeded was following the failure of the asylum application and appeal. In the case of the US, this dotted line appears far earlier, and represents the fact that these challenges occur almost immediately on arrival to the country. In the US context, there is no guarantee of healthcare for even legal residents of the country. The limitation to healthcare access afforded legal residents renders undocumented migrants even less likely to receive services. While the law, in large part, determines the disposition of this dotted line, the lack of an extensive publicly funded health system in the US decreases the likelihood of manipulating this aspect of the theoretical model through legal reform.

This theoretical model was an initial attempt to define the relationship between variables involved in undocumented African migrants' attempts to gain healthcare services in the US. As is the case with studies of this kind, additional exploration of these phenomena are necessary in order to fully identify the relationship between the variables presented in this model. Further, it is essential that other methods, including qualitative,

quantitative and mixed methods be used to further explore these variables. The model does, however, outline the basic social processes involved in HIV positive African migrants' attempts to gain health related services.



Conclusion

The US phase of the study provided an outline of the basic social processes that underlie the activities of newly immigrated and undocumented African migrants. This included the delineation of the relationship between activities essential for life itself (IE survival, financial viability, the ability to remain in the country) and factors related to their need for care related to their HIV disease.

The first aim of the empirical phase of the study was to determine the patterns of access of African migrants living with HIV/AIDS to health services in the US. The empirical data provided a concise reflection on these patterns, which reflect a search for assistance within a very complex, resource scarce system. The result of this search, frequently, is that individuals fail to gain needed services, and are left to focus on gaining other life necessities. The second aim for the empirical phase of the study sought to examine cases where health services are gained and determine the most common modalities wherein African migrants living with HIV/AIDS gain access to health services. This element of the data reflected a fractious system, wherein individuals tend to gain emergent care when life-threatening situations arose, and otherwise make do with limited services through non-governmental agencies. This element of the data reflected heavily on the lack of access to routine care amongst African's who lack legal status. The final aim for the empirical study was to make a determination of the concordance between current regulatory instruments and actual practices in the US regarding undocumented African migrants living with HIV/AIDS endeavors to gain health services. This aim very clearly reflected upon the lack of a uniform pattern through which people are able to gain these badly needed services. While, in certain instances, services are

available, the climate is largely reflective of the limitations inherent to the law. The final chapter of the study will conclude with an exploration of the relationship between the US and UK aspects of the data.

Chapter 8 – Conclusions.

The goal of this chapter is to provide reflections on the implications of the data presented thus far. The chapter will begin with an examination of the empirical data and reflections on the application of applicable laws in the respective countries. These comparisons will provide a basis for an examination of these practices and the extant law in the context of common human rights instruments. The chapter will conclude with recommendations for reform.

A comparison of undocumented migrants healthcare access in the US and UK.

During this chapter, a variety of comparisons will be made between the UK and US components of the data. The comparisons will focus on both the data and theoretical models presented in Chapters 7 and 8.

A comparative analysis of the role of healthcare in the lives of undocumented African migrants in the UK and US.

The research upon which this thesis was based was undertaken in part due to the possibility that people in need of medical assistance have been suffering deprivation from needed healthcare resources. It is a logical assumption that individuals living with HIV/AIDS would place a significant emphasis on healthcare services. In truth, there were a variety of other issues, each inextricably linked to survival that were prioritized ahead of the need to gain HIV related services. The data in both the UK and US settings reflected a constant struggle to gain the resources necessary for survival that spanned all of the basic social processes observed in individuals so new to the respective countries where they dwell. These processes, which are detailed in Table-1 (See Chapter-6) and

Table-2 (See Chapter-7), are similar, and reflect commonalities between migrants to developed countries who lack necessary resources.

The UK data reflected upon the fact that the newly immigrated from economically underdeveloped countries are often characterized by a lack of resources at the time of immigration. This major theme within the data was characterized by the presence of three subthemes that contributed to the overall theme within the data. These included: 1) Gaining employment within the UK; 2) Working to secure adequate housing; and 3) Working to gain assistance from government funded social services agencies. Throughout data collection, the participants lacked experience with individuals who would have been considered illegal entrants to the UK. Instead, their reflections pertained primarily to individuals who had initially entered the country under legal circumstances, and who went on to fail to gain asylum.

The US phase of the study also reflected upon survival as a primary motivator in the context of the behavior of newly arrived migrants. The data reflecting upon issues of survival focused on several subthemes that arose from the data. These included the following: 1) Working to maximize earnings; 2) Establishing a household or living space; and 3) Building an infrastructure for long-term financial viability. These elements of the data reflect upon several cultural variables that appeared to be unique to Africans who were newly immigrated to the US. That is, their drive not only to survive, but to establish long term financial viability was an important factor within the data.

While the thesis was meant to focus on healthcare as a primary need of migrants, this assertion was short sighted. There is a theoretical basis for this argument that is supported by the work of Maslow and his long held theoretical assertions regarding

human behavior.⁴⁰³ The stepwise approach associated with Maslow's theoretical model reflects on the fact that individual's innate drive for survival motivates them to address needs in the following order: Physiological needs; Safety; Love and belonging; Esteem related needs; and Self Actualization.⁴⁰⁴ This theoretical model provides an important explanation for this behavior, since healthcare in most cases addressed by this thesis did not involve an immediate need. Rather, it represented a long term, albeit unavoidable, reality of life. Other needs such as food, shelter and employment constitute immediate needs with immediate associated consequences.

How does healthcare interact with the quest to gain legal status in undocumented African Migrants in the US and UK.

Africans tended to be characterized by the participants as having come from very dangerous countries in terms of the possibility of economic, political or physical harm. Thus, the issue of immigration, and ensuring that one can continue to dwell in their newfound home takes on a whole other appearance, and becomes an issue of quality of life. The UK portion of the data reflected intensely on themes related to one's ability to remain within the country. The participants reflected on the plight of newly arrived Africans initially by characterizing the means through which they entered the country, based upon the mechanisms whereby they became undocumented. Most Africans entered the country under legal grounds, for instance on a visitors visa. The majority of participants reflected upon the desire of undocumented migrants to remain in the country. This requires that these individuals receive leave to remain in the country by the Home Office. The sub-themes reflected in this element of the data included: 1) Navigating the

⁴⁰³ This was the first and seminal work of Maslow upon which all of his future work was based. Maslow, A. H. A theory of human motivation. (1943) 50(4), *Psychology Review*, 370, at p. 372

⁴⁰⁴ Ibid p. 374-390

initial asylum process; 2) Navigating the appeals process; and 3) Seeking hope and security after the failure to gain legal status on appeal. The basic social process represented by the need to gain asylum for newly immigrated Africans was the single most frequently cited factor during the study, and truly represents the overwhelming concern on the part of the participants.

The US phase of the study was similar to the UK phase in the context of the basic process of gaining the ability to legally remain within the country. During analysis of this category within the data three subcategories arose. These included: 1) Attempting to establish grounds for asylum; 2) Working to navigate the administrative requirements of the system; and 3) Seeking to establish a legitimate lifestyle in the US. The UK immigration process is characterized by a near universal ability to apply for asylum, and if unsuccessful, to make appeal in order to gain leave through the courts to remain. The US process is very different. The participants related this fact consistently, asserting that most individuals were not eligible for asylum initially, due to the way in which the State Department made determinations regarding the countries of origin that would avail one of eligibility. Thus, most individuals entering the US did so through visas that allow for limited stays, such as is in the case of visitors and students. Due to this phenomenon, the US participants reported a prominent theme which reflected upon the fact that many African's newly arrived to the US undergo significant efforts to avoid detection by immigration authorities. While there are periods during which individuals are closely tracked after the failure upon appeal in UK cases, the data failed to reflect the degree to which individuals feared, and then worked to avoid immigration officials in the US.

A comparison of access to primary care services by undocumented African migrants in the US and UK.

Immigration status is a primary determinant of one's ability to gain health related services within the UK context. The result in the UK context reflected that the asylum application became the proxy source of authorization for health services from the time of application through loss on appeal of a negative decision by the Home Office. Further, GP based practices may choose, under current regulations, to continue to offer services to undocumented migrants. The data reflected upon the fact that many GPs, based upon their long relationships with patients who have newly found lost their legal status, often continue to provide care to these individuals based upon their ethical and moral perceptions of their role as a care provider. The US system stands as a stark contrast to that seen in the UK, when it is considered in the context of primary care services. In the US, the system manifests itself in direct opposition to that seen in the UK, since immigration status plays no direct or indirect role in assuring services, even for a limited period of time. The free market system in the US makes no allowance for the care of the newly arrived. The individual African migrant must fund their primary care services. Highly limited forms of care might be available to these individuals, in the form of migrant health or federally funded community health centers; however, these programs are rare and are often geographically isolated from the cities where most Africans dwell. When one considers the financial status and relative poverty seen within the African migrant community in the US, the likelihood that they can purchase health services is unlikely.

A comparison of access to HIV specific healthcare services by undocumented African migrants.

Primary care services in the UK, according to the study's results, remain widely available to African migrants regardless of their immigration status. This appeared to be due to the dual effect of current regulation and the complex relationships developed between formerly legal immigrants and their respective GPs. HIV care in the UK context was considerably more complex. This was due in large part to the transitional period during which the data was collected. That is, prohibition of government-funded healthcare for undocumented migrants was relatively new to the NHS at the time the data was collected. This has resulted in a relatively limited administrative framework within which to enforce these elements of the current statutes. While there was little variance in reported access trends for GP services, there were considerable variations in access to HIV specific services within the GU Medicine clinics.

Undocumented migrants appeared to have regionally unique experiences in attempting to gain health services. This trend was reported by the participants, who reflected upon the trends in access according to the size of municipalities and the density of African migrants present in these regions. First, the size of municipality was often cited. In the context of size of municipality, larger areas were perceived to perform eligibility checks more often, and worked more diligently to deny services to individual Africans based upon ineligibility associated with their immigration status. This appears to be due to the availability of the infrastructure necessary to perform such eligibility checks. Further, areas that lack significant numbers of Africans tended to see relatively low numbers of undocumented individuals. The participants in the study indicated that

areas with limited numbers of Africans tended to experience a diminished financial burden of providing services, and as a result, failed to experience the urgency associated with profound financial losses due to large numbers of these migrants. Additionally, the data suggested that many of the health workers within the GU Medicine clinics were not willing to cease to provide services to long standing patients. This, much like the phenomenon seen amongst the GPs, was based largely upon moral and ethical grounds. The data reflected an inconsistent pattern of access to HIV specific healthcare services. This is significant given the presence of regulations designed to remove the ineligible from care within the GU Medicine clinics or at the time of admission to the hospital.

The data addressing the ability of undocumented African migrants in the US to gain HIV related care was significantly more static in the context of change. In truth, the situation that undocumented African migrants living with HIV/AIDS face in the US context is bleak. The data reflected several important processes that occur as individuals meet this realization including: 1) Seeking care within the traditional fee for service system; 2) Meeting the realization of cost associated with the system; 3) Attempting to gain assistance from state and federal agencies; and 4) Seeking care through non-governmental agencies which offer support to undocumented migrants. The key to each of these steps is the fact that migrant's socialization to the US system tends to include the reality of the service limitations that they will face in the context of the fee for service healthcare system. The data for the US phase of the study concluded with the realization that service limitations are a reality of the system, and that individuals are unlikely to gain services without having successfully negotiated the administrative processes inherent to the immigration system.

What are the successes and shortcomings? Instances where needed services are provided or denied to undocumented African migrants in the UK and US.

It is important to avoid the inclination to focus solely on negative events during the analysis of any social process. In fact, both the UK and US enjoy highly technologically advanced healthcare systems that supply high quality healthcare services. African migrants, conversely, come from countries with poorly developed healthcare systems characterized by profound limitations in their resources. Both the black letter and empirical components of this thesis have established one clear instance during which healthcare services are provided universally, regardless of national origin or citizenship status. This occurs in the case of emergent and life threatening illness where lack of care would result in immediate disability or death to an individual. The services available under these circumstances are clearly superior to those that an individual would receive in their country of origin.

In the case of the UK, there was a broad pattern of access to GPs, even in the case of undocumented migrants. Conversely, basic primary care services can be easily purchased within the US, although the economic status of migrants often prevents this. Africans living with HIV and AIDS are generally unable to gain consistent disease specific services. This phenomenon is regional in the UK, and nearly universal in the US. In the case of both countries, services are rendered to those at immediate threat of severe disability or death. In its current form, the system might well deny services until that point, only to see an individual become gravely ill. Then, at the point when they might die, the system will once again deliver care to the critically ill person. The system then sees to it that the person recovers, and then, in a startling turn of fate, begins anew to

deny the individual the very services that will prevent the recurrence of the initial event. While it is questionable if this pattern is counter to existing human rights law, it certainly begs the question of a program that serves to ensure the repetitive administration of highly costly critical care services, not to mention the cost in human suffering.

A functional analysis: Are undocumented migrants receiving healthcare despite the law?

The preceding sections provided reflections regarding the social processes involved in the immigration process and their relationship to one's ability to gain health related services. Primary care services, in the UK context, are freely available to undocumented migrants irrespective of the region of the country. Access to primary care services is possible in the US context, however, only in cases where the person possesses the resources to purchase healthcare. Otherwise, there are few resources available on a consistent basis within the US, save for emergency departments within hospitals, which do not provide comprehensive primary care services. There is a clear advantage for undocumented migrants in the UK when compared to those in the US where access to basic primary care services is concerned. In the absence of available financial resources, undocumented African migrants in the US cannot expect to reasonably access regularly available primary care services.

The issue of HIV specific services offered a less clear delineation of the degree to which individuals are receiving services in the respective countries. In the UK context, there are inconsistencies regarding the degree to which services within the GU Medicine clinics are available. Services tend to be more available in smaller towns, and in areas that experience a lower burden of HIV positive individuals, or that have fewer Africans. The availability of HIV related specialty services is scarce when considering

undocumented African migrants. While there are numerous clinics that would be available to these individuals, they require payment in advance for services rendered, and all medications must be purchased. Overall the data reflects that undocumented African migrants in the UK experience limitations to their ability to gain care on a regional basis. The US system is characterized by severe limitations to individual's access to HIV care. It would be difficult to characterize the overall level of access to HIV care in the UK and US as adequate; however, the UK's current level of services is clearly superior to that seen in the US.

The most clear and functional healthcare entity that offers services to the undocumented is the accident emergency department. This department is designed to offer extensive services to individuals with life threatening illness. The key factor to consider in the context of these departments is the fact that both countries possess a statutory regime that ensures that individuals with life threatening illness receive care. In both the UK and US contexts, however, the ineligible will be billed for services. This represents a dysfunctional approach, since these individuals are highly unlikely to pay for care. The ironic element of the relationship between primary care, HIV specific and emergency services is the fact that individuals are very likely to require emergency services when they cannot receive care for chronic disorders such as HIV. Thus, the limitations in HIV care in the UK and primary care and HIV services in the US significantly increase the likelihood that one will seek care in the accident emergency department. However, after recovery from acute illness these individuals may be ineligible for follow up care, thus fueling the likelihood of further life threatening exacerbations of their HIV disease.

Are non-governmental factors influencing undocumented migrant's health seeking behaviors: The Interaction between fear and perceived stigma?

Undocumented African migrants, according to the literature reviewed and the results of the empirical inquiry undertaken in this thesis are a group with challenges in many areas, not the least of which is the fear associated with the stigma that is often associated with HIV/AIDS. Stigma, as a non-governmental variable influencing health seeking behaviors was present across the data. Stigma represents a significant challenge to efforts aimed at reducing the proliferation and effects associated with the HIV/AIDS pandemic. In effect, stigma in the context of HIV/AIDS is a social and behavioral manifestation of fear associated with complex factors such as fear of contagion and judgment regarding the lifestyle choices of those afflicted with the disease. Stigma represents a significant challenge to the individual well being of persons living with HIV/AIDS.

Goffman, in one of the earliest studies of health related stigma, identified sources of stigma such as physical deformity and character-related factors as significant sources of stigma.⁴⁰⁵ This early work provided the basis for many of the current works on stigma in people living with HIV/AIDS.⁴⁰⁶ Researchers have focused on attitudes towards people living with HIV/AIDS in the general public, experiences of people living with

⁴⁰⁵ Goffman E. *Stigma: notes on the management of spoiled identity*. (Prentice Hall, 1963) at p. 12-23

⁴⁰⁶ Herek GM, Mitnick L, Burris S, and Chesney M. "Workshop report: AIDS and stigma: a conceptual framework and research agenda." (1998) 13, *AIDS Public Policy Journal*, 36; Malcom A, Aggleton P, Bronfman M, Galvão J, Mane P, and Verral J. "HIV-related stigmatization and discrimination: its forms and contexts." (1998) 8, *Critical Public Health*. 347 at p. 348; Snyder M, Omoto AM, and Crain AL. "Punished for their good deeds: stigmatization of AIDS volunteers." (1999) 42, *American Journal of Behavioral Science*. 1175 at p. 1179

HIV/AIDS under various social circumstances, and concerns about interactions with people living with HIV/AIDS. Prejudice toward people living with HIV/AIDS among lay people was described by multiple researchers in the 1980s and 1990s, and later studies confirmed that individuals at risk for HIV/AIDS or living with the disease often delay or fail to access care to avoid judgment and rejection by providers, families, and the general public.⁴⁰⁷ One of the most significant studies in recent times revealed that stigma towards those living with HIV/AIDS was significantly correlated with lack of social support, poor physical and mental health, and low income status.⁴⁰⁸

Early research in the healthcare settings indicated important correlations between HIV/AIDS and secondary individual variables.⁴⁰⁹ Factors considered to be personal choices (eg homosexuality) by individuals resulted in negative views of those living with HIV/AIDS. Subsequent studies have established the effect of individual reflections about those living with HIV/AIDS's personal characteristics and behaviors on attitudes towards them.⁴¹⁰

Generally speaking, stigma related to HIV/AIDS is well documented. As is the case with most socio-cultural variables, the literature has documented unique patterns of stigma specific to African Cultures. A common pattern observed in

⁴⁰⁷ Taylor B. "HIV, stigma, and health: integration of theoretical concepts and the lived experiences of individuals." (2001) 35, *Journal of Advanced Nursing*, 792 at p. 795; Kaplan AH, Scheyett A, and Golin CE. HIV and stigma: analysis and research program. (2005) 2, *Current HIV/AIDS Reports*, 184 at p. 187; Ogden J, and Nyblade L. *Common at its core: HIV-related stigma across contexts*. (International Center for Research on Women, 2005)

⁴⁰⁸ Logie C, Gadalla TM. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. (2009) 21 *AIDS Care*, 742 at p. 752-753

⁴⁰⁹ Harrison M, Fusilier MR, Worley JK. Development of a measure of nurses' AIDS attitudes and conservative views (1994) 74, *Psychology Reports* 1043

⁴¹⁰ Hayter M. Is non-judgemental care possible in the context of nurses' attitudes to patients' sexuality? (1996) 24, *Journal of Advanced Nursing*. 662. Chan KY, Stoové MA, Sringernyuang L, Reidpath DD. Stigmatization of AIDS patients: disentangling Thai nursing students' attitudes towards HIV/AIDS, drug use, and commercial sex. (2008) 12, *AIDS Behavior*. 146

African cultures involves people living with HIV/AIDS often being subjected to verbal abuse that often contributes to negative self-perception.⁴¹¹ Verbal abuse and ridicule are common, however, patterns of stigma in Africa have been shown to range from active modalities, for instance resulting in unemployment to physical abuse and gender-based violence.⁴¹² In the context of this thesis, feelings of stigma and the social challenges that spring from stigmatizing behaviors on the part of others represent very real threats to individuals, and thus, are likely to influence the behaviors of Africans even after migration.

The effects of stigma are so profound in African culture that secrecy, even by family members of those who are infected or who have died due to HIV, is a common means of avoiding public ridicule or stigmatization.⁴¹³ Hiding or avoiding activities that result in the possibility of discovery of one's HIV status has been shown to be the most common stigma associated behavior in Africans.⁴¹⁴ Stigma and perceived stigma continue to exert extreme social pressures, even in the case of children orphaned by HIV/AIDS.⁴¹⁵ The overall effects of stigma on African communities result in a set of behaviors designed to avoid disclosure of discovery of

⁴¹¹ Nattabi, B., Li, J., Thompson, S., Orach, C., Earnest, J. Factors associated with perceived stigma among people living with HIV/AIDS in Uganda. (2011) 23, *AIDS Education and Prevention*, 193.

⁴¹² Cloete, A., Strebel, A., Simbayi, L., van Wyk, B., Henda, N., and Ngeketo, A. "Challenges faced by people living with HIV/AIDS in Cape Town, South Africa: Issues for group risk reduction interventions." 2010, *AIDS Research and Treatment*.
<http://www.hindawi.com/journals/art/2010/420270/> Accessed 2 Sept 2011.

⁴¹³ Thupayagle-Tshweneagae, G., and Benedict, S. The burden of secrecy among South African Adolescents orphaned by HIV and AIDS. (2011) 32, *Issues in Mental Health Nursing*, 355 at p. 358-360

⁴¹⁴ Phillips, K., Moneyham, L., Thomas, S., Gunther, M., and Vyavaharkar, M. Social context of rural women with HIV/AIDS. (2011) 32, *Issues in Mental Health Nursing*, 374 at p. 377-378

⁴¹⁵ Cluver, L., Gardner, F., and Operario, D. Effects of stigma on the mental health of adolescents orphaned by AIDS. (2008) 42, *Journal of Adolescent Health*, 410

one's HIV status. Perhaps most concerning is the fact that stigma often influences poor adherence to HIV therapies in an effort to avoid subjecting oneself to stigma, for instance in cases where others discover the medications and thus, become aware of the diagnosis of HIV/AIDS.⁴¹⁶

The data presented in chapters 6 and 7 reflected on stigma. In fact, both the UK and US data reflects on stigma in a way consistent with the literature presented earlier in this section. The data from both the UK and the US reflects that the primary pattern of behavior observed by the participants includes activities designed to avoid public ridicule or discovery of one's HIV status. While stigma was not one of the primary variables investigated in the study, one of the UK examples puts into context the prevailing social realities of HIV in the UK. This case involves the association between perceived sin, HIV and faith in determining one's recovery from the disease. NGO workers cited this pattern as a prime example of the effects of stigma in the UK on African migrant's ability to engage in treatment and gain social assistance. While governmental variables play a key role in influencing the ability to seek treatment, the association of social variables such as stigma, according to the data, presents a significant challenge to health seeking behaviors in undocumented African migrants.

Further Consideration of Non-Governmental Factors: The Relationship Between Fear, Poverty and the Effect Medical Care and Public Health.

The role that poverty played in the lives of undocumented migrants was one of the key factors that appeared to influence the actions of individual migrants. In

⁴¹⁶ Izugbara, C. and Wekesa, E. Beliefs and Practices about antiretroviral medication: A study of poor urban Kenyans living with HIV/AIDS. (2011) 10, *Sociology of Health and Illness*. 1457 at p. 1162

chapters 3 and 4 literature was reviewed that indicated the profound nature of the effect resulting from poverty. The UK literature indicated a lack of access to basic services associated with poverty.⁴¹⁷ Poverty in African migrants was shown to stem, in large part, from their difficulties in gaining employment,⁴¹⁸ or maintaining housing.⁴¹⁹ There was a pervasive reflection of the effect of poverty on the lives of undocumented African migrants present in the literature that indicated the overwhelming drive to maintain an adequate standard of living.⁴²⁰ The empirical data, detailed in Chapter 7, reflected strongly regarding the focus that undocumented African migrants in the UK have regarding survival, due to their experience of poverty. The UK data as well, provided a profound realization that poverty and fear regarding survival was prioritized above health related needs. Poverty in the context of this study was directly linked to asylum status. Thus, fear regarding the possibility of failure of the asylum package became the key factor determining if one could gain the means of escaping poverty. The findings of the UK portion of the empirical data were consistent with literature indicating the profound influence of poverty.

In the US context socioeconomic factors have historically represented important variables that influence the likelihood that individuals will seek healthcare.⁴²¹ The literature indicated that African migrants manifest even lower levels of access to basic

⁴¹⁷ Lewis, H. *Still Destitute: A Worsening Problem for Refused Asylum Seekers*. (Joseph Rowntree Charitable Trust, 2009) at p. 23-35

⁴¹⁸ Doyle, L. *"I hate being idle": Wasted skills and enforced dependence among Zimbabwean asylum seekers in the UK*. (Refugee Council, 2008)

⁴¹⁹ Refugee Council. *Hungry and homeless: The impact of the withdrawal of state support on asylum seekers, refugee communities and the voluntary sector*. (Refugee Council, 2004) at p. 11-19

⁴²⁰ Chauvin, P., Parizot, I., and Simonnot, N. *Access to healthcare for undocumented migrants. In 11 European Countries*. (Medicins Du Monde, 2008)

⁴²¹ Derose, K., Escarce, J., and Lurie, N. Immigrants and healthcare: Sources of vulnerability. (2007) 26(5), *Health Affairs*, 1258 at p. 1261

services and far lower earnings than their US borne (*African American*) counterparts.⁴²²

These inequalities are significant in that undocumented migrants to the US suffer higher rates of socioeconomic deprivation even when compared to African migrants to other developed countries.⁴²³ The empirical data from the US phase of the study demonstrated the dual effects of poverty and fear on the ability to gain necessary resources. When compared to the UK data, the most significant difference stems from the high degree of difficulty in gaining the ability to apply for and gain asylum in the US. Thus, survival in the US context was not linked to asylum status in the way that it was in the UK. In the US context, this introduced an additional fear regarding the possibility of scrutiny from government officials and law enforcement. The fear of government scrutiny paralleled the effects of poverty, both of which decreased individual migrant's focus on their HIV/AIDS status.

The joint consideration of the UK and US literature, and the empirical data reflecting upon the experiences of undocumented migrants to these countries, provides a cogent and nearly parallel representation of the interaction between poverty and fear in this population. While the focus of this thesis is on healthcare, the effect of these fears is notable. That is, the focus on survival clearly diverts individuals from gaining health services. The result of this focus, as detailed in chapter 4 are delays in seeking health services. These delays invariably result in later presentation for disease management, and

⁴²² Siddiqi, A., Zuberi, D., and Nguyen, Q. The role of health insurance in explaining immigrant versus non-immigrant disparities in access to health care: Comparing the United States to Canada. (2009) 69, *Social Science and Medicine*, 1452 at p. 1158-1159.

⁴²³ Siddiqi, A., and Nguyen, Q. A cross-sectional comparative perspective on racial inequalities in health: The USA versus Canada. (2010) 64, *Journal of Epidemiology and Community Health*, 29 at p. 34-35

a higher acuity on presentation.⁴²⁴ In simple terms, the fears linked to poverty divert individuals from gaining health services, thus speeding the progression of HIV/AIDS. As discussed earlier in the thesis, public health related concerns hinge, in part, on the control of communicable disease. In essence, fear, poverty and the resultant delays in care increase the likelihood of poor disease outcomes. From a public health perspective, individuals who fail to gain treatment are at a greater risk of transmitting HIV, further exacerbating the effects of the HIV epidemic on societies.⁴²⁵

The professional standards issue: Do healthcare workers have a moral imperative to provide care?

The medical professions have enjoyed a long history related to the beneficence associated with their caring role. As is the case with many professions, professional codes underlie the behaviors expected of its members. While the oath finds its origins in ancient Greek culture, it has served as the basis for current medical professional standards which underlay the principle of ‘doing no harm’.⁴²⁶ The issue of harm is central to medical practice on an international basis, and has continued to guide professional bodies within medicine in the context of the duty to perform humanely and with regard for the health of individual persons without regard for their social standing.⁴²⁷ The oath is associated with a series of ethical obligations that include respect for the autonomy of the individual, respect for the individual’s right to privacy and the moral responsibility of the medical professional to behave justly and without the intent to harm those under their

⁴²⁴ Acuity refers to a degree of illness. In this context, the term refers to the likelihood that individuals will present in the advanced phase of immune system degradation.

⁴²⁵ Wilson, D., Law, M. G., Grulich, A. E., Cooper, D. A. and Kaldor, J. Relationship between HIV viral load and infectiousness: A model-based approach. (2008) 372, *Lancet*, 314 at p. 316

⁴²⁶ Girdner, P. A virtue ethics approach to moral dilemmas in medicine. (2003), 29, *Journal of Medical Ethics*, 297 at p. 299-300

⁴²⁷ Hurwitz, B., and Richardson, R. Swearing to care: The resurgence in medical oaths. (1997) 315, *BMJ*, 1671 at p. 1672

care.⁴²⁸ While there is considerable literature in this area, the aforementioned passages detail the very strong moral imperative associated with the medical professions.

The issue of moral duty is pertinent to the current study, in particular, due to the actions of medical professionals recorded within the empirical data. While this element of the data was not seen amongst the US participants, it was prominent amongst the UK participants. That is, despite their awareness of the law, they continued to provide care to clients based upon their established doctor-patient relationship. This phenomenon appeared prominently in the data reflecting upon the GU medicine clinics, where consultants provide care to people living with HIV/AIDS. Multiple instances arose in the data detailing circumstances where care was provided to individuals after the full realization that the patient in question had lost on appeal and thus found themselves undocumented migrants. This was due to moral duty (eg the Hippocratic Oath), and was in full defiance of the law.

This element of the empirical data reflects upon one of the major difficulties associated with the use of the law as an instrument designed to deny care to individuals. While the law can clearly delineate the boundaries for supplying care in a government run healthcare system, other variables play a prominent role. This leaves to question the degree to which absolute denials of care might be enforced by such laws. One might question the degree to which medical professionals within the healthcare system are influenced by such moral issues. The data reflected on this question, through the realization that discovery by hospital administrators at the time of hospitalization, often resulted in removal from the system. That is, while HIV consultants were able to continue

⁴²⁸ Jotterand, F. The Hippocratic oath and contemporary medicine: Dialectic between past ideals and present reality. *Journal of Medicine and Philosophy*, 2005, 30, 107-128.

administering care after the loss of the individual's asylum appeal, hospital administrators generally acted to designate individuals as ineligible, thus removing the ability of medical personnel to continue to offer them care. This offers support to the notion that medical professionals have specific moral obligations that influence their view of the law, while administrators are more likely to act in a way counter to this. These moral obligations (ie the Hippocratic Oath) heavily influence their observance and execution of regulations designed to limit their provision of care to undocumented migrants.

Is there direct harm to individual migrants due to the current approach in the UK and US?

The issue of medical care for undocumented migrants in the UK and US presents two very different circumstances. In the context of the UK, the general pattern involves a period of varied duration when individuals have full access to HIV care offered in specialty clinics within the NHS (ie GU Medicine Clinics). This period ends after loss on appeal of the asylum application, rendering the individual without legal access to care. Healthcare practitioners, however, were shown to continue providing care in many cases, even under these circumstances. Many individuals eventually lose access to care, and thus, cease to take their HIV medications. The US system is different, in that there is no uniform method of gaining treatment from a consistent source. This was observed in both the black letter and empirical aspects of the study, with the caveat that individuals frequently gained limited care through non-governmental charity organizations. Thus, in the US context, most undocumented migrants find themselves incapable of gaining care. These two circumstances would appear to indicate a degree of superiority in the case of the UK system, wherein individuals have access to some care. An examination regarding the science surrounding HIV therapies, however, is necessary to fully explore this issue.

HIV is treated with antiretroviral medications. These medications inhibit vital elements of the reproductive cycle of the virus, thus limiting the proliferation of the virus in the body's immunologic tissues. The primary factor that differentiates HIV antiretroviral medication from other antimicrobial medications is the rapidity through which viral resistance can develop.⁴²⁹ Resistance can develop rapidly rendering the individual's strain resistant not only to the medication that they are currently taking, but to other medications with similar composition.⁴³⁰ The process involves a given person's strain of the virus developing resistance to antiretroviral therapies, thus rendering them ineffective. Resistance can develop in as few as 2-3 missed doses.⁴³¹ This pattern of resistance, when accompanied by the cessation of therapy due to loss of healthcare access, creates circumstances wherein individuals are very likely to develop resistance.⁴³² The end result of resistance is a situation wherein a person suffering HIV will no longer respond to key medications, thus limiting treatment options and speeding immune system degradation.

⁴²⁹ Parienti, J., Massari, V., Descamps, D., Vabret, A., Bouvet, E., Larouze, B., and Verdon, R. Predictors of virologic failure and resistance in HIV infected patients treated with Nevirapine or Efavirenz-based antiretroviral therapy. (2004) 39, *Clinical Infectious Diseases*, 1311 at p. 1315-1316

⁴³⁰ Wang J., Zhang G., Bambara R. A., Li D., Liang H., Wu H., Smith H. M., Lowe N. R., Demeter L. M., Dykes C. Non-nucleoside Reverse Transcriptase Inhibitor (NNRTI)-resistant Virus is Stimulated by Efavirenz (EFV) During Early Stages of Infection. *Journal of Virology*, 2011, 10, epub ahead of print.

⁴³¹ Izopet, J., Massip, P., Souyris, C., Sandres, K., Puissant, B., Obadia, M., Pasquier, C., Bonnet, E., Marchou, B., and Puel, J. Shift in HIV resistance genotype after treatment interruption and short-term antiviral effect following a new salvage regimen. (2000) 14, *AIDS*, 2247; Verhofstede, C., Van Wanzeele, F., Van Der Gucht, B., De Cabooter, N., and Plum, J. Interruption of reverse transcriptase inhibitors or a switch from reverse transcriptase inhibitors to protease inhibitors resulted in a fast reappearance of virus strains with reverse transcriptase inhibitor sensitive genotype. (1999) 13, *AIDS*, 2541; Oyugi, J., Byakika-Tusiime, J., Ragland, K., Laeyendecker, O., Mugerwa, R., Kityo, C., Mugenyi, P., Quinn, T., and Bangsberg, D. Treatment interruptions predict resistance in HIV-Positive individuals purchasing fixed-dose combination antiretroviral therapy in Kampala Uganda. (2007) 21, *AIDS*, 965

⁴³² Ibid

The legal literature, currently, does not reflect upon the association of treatment interruption in HIV as a violation of human rights. However, based upon the findings within this thesis, I assert that this is an emerging human rights concern. Given the high probability of resistance after therapeutic interruptions, it is clear that once an individual begins therapy, they must continue in order to remain well, and will be harmed if therapy is ceased. Thus, policies that result in interrupted therapy do direct harm to individuals. In essence, the US system, where therapies are generally unavailable, may be safer than a system that often guarantees that an individual will suffer an interruption to therapy. Further, this is a violation of common human rights principles, for instance Article 3 of the European Convention on Human Rights with accompanying enforceability associated with the Human Rights Act that forbid cruel or inhuman treatment. Treatment interruption also violates the International Covenant on Economic, Social and Cultural Rights that asserts the right to optimal health and health care. Certainly a practice that speeds an individual's death violates the Article 3 prohibitions in the European Convention on Human Rights. The US system, conversely, treats undocumented migrants in a manner similar to citizens, and thus, does not violate their rights in this manner, as therapy is seldom initiated in the first place. The US system does not induce resistance through therapeutic interruption. The failure to make therapy available places individuals at significant risk and leads to suffering by people who cannot gain care.

What are the State's obligations regarding the provision of care to HIV positive undocumented migrants?

The issue of state's obligations is complex in the context of healthcare. State's obligations are most effectively examined in the context of international human rights treaties, which frequently make reference to health related issues. Thus, one would have

to examine the obligations incurred by the respective countries as they relate to instruments that designate specific obligations in this area. In the case of the UK, there is a clear pattern of enjoining the human rights movement. This includes their full participation in The Universal Declaration of Human Rights, The International Covenant Economic, Social and Cultural Rights, The International Covenant for the Elimination of All Forms of Racial Discrimination, The Convention of the Elimination of All Forms of Discrimination Against Women, and The Convention on the Rights of the Child. Perhaps most significant is the Human Rights Act, established in 1998, which established legal grounds for the implementation of the European Convention on Human rights under UK law. The case law, for instance, as seen in *D v United Kingdom* and *N v United Kingdom*, further delineate parameters for enforceability of the European Convention on Human Rights. All told, there is a significant positive obligation undertaken by the government of the UK to provide health services, especially under life threatening circumstances. The obligations that relate to treaties enjoined by the UK that specifically identify rights to health care are less clear, for instance, as is the case under Article 12 of the International Covenant Economic, Social and Cultural Rights. Enjoining such treaties, as well, established positive obligations on the part of the government, even if it is the case that there has been a historical pattern of disregard and lack of enforceability in many common human rights instruments.

In the US context, the process differs slightly. While the President may sign treaties, the US Senate must ratify them.⁴³³ The US have signed all of the aforementioned human rights instruments, but have failed to ratify The International Covenant Economic, Social and Cultural Rights, The Convention of the Elimination of

⁴³³ US Constitution, Articles I and II.

All Forms of Discrimination Against Women and The Convention on the Rights of the Child. The US, fully enjoined the Universal Declaration of Human Rights that reflects the provisions of the International Covenant Economic, Social and Cultural Rights. There is a less clear pattern of legislation in the US context that establishes positive obligations to provide health services even in the case of citizens. Statutory law in the US, does, however, provide an enforceable regime under which care is assured to individuals under life threatening circumstances.⁴³⁴ Notably, US Supreme Court precedent has established the provision of healthcare to prisoners as essential based upon the legal rationale that refusal to do so would constitute cruel and inhumane punishment.⁴³⁵ While this rationale is extended to prisoners, it is not afforded other inhabitants of the country, citizen and non-citizen alike.

Both the UK and US have committed to provisions directly related to health in the context of the aforementioned human rights instruments.⁴³⁶ While many rights are delineated in these, it is clear that all human rights, to a degree, are interrelated.⁴³⁷ In essence, these legal instruments require that states that fully enjoin them offer a minimal level of health protection, essential healthcare and basic human needs.⁴³⁸ This, in essence represents a requirement that states attempt to remove barriers for the achievement of health, including health services sufficient to provide for the health needs of the people living within a given nation. Difficulty arises however, when one considers that every nation does not have an identical capacity to provide adequate services to all persons, and

⁴³⁴ United States Code, 42, 1395dd (Emergency Medical Treatment and Active Labor Act)

⁴³⁵ Article 8, United States Constitution (1787).

⁴³⁶ Kinney, E. The international human right to health: What does this mean for our nation and the world. (2001) 34, *Indiana Law Review*, 1457 at p. 1457-1458

⁴³⁷ Ibid at p. 1460

⁴³⁸ Hendricks, A. The right to health and international jurisprudence. (1998) 5, *European Journal of Health Law*, 389 at p. 401-405

thus often fall short of this goal.⁴³⁹ Thus, the requirement to sustain some level of progress, taking into consideration a nation's resources and capabilities, is an essential component of this obligation.⁴⁴⁰ This mechanism allows individual nations to pace their progress in terms of instruments such as the International Covenant Economic, Social and Cultural Rights internally, and thus, international enforcement of these treaties has a very poor prospect of materializing.⁴⁴¹ The obligations undertaken by the UK have enforceable components, as is the case with the Human Rights Act, and positive obligations in the forms of treaties with less inherent enforceability. The US conversely has entered into few treaties that would denote a positive obligation to provide health services even in the case of the country's citizens. In the case of the UK engagement in human rights instruments, there remains a clear legal moral obligation associated with entrance into such treaties.⁴⁴² The US has engaged these human rights instruments in a limited manner, thus incurring moral obligations with highly limited associated legal enforceability.⁴⁴³

These issues are clearer when one considers the possibility of harm to an individual based upon a policy or set of policies. That is, harm to an individual is a more clearly understood and enforced human right, especially in the context of the body of human rights law.⁴⁴⁴ During the earlier sections, this obligation was explored in the case

⁴³⁹ Ibid

⁴⁴⁰ Smith, G. Human rights and bioethics: Formulating a universal right to health, health care or health protection? (2005) 38, *The Vanderbilt Journal of Transnational Law*, 1295 at p. 1319-1320

⁴⁴¹ Ibid at p. 1317

⁴⁴² Ruger, J. Ethics and governance of global health inequalities. (2006) 60, *Journal of Epidemiology and Community Health*, 998 at p. 1000

⁴⁴³ Ibid at p. 1002-1004

⁴⁴⁴ Toebes, B. Towards an Improved Understanding of the International Human Right to Health. (1999) 21, *Human Rights Quarterly*, 661 at p. 678-679

of antiretroviral therapies and the detrimental effects of treatment interruption. While this element has not been addressed directly in UK or US courts, access to medications has been found enforceable in the courts of several countries.⁴⁴⁵ This has been the case in Latin American courts, where medicines that were of a life preserving nature (as it the case with HIV antiretrovirals), were considered.⁴⁴⁶ The interaction between harm, and the provision of life saving care is key in the context of state's obligation to provide for the health of the people dwelling within a particular country that has fully engaged human rights instruments.

When considering state's obligations more broadly, an interesting picture arises. Both the UK and US are at the forefront of developed nations. Thus, elements of the law designed to facilitate developing nations do not fully apply to them. That is, both countries have a significantly well-developed healthcare capability, and thus, do not have the resource limitations of developing nations. The UK, in supplying universal health coverage that includes asylum seekers, has fulfilled many of the provisions represented by their human rights obligations. The UK, however, has failed in some of their obligations, such as was seen in the case of *D v United Kingdom*. The continued prohibition against providing health services to undocumented migrants, while likely unenforceable, is inconsistent with human rights law enjoined by the UK. The US, conversely, does not even provide universal health services to its citizens, and thus, has failed to meet the full range of obligations associated with the limited human rights instruments that they are party to, with the exception of programs that provide care to

⁴⁴⁵ Hogerzeil, H., Samson, M., Casanovas, J., and Rahmani-Ocora, L. Is access to essential medicines as part of the fulfillment of the right to health enforceable in the courts. (2006) 368, *Lancet*, 305 at p. 307

⁴⁴⁶ *Ibid* at p. 310

specific populations such as the poor and the elderly and life saving care provided for under Emergency Medicine Licensure and Treatment Act.

What is the legal point at which lifesaving care may be withdrawn?

The previous sections detailed the degree to which therapeutic cessation in the context of HIV therapy is harmful. While there is not a current body of law reflecting upon the withdrawal of HIV therapies, there is a substantial body of well-established law related to the withdrawal of care in other contexts. The harm associated with the withdrawal of care in the case of persons living with HIV/AIDS is clear, however, at what point does the law authorize the withdrawal of care in the case of other diseases. That is, when is the withdrawal of care legally defensible?

This is an issue that has been addressed in both the UK and US courts. While this section will address the issue of withdrawal of care, it must be stated that an exhaustive review of the literature in this area is outside of the purview of this thesis. The legal precedents in this area, however, offer a keen insight into the legal thinking that has guided these decisions. The courts have generally been forced to address end of life care in the context of terminal illness. That is, in determining when care, if provided, would represent a futile act in situations where medical practitioners deem that there is no realistic expectation of recovery.

The ability to withdraw care in a terminally ill person in the UK, including the discontinuation of artificial nutrition and hydration, requires the authorization of a High Court.⁴⁴⁷ The court order arising from such an action requires that one meet the burden of the *Best Interests Test*, wherein such withdrawal of care is clearly diminishing the

⁴⁴⁷ *Law Hospital NHS Trust v Lord Advocate* (1996) S.L.T. 848.

ongoing suffering of a person found to be in an irreversible terminal health state.⁴⁴⁸ The more recent case of Burke versus the General Medical Council further supported this aspect of the law and provided important clarification on the part of persons who are both competent and who have a very poor prognosis.⁴⁴⁹ The case of Burke involved a man with a degenerative brain disease which would eventually progress to the point that Mr. Burke would become unresponsive to external stimuli, but would likely render him aware of physical sensations like hunger or pain. Mr. Burke contended that current applications of the law were inhumane, due to the ability of medical officials and family members to withdraw care, including artificial feeding and hydration. Mr. Burke's concerns stemmed from his fear that he would remain completely aware that he was, in effect, starving to death. Mr. Burke contended that he preferred a death through the processes inherent to his neurological disease, and requested that he continue to receive water and nutrition in the case that he became incapacitated at some future point in time. While the courts initially upheld the right of the medical staff to withdraw care in such cases, the High Court decision eventually found that Mr. Burke was within his right to require the medical team to provide such care. This raised serious questions within the NHS, in that this opened up the prospect of patients demanding and receiving care even when such care is against the judgment of the medical team.⁴⁵⁰ This, in effect represents a positive obligation for the government to provide care in such situations.

The US system is similar to that of the UK in the context of withdrawal of care. The most significant early case in the US addressing this issue was the case of Quinlan,

⁴⁴⁸ *Airedale NHS Trust v Bland* (1993). A.C. 789 at 805.

⁴⁴⁹ *Burke v. General Medical Council* (2005). E.W.C.A. Civ. 1003.

⁴⁵⁰ Bell, D. The legal framework for end of life care: A United Kingdom Perspective. (2007) 33, *Intensive Care Medicine*, 158 at p. 160

wherein the court found that a woman who was terminally ill and who was in a persistently vegetative state could be removed from life preserving artificial support on the consent of her parents.⁴⁵¹ In a later case, *Cruzan versus Missouri Department of Health*, the courts found that ‘clear and convincing evidence of a patients wishes’ was required prior to withdrawing care.⁴⁵² In *Cruzan*, the courts findings effectively limited the authority of surrogates in cases where care was to be withdrawn, placing a greater burden medical care providers to determine the wishes of the individual prior to altering their care. This served as one of the major factors in the advent of living wills as a mechanism to determine one’s end of life wishes in the US. There have been no cases to date, in the US context, that serve to allow others to withdraw the care of an alert and legally competent patient.⁴⁵³

The laws of both the UK and the US have in common the inability of healthcare authorities to discontinue care against a person’s wishes in cases where a person is fully conscious and competent to make their own medical decisions. This element of the law demands examination when considering the possibility of withdrawing HIV medications based upon the loss of an immigration appeal. In the context of this thesis, earlier sections established the life preserving nature of these medications and the harm associated with their cessation, even in cases where the medicines might be made available at a later date. While this supposition has not been tested in the courts, one could logically reason that UK or US courts might protect an individual in hospital with advanced HIV/AIDS in a case where physicians sought to cease treatment based upon the incurable nature of the

⁴⁵¹ *Re Quinlan*, 70 N.J. 10, 355 (1976)

⁴⁵² *Cruzan v. Missouri Dept of Health* 497, US, 261 (1990).

⁴⁵³ Meisel A., Snyder, L., and Quill, T. Seven legal barriers to end of life care. (2000) 284, *JAMA*, 2495 at p. 2500-2501

disease. In effect, the body of case law in both countries concerning the withdrawal of care in such cases offers support for human rights based arguments hinging upon the harm associated with the act of ceasing to provide medical therapies to someone with a reasonable likelihood of continued life.

Is the current situation satisfactory?

The theoretical models presented in Chapters 6 and 7 had many similarities, many of which are based upon the common needs of displaced or migrating persons regardless of the country in which they dwell. The interaction between their experiences and the law, however, is different. This difference was best illustrated by the dotted line in the theoretical models that denotes the point at which one becomes ‘undocumented’, hence losing legal access to services. The law itself plays the primary role in determining when or if this event occurs. This fact is of vital importance to this thesis, since the loss of legal status results indirectly in harm to individuals in a way which is counter to various human rights instruments which establish an adequate standard of living, well being, and adequate healthcare as basic components of life.⁴⁵⁴ In the case of the UK, the case for violation of these stipulations is clear, since medications are provided to individuals suffering HIV/AIDS and then are promptly withdrawn resulting in a high likelihood of short-term harm, resistance to future medications and eventual deterioration in their health status. The US system fails at every level in that individuals are very likely to remain untreated throughout their time in the country. Both countries act, through

⁴⁵⁴ United Nations. Universal declaration of Human Rights. Resolution 217 A (III), 1948.

respective legislation, to offer care only during the final phase of health compromise, and then cease to provide that care promptly after stabilization.⁴⁵⁵

The theoretical application of law is generally a far simpler exercise than the actual application of such laws. Generally speaking, undocumented migrants, whatever their origin lack the authorization to remain within both the UK and US, and thus, lack authorization to participate in most publicly funded programs. This simple fact underlies many of the public reflections on immigration. When one considers healthcare laws there is a clear theoretical predisposition towards diminishing the access of individuals who lack authorization to remain within the respective countries to health services, except in cases where they are at immediate risk of death. The empirical data from this study indicated that these laws diminish rather than prevent access to services. This is an important distinction since political entities on both sides of the Atlantic, often citing the need to preserve resources, oversimplify this issue.

The fact that access to health services is made more difficult, but never completely prevented, has a firm theoretical basis. In the context of the UK, a long-term commitment to international and European human rights treaties prevents the absolute prevention of all forms of healthcare access. This is due to the imperative to avoid service denials that would result in immediate harm or death. Thus, while cases such as *N v. The United Kingdom* appear to stretch the boundaries of the withdrawal of health services, they do so only in the context of the definition of death or serious harm.⁴⁵⁶ That is, medical technology in the care of HIV/AIDS has progressed rapidly since early cases that

⁴⁵⁵ For instance, in the case of EMTALA, United States Code, 42, 1395dd (Emergency Medical Treatment and Active Labor Act)

⁴⁵⁶ *N. v United Kingdom* (2008) European Court of Human Rights (Application Number 26565/05)

were supported by the Article 3⁴⁵⁷ prohibition against torture or maltreatment, for instance as in *D v United Kingdom*.⁴⁵⁸ Thus, while early cases reflected treatment that would certainly result in serious harm or death, the availability of effective therapies for HIV or AIDS has improved to the degree that the disease is now viewed more so as a chronic condition like diabetes or hypertension, rather than a condition associated with an acutely inevitable demise. The aforementioned trend in law is nearly identical within the US legal system, save for the fact that the US does not base their position regarding such issues on human rights legislation, rather, they focus more so on the protections described in the United States Constitution. The US, instead, relies on statutes that ensure that serious harm or death does not befall those who find themselves ineligible for care.⁴⁵⁹

The data presented in the empirical phase of the study reflects heavily upon the theoretical application of law. In fact, the data reflects that, to an extent, the laws regarding healthcare access for the undocumented are being observed. There are challenges, however, in both the UK and the US. In the UK there are regional variations regarding HIV positive undocumented African migrants' ability to gain services in the GU Medicine clinics. While a variety of factors influence such practices, there are clear ethical principles held by healthcare workers that greatly complicate the act of either denying service to individuals altogether, even in cases where a long-term care giver-patient relationship exists. The US, however, struggles less with such issues for what amounts to a very simple reason. That is, no person, citizen or otherwise is guaranteed healthcare in the US. Thus, it is difficult to consider the degree to which individuals can

⁴⁵⁷ See European Convention on Human Rights

⁴⁵⁸ *D v United Kingdom* (1997) ECHR 30240/96 (UK)

⁴⁵⁹ United States Code, 42, 1395dd (Emergency Medical Treatment and Active Labor Act)

access care that is not guaranteed under legal circumstances. This is a key element of arguments that hinge upon access to service in the US context, since it is more difficult on a societal level to make allowances for the care of African migrants when many US citizens lack such access to services. Thus, when one considers the current state of the law, and application of the law, one might posit that it is lacking to the degree that the ineligible often receive care to which they are not entitled in the UK. The US system, with its current prohibition against even legal immigrants access to publicly funded care is clearly addressing the societal prohibition on the provision of publicly funded services to this population.⁴⁶⁰

Public Health considerations

Public health endeavors focus on the provision of population-based healthcare in such a way that the collective good of a particular population is facilitated. Public health based arguments, thus, should focus on the degree to which the provision of care to persons living with HIV, regardless of national origin is of benefit to society. This begs the question: To what degree does the provision of healthcare to undocumented African migrants suffering from HIV disease offer some benefit to society? The control and prevention of communicable disease is the cornerstone of public health. Since laws tend to guarantee care during acutely life threatening instances, it is important to address the degree to which there should be concern on the part of society regarding the treatment of HIV disease.

HIV comes from the family referred to as lentiviruses, which are transmitted through contact with the blood and or body fluids of a person who is infected with the

⁴⁶⁰ The law prevents full access to publicly funded services until the individual in question has dwelled in the US for a period of 5 years. Personal Opportunity and Work Reconciliation Act of 1996 (US).

disease.⁴⁶¹ There are several factors that determine whether or not one will transmit the virus during serial contacts with others. The first, and most widely held mechanism of transmission requires that one engage in a behavior that is considered high-risk. That is, in order to expose another to the virus, they must engage in behaviors including intravenous drug use or unprotected sexual contact.⁴⁶² This element of transmission is often addressed through programs, often of a public health nature, that are designed to assist individuals in making more productive choices.⁴⁶³ The second determinant of infection is related to the biologic nature of the disease. This centers on a principle referred to as viral burden, or often, viral load.⁴⁶⁴ Viral load reflects the concentration of virus in an individual's blood. Simply stated, the higher an individual's viral burden, the more likely it is that an individual will infect another. Conversely, an individual who is being aggressively treated with Anti-Retroviral medications may have an almost completely suppressed viral load.⁴⁶⁵ This person, therefore, is very unlikely to transmit the virus, even at times when they engage in high-risk sexual or drug related behaviors. Thus, there is clear evidence that suppressing one's viral burden through treatment results in the decreased likelihood that the virus will be transmitted.

Pragmatic considerations hinging upon the notion that individuals who are treated with antiretroviral medications are less likely to transmit the virus are important to this

⁴⁶¹ O'Farrell, N., Lau, R., Yoganathan, K., Bradbeer, C., Griffin, G., and Ponziak, A. AIDS in Africans living in London. (2005) 71, *Genitourinary Medicine*, 358 at p. 360

⁴⁶² Izopet, J., Massip, P., Souyris, C., Sandres, K., Puissant, B., Obadia, M., Pasquier, C., Bonnet, E., Marchou, B., and Puel, J. Shift in HIV resistance genotype after treatment interruption and short-term antiviral effect following a new salvage regimen. (2000) 14, *AIDS*, 2247 at p. 2250

⁴⁶³ Ibid at p. 2254

⁴⁶⁴ Libman, H., and Makadon, H. *HIV* (3rd ed., American College of Physicians, 2007) at p. 25-29.

⁴⁶⁵ Ibid, p. 33.

argument. The empirical data regarding the UK phase of the study reflected, at best, a sporadic regional or often individual ability to maintain treatment. The US phase of the study reflected considerable challenges for individuals who sought to maintain treatment. When one further considers the degree to which individuals in both the UK and US choose to emphasize issues of survival and their efforts to gain legal migration status, a concerning picture, wherein individual behaviors and concurrent difficulties in gaining care under the best of circumstances conspire to ensure that individuals maintain a very high viral burden (or viral load) arises. When one considers the current situation from a pragmatic point of view, the public health related ramifications of individuals who receive suboptimal are unacceptable.

Human rights considerations

The issue of human rights pertaining to the issue of healthcare access has been addressed at several points in this thesis. While international conventions indicate the essential nature of healthcare, there is no guarantee of access to health services that ensures that all persons within a country's borders will receive such services, despite the UK and US having signed many of the common human rights treaties. Current trends within international legal systems, for instance as in *N v The United Kingdom*, indicate a trend towards guaranteeing access to treatment only when life is imminently threatened.⁴⁶⁶ Concurrently, the domestic laws within the UK and US support this notion. While the current trend in law is clear, these developments are counter to the spirit of basic human rights instruments such as the International Covenant Economic, Social and Cultural

⁴⁶⁶ *N v United Kingdom* (2008) European Court of Human Rights (Application Number 26565/05)

Rights, in that they establish the legal means of denying a person healthcare under most circumstances.

The most significant finding detailed earlier in this chapter involves the issue of harm related to the cessation of HIV therapies in cases where individuals lose their access to healthcare services. This element of the data reflected upon two vital points where therapeutic cessation might occur. The first occurs at the time that an individual fails on appeal of their asylum request. This is unique to the UK, and is moderated by healthcare provider behaviors. That is, many healthcare providers continue to provide care despite the governmental prohibition on doing so. The second point came about due to data gained regarding immigration detention in both the UK and the US. Immigration detention facilities manifested highly varied rates of provision for detainee medical needs. This provides yet another case where an individuals therapy could be ceased, resulting in viral resistance. In any case, the issue of harm is more directly in violation of human rights instruments than the issue of access to services.

Human rights treaties such as those presented throughout this thesis are open to interpretation of the courts. When addressing the UK, the key area of enforceability of human rights law arises from the Human Rights Act, and its functional provision of enforceability of the European Convention on Human Rights. Thus, cases such as *D v United Kingdom*, and later *N. v United Kingdom* offered a fairly clear delineation of individual human rights in the context of HIV disease. Both the UK, and to a lesser degree the US, have fully enjoined a variety of less enforceable human rights treaties, for example, the Universal Declaration of Human Rights and many subsequent instruments. While enforceable instruments offer important legal means through which to guarantee

human rights, states do incur obligations when they enjoin less enforceable instruments. Thus it is my position, that while many of these instruments are not clearly enforceable, the positive obligations that nations incur are significant, and should be fully observed.

Do/should undocumented migrants have rights to healthcare services?

During the previous section, issues regarding the elements of healthcare access for undocumented migrants were addressed. The issue of access to healthcare for undocumented migrants is highly charged, especially given the current global economic downturn. After all, resources are highly limited in all countries, and logic dictates that resources for legal inhabitants of a country be prioritized. One of the primary arguments against providing health and services to undocumented migrants has traditionally stemmed from worries regarding the likelihood that individuals will migrate to countries that offer such services solely based upon service availability. Such a trend would, obviously, add significantly to the roles of covered individuals, and thus, would cause a significant increase in cost within any country.

While it was not a primary element of the thesis, data regarding persons within immigration detention in the UK and US were included. The provision of care within such facilities is notable in several respects. First, it may very well be the case that, while an individual dwelling within the community in the UK may lack the ability to obtain HIV therapies, these therapies, however intermittently, may be available within immigration detention in both the UK and US. In the case of the US, persons in immigration detention may very well experience far superior access to health-services, as compared to the general population of the country. This does offer a situation under which these individuals are cared for, however substandard these services might be.

While arguments focusing on the parallel between the services provided in the detention centers and communities are likely to fall short of explaining the existence of a strong reason to provide healthcare to undocumented migrants, the case of HIV offers the possibility of a more effective argument. Both the UK and the US possess healthcare systems that are well equipped to address a variety of communicable infectious diseases ranging from influenza to tuberculosis. If these other diseases are covered in order to preserve the health of the greater public, how is HIV different? During the previous section the biologic reasons for HIV management were discussed. The fact that disease transmission is a significant factor to the greater public is perhaps the strongest argument for the provision of more comprehensive healthcare to undocumented migrants. When this is coupled with the permanent harm associated with therapeutic interruption, some clear rationales for providing care arise.

When one combines public health concerns, the enforceable requirements of the law and the positive obligations incurred by nations through other less enforceable human rights instruments, it becomes apparent that arguments supporting access to some form of HIV related health services are logical. The major question here is to address the problem with a mind towards demonstrating the greatest good to the individual migrants, the healthcare system and society in general. An approach such as this, which is in full compliance with common human rights instruments, is essential.

What is the answer?

In the following section, proposed solutions to the problems presented throughout the thesis will be outlined.

(a) Reform of the law?

Any question of legal reform in the context of the ability of healthcare access for undocumented migrants would hinge upon the notion that there were functional disparities in the current laws to the degree that they fail to protect those who they are meant to serve. There is a delicate balance between the duty of law to fulfill the obligations of a state, and conversely, individuals. While healthcare laws tend not to be absolute, there is an area of law that is clearly present in both the UK and the US, although under distinctly different legal mechanisms. This is the notion that healthcare must be provided to those who are at immediate risk of death or serious injury if they fail to receive treatment. This mechanism of the law is meant to serve the individual, by preventing them from coming to harm. The empirical data in this study provided no indication that this form of care was being restricted in either the UK or the US.

An interesting pattern appeared in both the black letter and empirical data. It reflected upon the degree to which persons held in immigration detention were able to access basic, however limited, health services. In fact, both the UK and US possess mechanisms through which individuals can receive healthcare. In the UK context, GPs maintain the ability to visit with their patients who have failed to gain asylum. This was reflected throughout the data. The major limiting factor to the care provided by GPs in the UK is their lack of ability to provide HIV specific care. In the US context, there are migrant health centers that are federally funded through the mechanisms that allow for the care of medically indigent undocumented migrants. These centers, like their UK GP clinic counterparts, do not provide HIV related care. The major limiting factor associated with these clinics is their geographic distribution, which tend to cater to clientele from Mexico, Central and South America who work in agricultural regions. Africans

conversely, are concentrated in major metropolitan areas. Interestingly, federally funded community health centers are centered in these same urban areas, but are not designed to provide care to migrant populations. The presence of healthcare facilities which do not possess the capabilities to care for HIV positive individuals, but who can legally provide them care is an important aspect of this analysis. While there is often significant public opposition to initiatives that fund services for undocumented migrants, it may well be the case that modifications to the current way of implementing existing laws is a more effective means through which to address this problem. This is, in part, due to the previously discussed public health aspect of HIV disease, wherein failure to treat individuals raises the likelihood of infection for the entire population.

(b) Change in practical implementation of the law?

During the previous section several factors related to the provision of healthcare to undocumented migrants were proposed. The issue of point of access to health services is of vital importance. This was a key element of the theoretical models presented in this thesis, since the dotted line represented by the law is clearly movable based upon the state of laws in a given nation. To a degree, this is the single factor that defines a healthcare system. That is, in a system that focuses on prevention, the access point to care should be one that people could reasonably be asked to access prior to the onset of diseases, or routinely in the maintenance of diseases. A system that is based primarily on the treatment of conditions tends to structure itself in such a way that care is accessed based on the presence or absence of a variety of symptoms. In the context of the arguments contained in this thesis, the UK would represent the prior, and the US, the latter of the aforementioned definitions.

There are, however, pragmatic ways in which the public health concerns associated with HIV in undocumented migrants can be addressed. The UK is perhaps simpler, due to the fact that there is a system of universal healthcare in place that allows for the provision of GP related healthcare to many undocumented migrants. Thus, the extension of the nature of services provided by GP based clinics could be reasonably implemented. In the context of HIV care, such an initiative could be implemented through the use of clinical protocols that would guide GPs in the provision of basic HIV related services. While this would be less beneficial than care provided by specialist consultants in HIV care, it would provide a direct means by which undocumented migrants could receive anti-retroviral therapy during the period spanning the failure on appeal and their eventual return to their nation of origin. This could be accomplished in a more cost effective manner, and would also relieve GU medicine clinics of much of their current caseload. Further, this would decrease the likelihood of individuals seeking care during times of grave illness. Thus, this approach would capitalize on the wider availability of GP based care delineated in the empirical portion of the study.

The US context is more challenging due to the lack of universal healthcare for any inhabitant of the country. There is, however, a shared burden in the country that is induced by healthcare prices and the effect of uninsured losses on healthcare facility's financial health. To an extent, systemic prices rise due to these losses. This is particularly true when high prices result from gravely ill patients, such as is the case with untreated HIV patients who often present to emergency departments and are hospitalized. While it may be unpopular to provide care to undocumented migrants, the previous section detailed the presence of already established migrant health clinics and federally funded

community health centers. Much in the same manner as seen with the proposed protocol based provision of anti-retroviral therapies in GP clinics, this could be accomplished through these US facilities in a similar manner. While this is unlikely to supply the widespread services that would result if this were implemented in the UK, it would certainly make available basic therapies to far higher numbers of individuals. Current healthcare reform within the US is slowly progressing towards universal coverage; however, this will not mirror the UK system of universal healthcare.⁴⁶⁷ This solution, as well, would diminish the potential harm associated with therapeutic interruptions. If this were coupled with access to services in immigration detention, individuals would suffer no harm in their host country prior to removal to their country of origin. The provision of a minimal offering of HIV related services in both the US and UK would more fully observe the human rights related obligations of the UK and US. In the case of the UK, this service offering would avoid the possibility of violations based upon the Human Rights Act, on the grounds of Article 3 violations of the European Convention on Human Rights, and would bring the country into fuller compliance with the International Covenant Economic, Social and Cultural Rights. In the case of the US, the provision of basic services would diminish the likelihood of care provided incident to the Emergency Medical Treatment and Licensure Act while aligning the treatment afforded to undocumented migrants with the Universal Declaration of Human rights. In the case of both countries, these changes would minimize the degree of suffering experienced by undocumented migrants living with HIV/AIDS.

⁴⁶⁷ The Patient Protection and Affordable Care Act (2010), P.L 111-148.

Pitfalls in the law: Can law solve the problem of healthcare access for undocumented migrants or will use of the law create more problems than it solves?

When one considers the many challenges associated with legal reform, the possibility that legal reform will alter the current situation is real. That is, the simple act of altering the point of access to service does not, in itself, guarantee that individuals will wholly adjust their behavior. There is a real possibility, in any case, that individuals who become eligible for HIV care will simply continue to delay seeking care even when it is made available. The possible reasons for this will be discussed in the following paragraphs. It is important, at this point, to stress the degree to which the governments of the UK and US have no power to enforce such an initiative. That is, the current legal frameworks of both countries prevent them from refusing care during grave illness or injury. This being the case, the governments might suggest, but cannot completely legislate the point at which an individual seeks care.

This then begs the question: Why would one not access legally available care? To an extent, the previously presented empirical data provides an excellent forum for this element of the discussion. The two factors that were clearly evident in the data from both countries are the issues of HIV related stigma and the combined effects of poverty and fear, which seemed to be particularly prevalent in African communities. A foremost concern is the focus of the African community on survival and their experience of poverty and the associated fears. That is, the possibility that one might be identified as HIV positive could well limit the likelihood of their seeking care. Perceived stigma is a significant reality that appears to be heavily associated with HIV disease. Further, there are clear legal reasons for avoiding care in government-operated clinics. This element of

the data was far more profound in the US, likely due to the fact that a small percentage of Africans in the US negotiate the asylum process as compared to the high rates in the UK. Suspicion regarding the intent of government programs is a prevailing threat to the likelihood of these individuals seeking care in government run entities. In short, individual choice, a key component of the UK and US systems, coupled with the requirement to provide care to the gravely ill or injured, may well conspire to decrease the effectiveness of such legal regulation.

The political realities of establishing health services for undocumented migrants in the UK and US.

The provision of any form of service tends to be a catalyst for controversy within any society. This effect is perhaps more profound during times of economic turmoil. When one considers the effects of the current global economic trends on the economies of the UK and US, it is clear that any initiative to address the problem outlined in this thesis be accomplished gently. That is, any legal or legislative change must be undertaken in such a way that it addresses the cost to society associated with the problem, while acting in a way beneficial to those receiving this care. The issue of immigration, as well, is contentious. In the context of this form of change, the alterations to the desired point of care should be accomplished independent of immigration policies. That is, persons seeking care in this way should continue to bear the burden of navigating the immigration system as they have in the past. Simply put, these alterations must only alter their access to services during their stay in the country in question. Only through such an approach can one reasonably expect to achieve a situation where minimally adequate and humane medical care can be provided to HIV positive migrants.

While solutions for a problem affecting undocumented migrants are politically difficult to implement, there is a point at which a minimal approach directed towards the observation of the law is essential. In the case of the harm associated with therapeutic interruption, this is just such a point. That is, any governmental action that results in direct harm is wrong, and flies in the face of both domestic and international human rights laws. Thus, the minimal remedy for the harm associated with this policy is the suspension of policies that result in therapeutic interruption. While this is far from a comprehensive remedy for the problem of healthcare access for undocumented migrants suffering HIV disease, it does provide the minimal protection against harm demanded by the law.

Final Conclusions

During this thesis a highly controversial issue was addressed. In the context of the current work, empirical data based upon the Grounded Theory Method provided an examination of these issues from the viewpoint of individuals working with the communities in question. The time investment in this data collection was extensive, however worthwhile, as it provided the researcher with a face to face examination of the issues associated with the constructs involved in the study. This provided an excellent context in which to compare the legal frameworks of these countries and the extent to which the laws have or have not had effect. While the questions addressed herein are complex, the conclusions of the thesis are not. The current approach in both countries is neither pragmatic nor humane. The result of the current approach presses individuals to present for care with advanced AIDS, a completely preventable condition. Thus, the cost to the individual is suffering and possible loss of life. The cost to society can be measured

in pounds sterling or dollars, as the countries expend highly technical healthcare resources that might not have been necessary had care been provided earlier in the disease process. Most importantly, human rights law exists independent of government budgets and cost concerns. Thus, nations must fully observe the obligations into which they have entered regardless of cost. There is no simple solution, however, as any legal reform would have to be accompanied by significant public health programs directed towards altering the behavior of African migrants. While a complex undertaking, the benefits to society, while likely politically contentious, will benefit all involved.

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Appendix A

Non-Governmental Organization

Demographic Questionnaire

During this questionnaire, provide the most complete answers that you are capable of.

ID Number_____ (provided for each site).

Country: United Kingdom United States

Position of person completing document_____

Experience level of person completing document_____

Describe the work of your organization_____

Primary population served_____

Number of total monthly client contacts _____

Number of monthly contacts with undocumented migrants _____

Primary services provided to individuals visiting your agency:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

Appendix A (Continued)

Does your agency have a stated aim that, in part, provides for the health or social care of undocumented migrants.

Yes No

Does your agency receive funding from the government that pays for the healthcare of undocumented migrants?

Yes No

Appendix B

Non-Governmental Organization Interview: US or UK

ID Number_____

“Answer the following questions to the best of your ability. Please request clarification of any item that you do not understand. Refrain from identifying yourself, any person who works in your agency, or the name of your agency during your answers”.

1. Based upon your experiences, what are the most significant health related needs of undocumented migrants?
2. Are there social or legal barriers to gaining health services for undocumented migrants?
3. If barriers exist: What are the most significant barriers to gaining health services for undocumented migrants? Please be comprehensive in your answer.
4. What approaches have been most effective in gaining needed health services for undocumented migrants?
5. What types of agencies have proven to be the most ready access points for undocumented migrants in your, and your agencies experiences?
6. Please provide several examples, without identifying individuals by name, where you have been able to successfully gain healthcare services on behalf of someone in need? Work to obtain 3-4 examples of experiences while delineating:
 - a. The persons' situation including country of origin and social situation.
 - b. The services required and reason that this need is unmet.
 - c. The nature of agencies approached to cover this need.
 - d. The method used, eventually, to access services.
 - e. The agency or site (by type not name) where the service was gained.
7. Please provide some examples where services were needed, but could not be obtained for an individual despite your, or your agency's efforts. Work to clarify:
 - a. The persons' situation including country of origin and social situation.
 - b. The services required and reason that this need is unmet.
 - c. The nature of agencies approached to cover this need.
 - d. The reason that services were not gained.
 - e. The effect on the individual that resulted from the failure to gain services.
8. Given the current state of the healthcare system, what specific rules or regulations are the greatest barriers to obtaining care for undocumented migrants?

9. Given your and your agencies experiences, what rules or practices on the part of healthcare agencies facilitate the ability of undocumented migrants to obtain needed health services?

Appendix C

Informed Consent Document

I freely and voluntarily and without element of force or coercion, consent to be a research participant in the research entitled “Laws Governing Access to Healthcare for Undocumented Migrants to the UK and US: An empirical Examination of Law in word and Practice” In particular, my participation, or choice not to participate, is made freely and of my own will.

This research is being conducted by James Whyte IV a PhD student at The University of Leicester in Leicester England. I understand that the purpose of this research project is to better understand factors that play a role in individuals ability to obtain health related services.

I understand that the study will involve the completion of a questionnaire that collects basic information regarding my or my organizations status. Additionally, a taped interview will be performed which will elicit information related to my experiences within the healthcare system of the country where I dwell. I further understand that my involvement in the study will include 1) 10-15 minutes to complete the demographic form and 2) 30-45 minutes to complete the taped interview.

I understand that no research material, either written or taped, will contain my name or any identification number that could be used to associate my name with my answers or demographic information. Additionally, I understand that all information provided is confidential, therefore, it will be protected to the maximum extent allowable by law. Information will be reported in written reports, including a thesis, in a way that does not identify me in any way. The vast majority of this data will be reported as ‘group’ data, and therefore will not be attributable to any one person or organization under any circumstances.

I understand that there is minimal risk associated with my participation in the study. I understand that I might experience some anxiety during my participation in the study. Thus, I am able to stop my participation at any time if I wish.

I understand that there are benefits for my participation in this research project. First, the information that I provide will be used to reflect upon the manner through which healthcare services are provided. I will also be providing valuable insights into how people are able to adapt to the healthcare systems inherent to countries as they immigrate.

I understand that this consent may be withdrawn at any time prejudice, penalty or loss of benefits to which I am otherwise entitled. I have been given the right to ask and have been given answers to all of my questions to my fullest satisfaction.

I have read and understand this consent form.

Subject

Date

Appendix D

Initial Contact Letter to NGO Officials.

Hello,

My name is James Whyte. I am a PhD student at the University of Leicester. My supervisors are Professor Jean McHale and Dr. Loveday Hodson. I am currently seeking contacts through which I might recruit participants for my research. Because of the mission of your organization, I am very interested in collaborating with you in order to perform a portion of my research.

My work in Leicester focuses on a very special and highly challenged population. My project is a study based upon interviews, and focuses on the experience of people who are not authorized to dwell in the UK but remain, and who have needs in the area of health services. While the study focuses upon individuals' experiences in accessing health services, I understand the sensitivities regarding these individuals. It is important, I believe, that I be clear from the outset. I will not seek the names or any other identifying factors regarding these individuals. I want only to document their experiences. They will remain completely anonymous in throughout my interactions with them.

In addition to interviewing individual beneficiaries of your organization, I would also seek to interview several administrative personnel within your agency who are familiar with the challenges associated with these individual's efforts in gaining needed services.

I would feel it a privilege if, over the coming months, I could make arrangements to visit your agency and perform confidential interviews on some of your staff and the people who you help to care for. I am highly sensitive to their life challenges having spent a lot of time caring for similar people, most of whom live in desperate poverty. Thus, if given this opportunity, I would be absolutely respectful of their fears and concerns in the context of their legal status. That is, I want to learn of their experiences and challenges in gaining health services. I do not want to know their names, their addresses ect.

I look forward to hearing from you.

Thanks very much,

James Whyte IV

Appendix E

Letter for Direct Communication with NGO Official.

Hello,

Thank you for voicing interest in participating in my study. Prior to our arranging a time to meet, I thought it important to be clear what will be asked of you. The research seeks to record your experiences in the context of assisting your clientele in gaining health services and your reflections regarding the challenges associated with this endeavor.

The key to the research is that your name, the name of your agency and any other identifying factors that might implicate you and/or your agency having participated will not be recorded in the data, in any form. Thus, none of your responses may be attributed to you or to the agency. This level of anonymity will prevent you from the perception that you might suffer ridicule of some kind for participating.

Your participation will take approximately 1/2 hour. During this period, you will be asked a structured set of questions that will require you to reflect on the many challenges to which undocumented immigrants are exposed. This interview will be transcribed into written form for analysis.

I look forward to scheduling your interview. If you desire to participate please contact me at your earliest convenience. If not, thank you for your time.

Sincerely,

James Whyte