Social Construction of Illness

Description
RNs and many of their most vulnerable patients understand that illness and disease, and how these are experienced, means so much more than simply the pathology of the disease. This course examines the role of social construction in how we understand illness. In particular, it considers the important function that culture and social and economic policies play in how we define, discuss, and treat an illness. The way we classify a particular illness can vary across cultures, time, and societies. Thus, the same disease can have different impacts and effects on different populations. By highlighting these aspects of disease and illness, the class outlines connections between neoliberalism, privatization, and health and illness. Through a case study, it examines how these work together to create a context of unequal access to health. In completing this course, RNs will strengthen their leadership and will be better able to advocate for their patients.

Objectives
Upon completion of this home study, participants will be able to:
1. Articulate the key ways in which social construction affects our understanding of disease and illness.
2. Discuss the important role social and economic policies play in how we understand a particular disease.
3. Convey the necessity for a strong public health system for the protection of your patients.

Introduction
As nurses, you are surrounded by various diseases every day at work and in community spaces. Diseases are biological phenomena, made up of various pathogen links. These pathogens live in a particular host, an individual. But, perhaps more importantly, the disease and individual live within a particular time and place and within particular understanding and policies of a society. In this sense, illness is a social phenomenon. This means that illness gives meaning to the disease. This is known as social construction. How we understand a particular illness is influenced by the nature of that illness, but also by our social institutions and social norms - attitudes, values, behavior, and beliefs. These attitudes, values, behaviors, and beliefs create systems of ideas and practices about everything, including illness and disease. All this helps shape how a society responds to a particular disease. This in turn, effects the official responses to particular illnesses, it helps determine what – if anything – should be done to limit disease exposure and transmission and how the disease should be handled.

The disease itself is studied in laboratories, where scientists seek to understand pathologies – the inner workings of the disease. This is different than the understanding that you, as nurses, and other healthcare professionals must have – an understanding of not just the nature of the disease, but one that incorporates the reality in which the patient lives with the illness. That means this social construction of illness varies place to place, time to time, and changes as beliefs change. How we understand a particular illness is a dynamic process. For example, advances in technology may change how scientists understand a particular disease. However, unless these technological changes also influence our beliefs and policies about the disease, the social construction of the illness may not change.

This home study will discuss, in-depth, the notion of social construction of disease. It will then focus on understanding how our current neoliberal policies and ideology influence this process. Finally, a case study discussing the changing understanding of HIV/AIDS in this country will be presented. Primary and
secondary sources are used throughout to demonstrate various ideas and notions around the social construction of illness.

**Understanding Social Construction of Illness – What Does it Mean and Why Does it Matter?**

Social and economic factors influence the way we understand a particular disease, its various stages of sickness, and treatment or cure. These social and economic factors often play a role in morbidity and mortality (Timmermans and Haas 2008). Meaning that, a particular ailment can have very diverse effects on different patient populations. It also means that our definition and classification of an illness can vary across cultures and societies and that our understanding of a particular ailment can change over time (Launer 2014). This is the social construction of illness. Class, race, gender, language, technology, culture, political economy, and institutional and professional structures of the patient and society alter the social construction of a particular illness. As nurses, it’s vital you understand how and why illnesses are socially constructed. By better understanding how institutional and cultural forces form our conception of health, illness, and healing, you will be better equipped to advocate for your patients and their needs (Brown 1995).

**Social Construction**

At its core, social construction simply means that our ideas, practices, and occurrences are the result of countless human interactions, choices, knowledge, decisions, and power relations. All of these are embedded in the culture and history of a particular society. Reality and how we understand the things in our world don’t just exist – we create them. This means that social construction is a dynamic process and that illness and diseases can be identified and acted upon in different ways (Conrad and Barker 2010, Brown 1995).

Social construction occurs at the individual level, through specific individual actions and personal relationships; at the community and establishment level in organizations such as hospitals and universities; and on a largescale level, through policy creation, legal frameworks and stratification. Stratification simply refers to the systems by which society ranks entire groups of people into hierarchies. These hierarchies perpetuate unequal economic and social rewards, as well as power in society. For example, our society stratifies by gender – men in our society (the U.S.) receive higher wages than women for performing the same job, hold more positions of power (in corporations, businesses, and government), and face fewer forms of discrimination than women.

In addition, social causes are a vital component of social construction. Social causes help determine how particular phenomenon are experienced, in this case, how a particular ailment is experienced by a patient and the health status of that patient. Causation includes three categories: first, “underlying social causes, such as social structural elements of the society (class, race, sex, military spending);” second, “proximate social causes, such as neighborhood structure, migration, and environmental and workplace hazards;” and third, “mediating social causes, such as social supports, social networks, and marital and family status” (Brown 1995:38).

Finally, social construction takes place in three realms: the social, physical, and individual. All three of these work together to create and delimit an individual’s reality. And, as mentioned, this reality is embedded in societal definitions and interactions. The social reality refers to the various interactions of the individual. The physical reality refers to an individual’s environment and current situation. Our social reality is partially influenced by our physical reality – our physical environment influences how we understand various things happening around us. Finally, our individual reality refers to the fact that each
one of us has a unique perspective. All three of these realms – the social, physical, and individual – work together to form our perceptions of various occurrences (Huber and Gillaspy 1998).

**Social Construction and Illness**

Social construction has a direct influence on how we understand disease and illness. Disease is the biological condition while illness is the social condition. The medical model views diseases as universal and unchanging over time or place. Conversely, social construction places heavy emphasis on culture and social systems, pointing to the fact that patients experience various diseases in the reality within which they live – realities comprised of particular attitudes, values, behavior, beliefs, and policies. The illness experience is directly influenced by all these things (Conrad and Barker 2010). One quick example will provide some grounding to this idea – some bio-physiological conditions are classified as a disability, while others are classified as disease. These classifications were made up by various scientists and healthcare professionals. They are not “natural” categories; meaning, they don’t make sense outside of the sense we place on them.

This is not to say that diseases are not biochemical entities that have specific diagnostic and clinical foundations and treatments. Indeed they are and do. However, just as disease has a biomedical framework, illness has an experiential framework that provides social and cultural meanings to that illness, which has consequences for the patients and healthcare (Conrad and Barker 2010). With this in mind, let’s turn our attention to the role that various social, political, and economic factors play in social construction and social construction of illness.

There are three general ways of understanding illness and disease:

1) Understanding illness through cultural meanings – this refers to how our culture and society help shape how we understand a particular illness and how we respond to those afflicted with a particular ailment;

2) Understanding illness (and the occurrence of illness) through social construction at the experiential level – this refers to the fact that individuals understand their illness and how to live with this illness through various social, political, and economic factors;

3) Understanding medical knowledge as being socially constructed – medical knowledge is not a given, but instead developed by various groups, including scientists, healthcare professionals, and interest groups (Conrad and Barker 2010).

Our societal culture influences how we understand a particular disease and, in particular, that not all diseases are the same. For example, some illnesses are stigmatized, while others are not; certain illnesses are contested, in that there is disagreement whether or not that pathology classifies as a disease; certain physical conditions are categorized as disease, while others as disability. These distinctions occur for social reasons, but can have social and biological repercussions for the patient. Stigma in particular can have severe consequences. Illnesses that are stigmatized aren’t done so for the same reason. Instead, they are stigmatized because of how the general public, media, and policy respond to the illness and its various manifestations or because of the type of individual most prone to suffering from the illness (Conrad and Barker 2010).

Social construction plays a paramount role in how we understand an illness and how that illness is experienced. The following example of leprosy demonstrates the ideas discussed above. Leprosy is one of the first diseases to be considered a stigmatized disease. For years, in the United States, missionaries disseminated and propagated the idea that leprosy was somehow connected to sin and “uncleanliness.” As a result, individuals suffering from leprosy were viewed as outcasts, often times labelled “lepers.” In
contrast, in India, leprosy was viewed as infecting individuals who were thought to be cursed or who were victims of witchcraft. The difference in the understanding of this illness is due to the existing cultural beliefs of those societies at that time. Today, leprosy is understood as a disease that is most likely to afflict those living in poverty, but anyone can contract it. It is most likely to be transmitted through coughing or sneezing. A multi-drug therapy is used to treat the disease. This changing understanding of leprosy has also had social repercussions. No longer are those afflicted with this illness viewed as “deserving the disease” nor are they ostracized. The word “leper” is now considered offensive. Medical treatment is sought as quickly as possible and prevention education often comprises a key component of fighting the illness.

Understanding that illnesses have cultural and social meanings and causes is crucial to our understanding of health and illness. Identifying and comprehending these is important “because epidemiological and biomedical knowledge has shifted the causes and consequences of disease from fate, accident, and bad luck to factors that are under some human control” (Link 2008:367). This means we can no longer only be concerned about fixing the individual, but we must now consider how to repair social, political, and cultural contexts that give rise to negative prognoses of illnesses. In studying the social construction of illness, we investigate the way in which social forces, at their various levels, form our understanding of and the way we deal with health, illness, and treatment. Health, illness, and treatment involve and are impacted by our underlying social stratification system, the roles of professionals, institutions, governments, media, pharmaceutical companies, patients, and people with illness as well as their families (Brown 1995). Because the way we view particular illnesses influences the policy making around those illnesses, we must be examine our current behaviors, policies, and institutions (Link 2008).

Right now, one of the key ideas that influences social forces at all levels is our current socio-economic and political system: neoliberalism.

**NEOLIBERALISM**

Neoliberalism is a political and economic philosophy – a set of ideas – that has taken over and caused global and national institutions to implement so-called neoliberal policies. Neoliberalism has been the dominant ideology and political mindset for the last 40 years and it has been the force that has been and still is shaping our world. These policies have touched and influenced every part of our society, including how we understand disease and illness – what constitutes as each and the appropriate response to these.

At its core, neoliberalism refers to a set of economic policies advocating unregulated market competition as the answer to all of our problems – social and economic. This economic, political, and intellectual movement sees the market as being the most efficient mechanism for organizing every aspect of human life. It calls for minimal “interference” by the government in our market economy. This means that little or no restrictions should be placed on manufacturing and commerce and free trade is the best thing for a country’s economic growth. Goods should travel from place to place freely, with as little regulation as possible. In our society, goods are owned by businesses and corporations, as such there should be as few regulations on corporations as possible (Harvey 2005).

Neoliberal theorists and economists maintain that when no restrictions are placed on the behaviors and actions of individuals, everyone will seek to maximize her/his self-interest. Consequently, there will be freer movement of goods, resources, labor, etc., in an attempt to find cheaper modes and means of production, which will maximize profits and efficiency and, in turn, make the economy grow. A hallmark
argument of anyone touting neoliberalism is that economic growth is a function of accumulated capital. The promotion of savings is central to the promotion of economic growth – greater savings permit greater investment, which generates economic growth. This economic growth will benefit everyone in society by increasing the opportunities we all have to participate in market activities. This is the idea of trickle-down economics.

Most importantly, neoliberalism sees the individual as wholly responsible for her/himself. As such, it’s no surprise that in a neoliberal society, success and happiness are correlated with material and monetary wealth and prestige. Likewise, it’s not surprising that neoliberalism advocates that, whenever possible, public programs should be replaced with programs run privately by corporations. This means that individuals are no longer viewed as citizens of states, but as consumers of everything – water, public safety, transportation, healthcare. All these things are no longer viewed as public goods to be paid for and provided by the state, but rather services to be sold by corporations to individuals (Esposito and Perez 2014; Harvey 2005).

The following are five key ideas of neoliberalism:

1. Privatization of public enterprises and reduction of public expenditures, particularly social spending – this means that free services, including things such as education and water, are eliminated. Consequently, if you aren’t able to afford to pay the fees to send your child to school, too bad, no quality education for your child. Or, as was the case in Detroit, Michigan, if you can’t afford to pay your water bill, you will not be able to access safe, clean water despite water being a basic human right. The mantra being that each individual must take care of her/himself. Privatization and reduction of public expenditure also includes massive government employee layoffs across all sectors.

2. Deregulation of the economy – this means that there should be little to no rules or regulations; essentially, anything goes. This creates a socio-economic context that results in the rapid externalization of costs, oftentimes coming in the form of harms to workers safety and the environment.

3. Liberalization of trade and industry and the expansion of international markets – this means that corporations and companies follow few, if any, rules in how they do business. When restrictions are removed on the exchange of goods and people between nations, businesses outsource to other countries. This often creates a socio-economic context for a race to the bottom for the cheapest forms of labor in any country.

4. Massive tax cuts – this includes tax cuts for everyone; however, when citizens do not pay taxes, states and countries have no money to keep bridges and roads safe, provide education, supply social security, among numerous other things.

5. Strict control on organized labor – this means that as unions are eliminated, workers can be increasingly exploited. Corporations seek to get as much labor out of an individual as possible, while paying her/him the lowest possible wage. Currently, in this country Right to Work legislation is threatening the ability of workers to unionize and protect workers’ rights across the country (Steger 2013:42).

The key idea behind each one of these five policy reforms is austerity. Austerity measures limit government spending in attempt to decrease supposed government budget deficits. These measures, however, tend to increase personal suffering and do little to balance the budget. In addition, neoliberalism holds up financial globalization, meaning that countries are now interconnected through the economy, so not interconnection just through diplomacy but through commerce and capitalism. Neoliberal policies have led to the opening up of global markets. This has increased opportunities for corporations to outsource production to countries where companies pay less and have few worker rights. So, less and less is produced in the United States and more and more is produced in countries
with little regulation. A race to the bottom is taking place. But, most importantly, these policies give more free reign to corporations and transfer wealth from the poor to the rich not the rich to the poor.

Neoliberal theorists and economists maintain that when the above policies are instituted, everyone will benefit. In reality, this does not happen. Instead, the result is erosion of decent paying jobs, continued reduction in wages, elimination of worker rights and benefits, relaxed government regulations, reduced expenditure on things such as education and health care, the dismantling of programs that aid the poor, and increased cost of living. The concentration of wealth increases in the hands of those who already have it, and the individual is placed as being entirely responsible for what happens to her/him. We’ve witnessed this over the last four decades – the rich have gotten richer, while the poorer are getting poorer. Inequality has and continues to increase. It’s not just the U.S. that is feeling the effects of neoliberal policies. The following article describes how neoliberal policies have increased inequality.


BEGIN ARTICLE

Neoliberalism is increasing inequality and stunting economic growth, IMF says

After forty years the international organization warns that parts of the economic approach are not delivering

Key parts of neoliberal economic policy have increased inequality and risk stunting economic growth across the globe, economists at the International Monetary Fund (IMF) have warned. Neoliberalism – the dominant economic ideology since the 1980s – tends to advocate a free market approach to policymaking: promoting measures such as privatisation, public spending cuts, and deregulation.

It is generally antipathetic to the public sector and believes the private sector should play a greater role in the economy.

The ideology was initially championed by Margaret Thatcher and Ronald Reagan in Britain and America, but was ultimately also adopted by centre-left parties worldwide, under “third way” figures like Tony Blair.

The approach has long been the target of criticism from the radical left and parts of the reactionary right – but has been endorsed as common sense by centrist parties across the world for decades.

Now a paper published in June 2016’s issue of the IMF’s Finance and Development journal warns that, after nearly forty years of neoliberalism, the approach is jeopardising the future of the world economy.

“Instead of delivering growth, some neoliberal policies have increased inequality, in turn jeopardising durable expansion,” the senior IMF economists who drew up the paper said.

The authors say that while the liberalisation of trade has helped lift people out of poverty in the developed world and some privatisations have raised efficiency, other aspects of the policy platform had seriously misfired.

“There are aspects of the neoliberal agenda that have not delivered as expected,” they said, focusing specifically on austerity and the freedom of capital to move across borders.

“The benefits in terms of increased growth seem fairly difficult to establish when looking at a broad group of countries.

“The costs in terms of increased inequality are prominent. Such costs epitomize the trade-off between the growth and equity effects of some aspects of the neoliberal agenda.
“Increased inequality in turn hurts the level and sustainability of growth. Even if growth is the sole or main purpose of the neoliberal agenda, advocates of that agenda still need to pay attention to the distributional effects.”

The paper was authored by Jonathan Ostry, the deputy director of the IMF’s research department; Prakash Loungani, its division chief; and Davide Furceri, an economist there. They go on to say that throwing open national borders to multinational corporations has had “uncertain” growth benefits but quite clear costs – due to “increased economic volatility and crisis frequency” which they say is more evident under neoliberalism.

On the issue of austerity, the authors say there is strong evidence that there is no reason for countries like Britain to inflict austerity on themselves.

“Austerity policies not only generate substantial welfare costs due to supply-side channels, they also hurt demand – and thus worsen employment and unemployment,” they say.

“In sum, the benefits of some policies that are an important part of the neoliberal agenda appear to have been somewhat overplayed.”

Shadow chancellor John McDonnell told The Independent the report reflected a “growing consensus” among economists.

“The International Monetary Fund has summarised what a growing consensus amongst economists across the globe now think, that Osborne-style austerity economics increases inequality and instability, and undermines growth,” he said.

“IT’s time for the Chancellor to listen to the experts, change course and put an end to his failed policy of austerity with a solid commitment by government to deliver an industrial strategy backed up by investment to create the high-tech, high-wage economy of the future.”

The IMF itself has long been regarded as one of the key international proponents driving neoliberalism in the developing world, often only giving financial assistance and loans on the condition that neoliberal reforms would be implemented in the target country.

In recent years the organisation has appeared to equivocate more on the issue, however. In 2013 director Christine Lagarde admitted that the IMF failed to foresee the damage that austerity policies would do, particularly in Greece.

A long-term analysis by the Office for National Statistics published in 2013 found that the rate of UK recessions has increased since the 1970s, when neoliberalism started to influence policymaking. “Between 1948 and 1973, GDP increased consistently on an annual basis. On a quarterly basis, there were a number of contractions. However, these were generally isolated and did not result in annual downturns in output in these years,” the analysis said.

By contrast, it noted: “There has been one downturn in annual output in every decade since the 1970s, the most pronounced of which is the current economic downturn which started in 2008.” The Institute for Economic Affairs, a think-tank that was instrumental in shaping the direction of neoliberal policy in the 20th century, told The Independent the approach had a good record overall. “In a context of weak institutions and greedy governments, there may be a point in controlling short-term capital flows to prevent acute crises – although capital controls have not saved Venezuela from economic collapse,” Diego Zuluaga, the organisation’s financial services research fellow said.

“Moreover, international bodies such as the IMF may worry about rising inequality as economic growth rewards some more than others within an economy. “But even a superficial look at the evidence from the past 35 years shows the amazing progress made – especially by poorer countries – under the so-called ’neoliberal agenda.’ This progress is sadly overlooked in the article.”

Neoliberalism’s adherents do not tend to self-identify as neoliberals themselves because the ideology is almost a given in most establishment policymaking circles.
A Treasury spokesperson said: "This report does not represent an official IMF view of UK economic policy. In fact, the IMF's most recent formal assessment of the UK economy two weeks ago supported the government's economic plan.

“The UK economy is growing, our employment rate is at a record high and the deficit has been cut by almost two-thirds as a share of GDP. At the same time, inequality is falling and living standards reached their record highest level last year.

“But the job of building a resilient economy is not done - that's why we must stick to the plan that is delivering economic security across Britain.”

END ARTICLE

It’s important to understand that neoliberalism is far more than a set of policy prescriptions. It promotes, maintains, and reinforces a particular order and vision of world where all aspects of our lives – social, cultural, and economic – are shaped by “market rationality.” The market is viewed as the organizing principle of life. Meaning that, everything – all goods, actions, and practices – are assessed as “valuable, acceptable, or desirable by the ‘market.’” Following this line of thought, neoliberalism heralds the market as being a self-regulated entity and one that is legitimate in its own right. Thus, it’s no surprise that people are encouraged to alter their attitudes, practices, and behaviors to fit market demands (Esposito and Perez 2014). The people are here to serve the market economy rather than vice versa.

It should be noted that while neoliberal ideology calls for no interference in the market, the market and economy are systematically altered through policy changes that favor and protect the interests of corporations and investors. When crises do arise, neoliberals accuse the government’s overregulation as having led to a distortion of the market. Likewise, labor unions are also blamed for demanding too high wages and benefits (Esposito and Perez 2014). However, we know that higher wages lead to greater wage equality and fewer market disruptions. Moreover, when corporations and investors find themselves in trouble, they are quick to turn to the government for help, as we saw during the auto bailout in 2008.

Additionally, neoliberal ideology promotes individual responsibility, viewing failure as failure of the individual not of society. For example, if an individual is poor, it is her/his fault that she/he didn’t pursue the right amount and line of education, didn’t apply to enough jobs, and didn’t work hard enough to ensure a decent livelihood. No blame is placed on the cycle of poverty, the exorbitant price of higher education, or on racial and gender stratification. Instead, the individual is at fault for not working to overcome all of these obstacles. Social and economic justice are not of concern to neoliberalism. Indeed, larger social and political institutions that influence our lives are viewed as having market solutions on the individual level.

Neoliberal policies were first introduced in the United States in the late 1970s and early 1980s. This was the time when numerous politicians successfully introduced reforms, fought the trade unions and worker power, who were opposed to these policies, and began to destroy market regulation. Since that time, numerous politicians have pushed and continue to push the neoliberal agenda. But this agenda is not just pushed by politicians, it is also pushed by the corporate sector, think tanks, and research centers such as the Brookings Institute, the Cato Institute, and the National Endowment for Democracy, among others. The neoliberal view, mindset, and ideology has extended to the international level and has essentially changed how the world operates.
Neoliberalism and Health

Neoliberal policies have affected how we think about health, healthcare delivery and access, and illness. Moreover, these policies have directly affected the health of individuals living under these policies in the United States and abroad.

First and foremost, neoliberal policies call for the privatization of social services and the defunding of social programs; this includes health services provided to the population. Thus, over the last several decades, ensuring one has access to healthcare has been the individual’s responsibility. It is up to the individual to ensure she/he has health insurance, which will allow her/him to access various health treatments and options. In the United States, health insurance is offered through private insurance companies. Only the poorest and elderly are able to access government assisted health insurance (Medicaid and Medicare). Insurance schemes in this country generally include deductibles and co-pays that the individual must pay. Furthermore, each insurance plan does not guarantee coverage for a potential malady one may become afflicted with.

But neoliberalism has more pernicious consequences for health. Inequality and poverty created by neoliberal policies put the health of many at risk. Inequality and poverty lead to unequal access to most health-related resources (Coburn 2004). What’s more, inequality literally makes us sick. Socio-economic status is an important variable in health. Individuals of low socio-economic status have been found to have poorer health than those of higher socio-economic status. One’s socio-economic status influences the sort of resources one can make use of to avoid risks and adopt precautionary practices. Knowledge, power, money, prestige, and favorable relationships all prove to be important in health. And, as one’s socio-economic status increases, so does access to these resources. For example, an individual of high socio-economic status is able to live in a wealthier neighborhood where the majority of residence have high income, education, and prestige. As such, this community is able to effectively ensure that crime, pollution, violence, and noise are limited. In addition, they are able to fight for and safeguard sanitation, playgrounds, parks, food stores, and healthcare facilities. All of these factors improve health and well-being (Phelan, Link, and Tehranifar 2010). Accordingly, socio-economic status influences health in four fundamental ways: “first, it influences multiple disease outcomes, meaning that it is not limited to only one or a few diseases or health problems. Second, it affects these diseases or health outcomes through multiple risk factors. Third, it involves access to resources that can be used to avoid risks or to minimize the consequences of disease once it occurs. Finally, the association between a fundamental cause and health is reproduced over time via the replacement of intervening mechanisms” (Phelan, Link, and Tehranifar 2010:529).

To be clear, by emphasizing the significance of resources at an individual’s disposal is not to deny the importance of the structures – social, economic, and political – of a society. Indeed, these very structures make it easier for certain groups to access resources, while making it nearly impossible for others. This is the fundamental reasoning behind stratification and its effects on our life course.

Neoliberalism also has a direct influence on how we understand health and medicine, perhaps most evidently seen through the medicalization and commodification of human life. Disease and illness are seen as a problem of the individual – the diagnosis, treatment, and prognosis are solely focused on the individual. This fits within the prevailing neoliberal logic in that it completely negates the importance of the social and physical contexts within which we live. Instead, our medical model views patients as self-contained agents, in charge of their own health. Dissociating diseases from social, economic, and political realities allows for harmful policies and practices to continue.
In addition, medicine is now market-driven, meaning that hospitals and clinics have in many ways been corporatized and view patients as consumers who are there to drive up their profits. Health is now viewed as a commodity, rather than a right. Diagnoses are viewed with profit-driven objectives – which treatment plan will save the hospital and/or insurance company the most money. Moreover, this mentality helps fuel the idea that pharmaceutical drugs and medical procedures are all that are needed to help ailing individuals. Viewing drugs and procedures as the only answer to diseases help fuel neoliberal logic and the medicalization of health in that it is an individualized answer to a problem that has many root causes. And so, the individual has become the sole focus of attention, while larger social, economic (including a profit-seeking, market economy), and political structures are ignored (Esposito and Perez 2014). Not surprisingly, oftentimes when individuals do place responsibility for any ailments they are suffering from (particularly mental health) on social, political, and/or economic forces, many view this as an excuse of the individual failing to own up to her/his problems. It is up to the individual to be able to afford the treatment needed and make the necessary life changes to ensure that treatment.

Neoliberalism’s ideological influence on the medical establishment has successfully forced a shift in how medicine is practiced. The central tent now being personal responsibility for one’s health. This individual, clinical approach is now doing more harm than good (Esposito and Perez 2014; Conrad and Barker 2010). Indeed, the health of the U.S. population has suffered as a result of social spending cuts (Link 2008). The following chart, produced by the Commonwealth Fund (http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/us-health-care-from-a-global-perspective) for their brief “U.S. Health Care from a Global Perspective” shows healthcare and social care spending in a number of Western countries. As can be seen, the U.S. has some of the highest health care spending, but lowest social care spending.

**Exhibit 8. Health and Social Care Spending as a Percentage of GDP**

![Chart showing healthcare and social care spending as a percentage of GDP for various countries.]

Notes: GDP refers to gross domestic product.
The following chart, from the same source, shows health outcomes and risk factors in the same countries. As can be seen, the U.S. has the lowest life expectancy and the highest infant mortality rate. One would think given the high spending on health care, outcomes in the U.S. would be better. However, it is precisely because social spending continues to be cut and social, political, and economic contexts are ignored, that our country has such abysmal health outcomes.

**Exhibit 9. Select Population Health Outcomes and Risk Factors**

<table>
<thead>
<tr>
<th>Country</th>
<th>Life exp. at birth, 2013(^a)</th>
<th>Infant mortality, per 1,000 live births, 2013(^b)</th>
<th>Percent of pop. age 65+ with two or more chronic conditions, 2014(^c)</th>
<th>Obesity rate (BMI &gt;30), 2013(^d)</th>
<th>Percent of pop. (age 15+) who are daily smokers, 2013(^e)</th>
<th>Percent of pop. age 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>82.2</td>
<td>3.6</td>
<td>54</td>
<td>28.3(^a)</td>
<td>12.8</td>
<td>14.4</td>
</tr>
<tr>
<td>Canada</td>
<td>81.5(^a)</td>
<td>4.8(^a)</td>
<td>56</td>
<td>25.8</td>
<td>14.9</td>
<td>15.2</td>
</tr>
<tr>
<td>Denmark</td>
<td>80.4</td>
<td>3.5</td>
<td>–</td>
<td>14.2</td>
<td>17.0</td>
<td>17.8</td>
</tr>
<tr>
<td>France</td>
<td>82.3</td>
<td>3.6</td>
<td>43</td>
<td>14.5(^d)</td>
<td>24.1(^d)</td>
<td>17.7</td>
</tr>
<tr>
<td>Germany</td>
<td>80.9</td>
<td>3.3</td>
<td>49</td>
<td>23.6</td>
<td>20.9</td>
<td>21.1</td>
</tr>
<tr>
<td>Japan</td>
<td>83.4</td>
<td>2.1</td>
<td>–</td>
<td>3.7</td>
<td>19.3</td>
<td>25.1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>81.4</td>
<td>3.8</td>
<td>46</td>
<td>11.8</td>
<td>18.5</td>
<td>16.8</td>
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<tr>
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<td>81.4</td>
<td>5.2(^c)</td>
<td>37</td>
<td>30.6</td>
<td>15.5</td>
<td>14.2</td>
</tr>
<tr>
<td>Norway</td>
<td>81.8</td>
<td>2.4</td>
<td>43</td>
<td>10.0(^d)</td>
<td>15.0</td>
<td>15.6</td>
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<tr>
<td>Sweden</td>
<td>82.0</td>
<td>2.7</td>
<td>42</td>
<td>11.7</td>
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<tr>
<td>Switzerland</td>
<td>82.9</td>
<td>3.9</td>
<td>44</td>
<td>10.3(^d)</td>
<td>20.4(^d)</td>
<td>17.3</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>81.1</td>
<td>3.8</td>
<td>33</td>
<td>24.9</td>
<td>20.0(^d)</td>
<td>17.1</td>
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<tr>
<td>United States</td>
<td>78.8</td>
<td>6.1(^e)</td>
<td>68</td>
<td>35.3(^d)</td>
<td>13.7</td>
<td>14.1</td>
</tr>
<tr>
<td>OECD median</td>
<td>81.2</td>
<td>3.5</td>
<td>–</td>
<td>28.3(^a)</td>
<td>18.9</td>
<td>17.0</td>
</tr>
</tbody>
</table>

\(^a\) Source: OECD Health Data 2015.  
\(^b\) Includes: hypertension or high blood pressure, heart disease, diabetes, lung problems, mental health problems, cancer, and joint pain/arthritis. Source: Commonwealth Fund International Health Policy Survey of Older Adults, 2014.  
\(^c\) DEN, FR, NETH, NOR, SWE, and SWIZ based on self-reported data; all other countries based on measured data.  
\(^d\) 2012.  
\(^e\) 2011.

It’s clear that our socio-economic status affects our health and how we understand disease. The policies that help form our socio-economic status serve as a major contributor to the social construction of illness. Neoliberal ideology influences our societal institutions, culture, and social norms – attitudes, values, behaviors, and beliefs. All these things, in turn, help create and shape systems of ideas and practices, including those about illness and disease. All this helps shape how a society responds to a particular disease. This in turn, effects the official responses to particular illnesses, it helps determine what – if anything – should be done to limit disease exposure and transmission and how the disease should be handled. Thus, social construction of illness is not just about how we understand that illness, but also how we respond to that illness. This is perhaps best seen through a short case study. So let’s turn now to a discussion on our changing understanding of HIV/AIDS.

**Case Study: Social Construction of HIV/AIDS**

The Centers for Disease Control and Prevention (CDC) estimates that in 2014, 44,073 people were diagnosed with the human immunodeficiency virus (HIV). The annual number of new diagnoses declined by 19% between 2005 and 2014. At the end of 2012 (the most recent year for which data is available),
1.2 million individuals were living with HIV in the U.S. In 2013, 6,955 individuals died from HIV/AIDS, making it the eighth leading cause of death among individuals aged 25-34, ninth for those aged 35-44, and tenth for those aged 45-54 (CDC 2016). While these numbers are high, proportionally, they are significantly lower than they were in the 1980s and early 1990s. In 1992, the World Health Organization (WHO) estimated that in the previous decade, 1.5 million died from AIDS and up to 11 million people were HIV positive. By 1996, the estimated number had increased to 14-15 million (Watts 1997). Indeed, HIV/AIDS is no longer viewed as a death sentence, but rather a disease that, with appropriate medications and lifestyle changes, can be managed. But before we go further and discuss our society’s changing understanding of and attitude toward HIV/AIDS, below is an excerpt from “History of HIV and Overview” accessed from AVERT, an organization dedicated to providing information on HIV/AIDS. 
http://www.avert.org/node/351/pdf

BEGIN EXCERPT – selected facts are included

History Overview

Pre-1980
It is widely believed that HIV originated in Kinshasa, in the Democratic Republic of Congo around 1920 when HIV crossed species from chimpanzees to humans. Up until the 1980s, we do not know how many people developed HIV or AIDS. HIV was unknown and transmission was not accompanied by noticeable signs or symptoms. While sporadic cases of AIDS were documented prior to 1970, available data suggests that the current epidemic started in the mid- to late 1970s. By 1980, HIV may have already spread to five continents (North America, South America, Europe, Africa and Australia). In this period, between 100,000 and 300,000 people could have already been infected.

1981
● In 1981, cases of a rare lung infection called Pneumocystis carinii pneumonia (PCP) were found in five young, previously healthy gay men in Los Angeles. At the same time, there were reports of a group of men in New York and California with an unusually aggressive cancer named Kaposi’s Sarcoma.
● In December 1981, the first cases of PCP were reported in people who inject drugs.
● By the end of the year, there were 270 reported cases of severe immune deficiency among gay men - 121 of them had died.

1982
● In June 1982, a group of cases among gay men in Southern California suggested that the cause of the immune deficiency was sexual and the syndrome was initially called gay-related immune deficiency (or GRID).
● Later that month, the disease was reported in haemophiliacs and Haitians leading many to believe it had originated in Haiti.
● In September, the CDC used the term “AIDS” (acquired immune deficiency syndrome) for the first time...

1983
● In January 1983, AIDS was reported among the female partners of males who had the disease suggesting it could be passed on via heterosexual sex.
● In June, the first reports of AIDS in children hinted that it could be passed via casual contact but this was later ruled out and it was concluded that they had probably directly acquired AIDS from their mothers before, during or shortly after birth.
● By September, the CDC identified all major routes of transmission and ruled out transmission by casual contact, food, water, air or surfaces.
● The CDC also published their first set of recommended precautions for healthcare workers and allied health professionals to prevent "AIDS transmission".

1984
In April 1984, the National Cancer Institute announced they had found the cause of AIDS, the retrovirus HTLV-III. A blood test was ready to screen for the virus with the hope that a vaccine would be developed in 2 years.

In July, the CDC stated that avoiding injecting drug use and sharing needles "should also be effective in preventing transmission of the virus."

In October, bath houses and private sex clubs in San Francisco were closed due to high-risk sexual activity. New York and Los Angeles followed suit within a year.

1985

In March 1985, the U.S. Food and Drug Administration (FDA) licenses the first commercial blood test, ELISA, to detect antibodies to the virus. Blood banks began to screen the USA blood supply.

In December, the U.S. Public Health Service issued the first recommendations for preventing mother to child transmission of the virus.

1986

In May 1986, the International Committee on the Taxonomy of Viruses said that the virus that causes AIDS will officially be called HIV (human immunodeficiency virus) instead of HTLV-III/LAV.

1987

In February 1987, the WHO launched The Global Program on AIDS to raise awareness; generate evidence-based policies; provide technical and financial support to countries; conduct research; promote participation by NGOs; and promote the rights of people living with HIV.

In March, the FDA approved the first antiretroviral drug, zidovudine (AZT), as treatment for HIV.

In April, the FDA approved the western blot blood test kit, a more specific HIV antibody test.

In July, the WHO confirmed that HIV could be passed from mother to child during breastfeeding.

1989

In June, the CDC released the first guidelines to prevent PCP - an opportunistic infection that was a major cause of death among people with AIDS.

1990

In June, the 6th International AIDS Conference in San Francisco protested against the USA's immigration policy which stopped people with HIV from entering the country. NGOs boycott the conference.

In July, the USA enacted the Americans with Disabilities Act (ADA) which prohibits discrimination against those with disabilities including people living with HIV.

In October, the FDA approved the use of zidovudine (AZT) to treat children with AIDS.

1992

In May, the FDA licensed a 10 minute testing kit which could be used by healthcare professionals to detect HIV-1.

1993

In March 1993, the USA voted overwhelmingly to retain the ban on entry into the country for people living with HIV.

The CDC added pulmonary tuberculosis, recurrent pneumonia and invasive cervical cancer to the list of AIDS indicators.

1994

In August 1994, the U.S. Public Health Service recommended the use of AZT to prevent the mother to child transmission of HIV.

In December, the FDA approved an oral HIV test - the first non-blood HIV test.

1995

In June 1995, the FDA approved the first protease inhibitor beginning a new era of highly active antiretroviral treatment (HAART).
The FDA approved the first home testing kit; a viral load test to measure the level of HIV in the blood; the first non-nucleoside transcriptase inhibitor (NNRTI) drug (nevirapine); and the first HIV urine test.

1997
- In September 1997, the FDA approved Combivir, a combination of two antiretroviral drugs making it easier to people living with HIV to take their medication.
- In 1999, the WHO announced that HIV/AIDS was the fourth biggest cause of death worldwide and number one killer in Africa. An estimated 33 million people were living with HIV and 14 million people had died from AIDS since the start of the epidemic.

2000
- In July, UNAIDS negotiated with five pharmaceutical companies to reduce antiretroviral drug prices for developing countries.

2001
- After generic drug manufacturers offered to produce discounted, generic forms of HIV/AIDS drugs for developing countries, several major pharmaceutical manufacturers agreed to further reduce drug prices.
- In November, the World Trade Organisation (WTO) announced the Doha Declaration which allowed developing countries to manufacture generic medications to combat public health crises like HIV/AIDS.

2002
- In November, the FDA approved the first rapid HIV test with 99.6% accuracy and a result in 20 minutes.

2007
- In May 2007, the WHO and UNAIDS issued new guidance recommending “provider-initiated” HIV testing in healthcare settings to widen knowledge of HIV status and greatly increase access to HIV treatment and prevention.

2010
- In January 2010, the travel ban preventing HIV-positive people from entering the USA was lifted.

2011
- In 2011, results from the HPTN 052 trial showed that early initiation of antiretroviral treatment reduced the risk of HIV transmission by 96% among serodiscordant couples.
- In August, the FDA approved Complera, the second all-in-one fixed dose combination tablet, expanding the treatment options available for people living with HIV.

2012
- In July 2012, the FDA approves PrEP for HIV-negative people to prevent the sexual transmission of HIV.
- For the first time, the majority of people eligible for treatment were receiving it (54%).

2015
- In September, the WHO launched new treatment guidelines recommending that all people living with HIV should receive antiretroviral treatment, regardless of their CD4 count, and as soon as possible after their diagnosis.

**END TIMELINE**

HIV infection and AIDS are a complicated disease processes. However, the social construction of this illness has made the pathological that much more complicated. Particularly in the early years of the disease, economic, legal, political, psychological, religious, social, spiritual factors served to magnify disease chronicity (Huber and Gillaspy 1998).

From the beginning, HIV/AIDS was stigmatized and this affected the course of treatment, relationships, and identities that HIV and AIDS patients had and have. However, individuals living with HIV/AIDS are significantly less stigmatized and ostracized today than 35 years ago. At the beginning of the outbreak,
in the late 1970s and well into the early 1990s, AIDS was viewed as a “Gay Man’s Disease.” Indeed, only those in “4-H Club”—homosexuals, heroin addicts, hemophiliacs, and Haitians—were thought to be able to contract the disease. The initial public reaction focused on isolation and ostracism of HIV/AIDS positive individuals. This was as much a reaction to lack of knowledge, and therefore fear, of this new disease as it was a reflection of society’s rampant homophobia. Fast-forward 35 years and while there are still some who ostracize individuals with HIV/AIDS, the public reaction now tends to focus on transmission prevention and patient life longevity. Thus, over the course of four decades, there has been a radical redefinition of HIV/AIDS and how we respond to it. The social construction of this illness has changed.

In 1981, it was first reported that a new infectious disease, Acquired Immune Deficiency Syndrome (AIDS), later understood to be the penultimate health status of people infected by the Human Immunodeficiency Virus (HIV), was sickening and killing individuals. The United States and its citizens were not prepared for such a development. Many believed that infectious diseases, in general, would soon be eradicated and confidence in the medical establishment was high (Watts 1997). As such, when an unknown disease began to spread, the initial and overwhelming response was fear.

Those living with HIV/AIDS were quickly stigmatized as researchers first identified a disease pattern in young men who had been previously healthy and identified or were identified by their physician as “homosexual.” This characteristic became the focus of physicians and researchers, who first referred to the disease as gay-related immunodeficiency (GRID). However, in doing so they, knowingly or unknowingly, glossed over the fact that other individuals, individuals who did not identify as homosexual man, were also coming down with similar disease symptoms. This not only served to strengthen stigmatization of the homosexual community, but also delayed discoveries about transmissibility of the virus through various bodily fluids, making all men and women susceptible to the disease (Wald 2008).

Even when it was discovered and made known that this virus is transmitted through various bodily fluids and activities—sex, blood transfusions, sharing needles—HIV/AIDS continued to be depicted and viewed as a sexually transmitted disease that was plaguing the gay community. Hemophiliacs and intravenous-drug users were mentioned and Haitians (for a number of reasons) pathologized. Indeed, these early years point to the initial social construction of the illness—patterns were identified and integrated into an understanding of the disease narrative, but they only served to demonize those afflicted (Wald 2008).

This narrative of HIV/AIDS as a “gay-man’s disease” was present in both the medical field and mainstream understanding. The Centers for Disease Control and Prevention (CDC), a government run public health institute, published the Morbidity and Mortality Weekly Report (MMWR), which in its June 5, 1981 edition reported that “Pneumocystis pneumonia (PCP), typically seen in immune-compromised individual, in ‘5 young men, all active homosexuals’ between October 1980 and May 1981 at three Los Angeles area hospitals. The men did not know each other, and they had no sexual or casual contacts in common; they shared only their same-sex object choices, their use of inhalant drugs, and the city of Los Angeles” (MMWR in Wald 2008:220). In July of that year, MMWR stated that Kaposi’s sarcoma (KS) and PCP had been diagnosed in “26 gay men in New York City and California during the previous 30 months” (Wald 2008:220). While neither report hypothesized on the link between homosexuality and KS or PCP, this was the one defining characteristic named. Moreover, Alvin E. Friedman-Kien, author of July 1981 MMWR, wrote in the Journal of the American Academy of Dermatology that physicians “be particularly concerned with their patients’ sexual orientation so that they can be better prepared to look for possible immunological defects, genetic susceptibility and related problems” (Wald 2008:220-1).
AIDS A NEW DISEASE'S DEADLY ODYSSEY
By Robin Marantz Henig
Published: February 6, 1983

Medical detectives are calling it the century's most virulent epidemic. It is as relentless as leukemia, as contagious as hepatitis, and its cause has eluded researchers for more than two years. Acquired immune deficiency syndrome, or AIDS, was first seen in homosexual men - particularly those who were promiscuous - but it has now struck so many different groups that its course cannot be predicted.

And despite a massive nationwide microbe hunt involving hundreds of investigators and millions of dollars, scientists simply cannot catch up with it. "We're always a few steps behind," says Dr. William W. Darrow, a research sociologist with the Centers for Disease Control (C.D.C.) in Atlanta, "and that makes us very, very concerned. The disease could be anywhere now."

While AIDS has continued to rage in big-city homosexual communities with terrifying and deadly results, it has also struck Haitian men and women, intravenous-drug users, female partners of drug users, and infants and children. AIDS has become the second leading cause of death - after uncontrollable bleeding - in hemophiliacs, and, most recently, a number of surgical patients who have received blood transfusions have contracted AIDS, raising fears among some observers about the nation's blood supply.

The mysterious AIDS organism is generally thought to be a virus or other infectious agent (as opposed to a bacterium) and to be spread in bodily secretions, especially blood and semen. It is responsible for the near-total collapse of the body's immune system, leaving the victim prey to cancers and opportunistic infections that the body is unable to defend against. And, while some of the diseases associated with AIDS can be successfully treated, the underlying immune problem is, apparently, irreversible. The AIDS patient may survive his first bizarre infection, or his second, but he remains vulnerable to successive infections, one of which is likely to kill him.

AIDS is deadly. According to the C.D.C.'s figures for late January, it has struck 958 individuals since it was first seen in 1979, and it has killed 365, a mortality rate of 38 percent; of the cases reported before June 1981, 75 percent are dead. Although these earlier cases probably received less experienced treatment than AIDS patients get today, some fear that the five-year death rate will be higher than 65 percent. Smallpox, by comparison, killed 25 percent of its victims.

According to Dr. James W. Curran, head of the AIDS task force at the C.D.C., "The incidence of AIDS has nearly tripled in the past year, from about seven new cases a week to 20 or more." In December 1982, the center received reports of 92 cases of AIDS - about one-third more than had been received in any other single month.

As AIDS threatens to move into mainstream America, efforts to find its cause and stop its spread have intensified. In January, Congress allocated $2 million to the C.D.C. for AIDS research. Homosexual communities in major cities have set up support groups that provide information and guidance for victims and raise money for research. Hemophiliacs, many of
whom depend on a clotting agent gathered from the blood of thousands of donors, have recently recommended that those at risk for AIDS be eliminated from the donor pool. Though the moral and legal implications of such screening have yet to be determined, blood suppliers are re-examining their procedures and the Department of Health and Human Services is working on proposals that would provide stricter screening of blood donors. Meanwhile, AIDS continues on its mysterious and perplexing course. "If Alfred Hitchcock were alive, he'd have his next movie," says Dr. Abe M. Macher, an infectious-disease specialist at the National Institutes of Health. "When people discuss this syndrome at scientific meetings, it sounds like something out of 'The Andromeda Strain.' " The search for the AIDS agent is being coordinated in Atlanta, at the Centers for Disease Control. There, 20 full-time physicians and other professionals (with help from 80 professionals working part-time) canvass the four corners of the outbreak - New York, San Francisco, Los Angeles and Miami. They also keep track of the laboratory and clinical experiments being mounted not only at the C.D.C. but at research hospitals across the country. The job of these medical sleuths is complicated by the unusual nature of the patients. Because the AIDS agent probably is transmitted both sexually and through blood, doctors must ask patients, and their survivors, intimate questions. "It's the hardest part of this job," says Dr. Harold W. Jaffe, a member of the C.D.C. task force on AIDS. "And I can understand people who don't cooperate. If I got a call from some guy who said, 'I'm with the C.D.C., and I want to know whether your brother was a homosexual,' I don't think I'd tell him anything." The job is complicated because the doctors know so little about the way many AIDS patients live. "We know that our Haitian patients often are involved in voodoo and spiritualism," says Dr. Sheldon Landesman, assistant professor of medicine at the Downstate Medical Center in Brooklyn. "But we don't know what in their rituals might be relevant to the transmission of AIDS."

Drug users are equally elusive, and, says Dr. Gerald H. Friedland, an associate professor of medicine at the Albert Einstein College of Medicine in the Bronx, some of whose AIDS patients are addicts, "getting good medical histories from them is very, very hard." Difficult though the task has been, however, the medical investigators have traced in broad outline the spread of the disease. In the spring of 1981, clinicians in New York City began to see a surprising number of cases of an extremely rare cancer called Kaposi's sarcoma. Dr. Linda J. Laubenstein, an instructor in clinical medicine at the New York University School of Medicine, recalls one of the first patients she saw with Kaposi's sarcoma. He was 33 years old and he arrived at the clinic with two purplish spots behind his ears. The patient responded well at first to anticancer drugs, but after 18 months his condition suddenly deteriorated, and he died with 75 lesions covering his body. Kaposi's sarcoma is usually seen in this country in elderly men of Mediterranean extraction. In its classic form, Kaposi's sarcoma is treatable; its victims usually live at least 10 years after the condition is diagnosed and they often die of other causes. So when clinics in the city began to report severe cases of the rare sarcoma in young men, the medical community was alarmed. "One patient was an interesting event," says Dr. Laubenstein; "two was an epidemic."

At about the same time, infectious-disease specialists throughout New York were noticing another bizarre occurrence. At the weekly citywide infectious-disease meetings sponsored by the New York City Department of Health, where physicians present their most perplexing cases, many of the cases mentioned involved a severe and potentially lethal form of pneumonia, Pneumocystis carinii.
Like Kaposi's sarcoma, Pneumocystis pneumonia was considered a rare disease. It also affected patients whose immune systems were severely compromised: cancer-chemotherapy patients and organ-transplant recipients. Now, a new group of patients was developing the disease. "Without even trying, we found 11 cases of Pneumocystis in young men," recalls Dr. Henry Masur, an infectious-disease expert then at New York Hospital-Cornell Medical Center and now at the National Institutes of Health. Within a year of diagnosis, eight of the 11 men were dead.

In mid-1981, the Federal Government became involved in the mystery. To investigate the outbreak, the C.D.C. formed a special task force, which published its first findings in June and July in Morbidity and Mortality Weekly Report, C.D.C.'s official publication. Of the 116 homosexual patients identified at the time, about 30 percent had Kaposi's sarcoma, about 50 percent had Pneumocystis pneumonia and about 10 percent had both. The remaining 10 percent had unusual infections that also usually affect only the immunosuppressed.

Half of the victims lived in New York City, and there was a large concentration of cases in California. Those studied were sexually promiscuous: Their average number of lifetime sexual contacts was 1,100; they frequented homosexual bars and bathhouses (where a typical visit may include sex with 15 to 20 deliberately anonymous men). Many of them also used "poppers," inhalant amyl nitrite and butyl nitrite, drugs said to have the effect of enhancing orgasm.

In the fall of 1981, the C.D.C. studied the sexual habits of 50 homosexual victims of AIDS. The investigators did not ask for the names of their partners. "We just didn't think they'd know any names," admits Dr. Darrow, a member of the C.D.C. task force who has spent 20 years studying the spread of sexually transmitted diseases. Later, to his surprise, some people came forward on their own to volunteer names.

"One guy in Los Angeles whose dear friend had died - a man with whom he had lived for many years - came to us and said, 'You really ought to know that my friend had sex with three or four of the other cases in Los Angeles and six more cases I know of throughout the United States,' " Dr. Darrow says. "Simultaneously, a patient who had been seen for syphilis told us, 'I had sex with five or six people I know of who have the gay plague.' That made us think that maybe the others would know the names of some of their contacts."

For 13 patients in Los Angeles, Dr. Darrow and Dr. David Auerbach, a C.D.C. officer based in the city, compiled a list of all the sex partners that the patients or their survivors could name for the previous five years. They then compared those names with the roster of all the cases in the country. The result: Of those 13 cases, nine had sex contacts in common, a finding that could not possibly have been a random coincidence. This was the so-called L.A. cluster of AIDS patients. Later, a missing link was found between Los Angeles and New York. An AIDS patient from New York was identified as having been a sexual partner of four men in the L.A. cluster - as well as of four other men in New York who also developed AIDS.

Epidemiologists developed many theories about why homosexual men were at risk for these rare infections and cancers. Sexually active homosexuals are prone to a host of diseases: syphilis, gonorrhea, genital herpes, hepatitis, amebiasis (one of the most common diseases in what doctors call the "gay bowel syndrome") and infections caused by fungi and protozoa usually seen only in the tropics. Indeed, bizarre infections are so common in the homosexual community that one scientist, presenting a report on these occurrences in 1968, called his talk "Manhattan: The Tropical Isle."

One theory was that the immune systems of the patients were being crippled after repeated infection by these sexually transmitted diseases. Other theories were that a new virus that could destroy immunity was being transmitted through oral-anal or anogenital contact; or
that the amoeba responsible for amebiasis was carrying with it a previously unknown virus; or that overexposure to sperm from many sources was having an immune-suppressant effect (in animals, sperm in the bloodstream is known to suppress the immune system); or that poppers were damaging the immune system (another theory that had some basis in animal research).

As the syndrome spread to other groups, however, early theories that attempted to explain the outbreak among homosexuals were discarded. Within months, intravenous-drug users - both men and women - who were not homosexuals were showing the same signs of immune suppression and developing the same unusual opportunistic infections. Then came Haitians, in both the United States and Haiti, who said they were neither homosexuals nor drug users but who developed what appeared to be an identical syndrome of acquired immune deficiency.

The Haitian connection was made almost by a fluke. An epidemiologist working for the C.D.C. on another matter had trained in Haiti and returned there on vacation. He mentioned to a former colleague the odd infections that were turning up among Haitians in Miami. To his astonishment, the Haitian dermatologist replied that he, too, had seen several cases of Kaposi’s sarcoma. Since then, teams of physicians from the C.D.C. and from the University of Miami, where many Haitian immigrants with AIDS are treated, have visited Haiti in an attempt to confirm that it really is the same syndrome and to determine if the agent originated in the Caribbean and moved north or whether it was transported to Haiti from this country.

In the spring of 1982, the C.D.C. received its first reports of AIDS in hemophiliacs. Some of these patients were probably exposed to the AIDS agent in a blood-clotting medication called factor VIII concentrate that is made from the blood of thousands of donors. Anywhere from 2,500 to 22,000 blood donors are used to make just one lot of this widely used product; one lot treats about 100 patients. To date, the C.D.C. has received a total of eight confirmed reports of hemophiliacs with AIDS, six of whom have died. All used factor VIII concentrate rather than an older, less convenient blood product called cryoprecipitate, which is made from the blood of a handful of donors. In view of the AIDS threat, some hemophilia experts are urging a return to cryoprecipitate, especially in mild or newly diagnosed cases.

In the summer of 1982, the C.D.C. received reports of three patients who contracted AIDS after receiving blood transfusions. Two of those patients were adults from the Northeast and the third was an infant in San Francisco who needed a transfusion to correct an Rh factor incompatibility. Four more cases of possible transmission of AIDS through blood transfusions are now being investigated.

By mid-January, the C.D.C. had received five reports of AIDS that had spread to female sexual partners of drug abusers. In four of those cases, the male partners had not even been sick. Thus, AIDS qualified as a sexually transmitted disease among heterosexuals. It also began to be clear that individuals could be identified who might be carriers of the AIDS agent, able to infect other people without themselves developing symptoms.

As of mid-January, the C.D.C. had also heard of 26 infants and young children with symptoms of AIDS. Thirteen of these children had opportunistic infections, indicating that they probably had AIDS; the 13 others had AIDS-like immune deficiencies, but no serious infections. Of the 13 children with infections, nine have since died. Many of the children are in foster care, and the C.D.C. is trying to trace their mothers and take Page 36 medical histories. The cases were found in New York, New Jersey and San Francisco. As far as the Federal agents could tell, most of the children were born to mothers with acquired immune deficiency syndrome, or at least to mothers at risk for the syndrome because of drug use. Dr.
James Oleske, a pediatric immunologist and associate professor at the University of Medicine and Dentistry of New Jersey, has treated eight young patients since 1979, four of whom have died. He believes the disease is passed on either in the womb or through normal contact between mother and child after birth. "It's a tragedy," he says of the cases he has seen. "The only thing to be said for it is that eventually AIDS will help us understand more about the immune system." Homosexual men still represent 75 percent of the disease's victims, and the specter of AIDS haunts every member of the homosexual community, especially in the cities where it is most prevalent (they are, in descending order, New York, San Francisco, Los Angeles, Miami, Newark, Houston, Chicago, Boston, Washington and Philadelphia)....

END OF ARTICLE EXCERPT

In the 1980s, homophobia was widespread and homosexuality demonized. Thus, it’s no surprise that the disease and illness quickly became stigmatized. Later, in the 1980s, Haitians, intravenous-drug users, and hemophiliacs were incorporated into the framework. Each of these groups was viewed as somehow having brought the disease onto her/himself and was vilified for her/his identity. Some accounts accused Haitians of bringing the virus into the United States. Intravenous-drug users were blamed for bringing the virus onto themselves because of needle-sharing. Homosexuals were blamed for the disease because of their sexual activity. Hemophiliacs were the only individuals viewed as undeserving. The stigmatization of gay men and "4-H club" persisted well in to the 1990s.

This mentality was also exemplified by the Regan Administration. Reagan was president when the HIV/AIDS epidemic first took hold of the country. However, it was a full five years before he said “AIDS” in public and seven years before he publically spoke about it. In addition, Reagan and his administration applied neoliberal logic in their understanding and depiction of HIV/AIDS. As HIV/AIDS spread, a number of states put into effect HIV-specific criminal exposure laws. When asked about the epidemic, a Reagan representative stated that this was a legal rather than medical problem. Instead of discussing the illness, the representative maintained that individuals living with HIV/AIDS had broken the law (Guardian 2016). Thus, the onus was on the individual – she/he had failed in personal responsibility. No mention was made of how the government had failed in understanding and educating about the disease. Nor was there any mention with regards to how the government would help sick individuals. This mentality persisted throughout the 1980s. In 1988, President Reagan’s Commission on the Human Immunodeficiency Virus Epidemic suggested that HIV-specific criminal statutes for intentional transmission could reduce the spread of the disease (CDC, HIV-Specific Criminal Laws).

All of these things influenced how we viewed and understood HIV/AIDS in the 1980s. These were all major contributing factors to the social construction of this illness. But this social construction has real consequences. In the face of being highly stigmatized, individuals diagnosed with HIV/AIDS were discriminated against and isolated. Many individuals were fired and/or denied employment, housing, and admission into schools, clubs, and organizations. Moreover, this social construction impacted education, prevention efforts, and treatment progress. As such, patients were often left to rely on other patients and community-based organizations for support (Huber and Gillaspy 1998). It is many of these organizations that began to advocate about HIV/AIDS and helped change our social construction of this illness.

Today, individuals living with HIV/AIDS in the United States continue to face stigma and discrimination. However, it is on a significantly lower scale than in 1980s. There is a better understanding of how HIV is
transmitted and the preventions that people and institutions (such as hospitals) should have in place to help avoid transmission. For example, all blood is now tested for the virus before being used in transfusions, needles are only used once, and all healthcare workers wear gloves whenever in a situation of possibly encountering bodily fluids. In addition, the medical, governmental, and public reaction now focus on transmission prevention and patient life longevity. Most importantly, education no longer focuses on identity characteristics of those most at risk, but rather behavioral traits. Thus, over the course of four decades, there has been a radical redefinition of HIV/AIDS and how we respond to it. The social construction of this illness has changed. Let’s take a closer look.

Today, HIV/AIDS is no longer viewed as a “Gay Man’s Disease.” It is now common knowledge that anyone can become infected. The conversation no longer focuses on one’s identity, but rather on the behavior that one engages in that may put her/him at risk. Likewise, HIV/AIDS is no longer viewed as a death sentence. Indeed, if one begins antiretroviral medication early on, she/he can expect to have a near normal life span. It is also possible that, with treatment, the viral load can become undetectable. This means that not only is there no active virus in the patient and that the infection is undetectable, but that there is also a significant reduction in the possibility of transmitting the virus. Finally, much of the focus on HIV/AIDS is international in scope. It is clear that developing country populations have higher rates of HIV/AIDS than in the United States. This is for a number of reasons, but what is particularly interesting is how the conversation of why these countries need help in curbing this disease is framed. Rarely do development agencies, such as the World Bank, focus on the humanitarian aspect – that living and dying from AIDS can be painful and that each person deserves a healthy, quality life. Instead, these agencies focus the conversation on the economic impact of the HIV/AIDS on a country’s economy. Specifically, when individuals with AIDS-related complications become increasingly sick, they are no longer able to work and must drop out of the workforce. In addition, as the disease progresses, patients are often not able to take care of themselves, forcing family members to leave the workforce and become caregivers. When this occurs, it is viewed as an economic loss to the country’s economy because now fewer workers are in the labor force, which in turn means, fewer consumers in the market. Thus, the framework is one of economics rather than health and humanity.

Regardless of whether HIV/AIDS is being discussed from an international or domestic perspective, it has become abundantly clear that socio-economic inequalities are at the heart of this disease. Not only does an individual’s socio-economic status potentially influence the probability she/he acquires HIV and develops AIDS, but it also helps determine the quality of life an HIV/AIDS patient will have – the sorts and amounts of treatment possibilities. Fewer socio-economic resources have been associated with increased risky behaviors – less frequent condom use and increased intravenous drug habits – that can lead to HIV infection. Individuals who are homeless or in unstable housing are also at an increased risk of becoming infected with HIV than individuals with stable housing. Likewise, HIV status affects one’s socio-economic status as it may impact an individual’s ability to work. If unemployed or employed only part-time, the individual may not have health insurance. While some HIV/AIDS patients qualify for Medicare or Medicaid, not all do. The presence and type of health insurance one has dramatically affects the sorts of treatments she/he is able to receive. Indeed, those of low socio-economic status have delayed treatment, reducing their longevity (APA 2016).

The below article from the New York Times shows our changing attitude and understanding towards HIV/AIDS


BEGIN ARTICLE
Cuomo Expands H.I.V. Benefits in New York City

By NIKITA STEWART
JUNE 24, 2016

Thousands of New York City residents who are H.I.V.-positive will become eligible for public assistance for housing, transportation and food under a significant expansion of a state program that some activists had feared was being delayed.

Gov. Andrew M. Cuomo announced on Thursday that low-income city residents who are H.I.V.-positive but asymptomatic would get the same assistance as low-income residents who show symptoms. About 6,500 to 7,000 additional people are expected to benefit from the expansion of the program, known as the H.I.V./AIDS Services Administration, or HASA, which now helps about 32,000 people.

The announcement came after what some advocates described as a series of broken promises by Mr. Cuomo, a Democrat, to expand the program, fully administer a plan meant to end H.I.V. and AIDS in New York by 2020 and finance that plan. Jeremy Saunders, an executive director of VOCAL-NY, a nonprofit focused on helping low-income people with H.I.V. and AIDS, said activists had been frustrated by Mr. Cuomo’s failure to move forward on the expansion more quickly.

Advocates were preparing to pressure Mr. Cuomo just before New York City’s annual gay pride parade and festival this weekend. “We are thankful to the governor that he has finally taken this step forward after a hard-fought campaign,” Mr. Saunders said.

Alphonso David, the governor’s counsel, said that Mr. Cuomo had always been committed to expanding the HASA program’s benefits, but that he had had to find a way around a reluctant State Legislature. To broaden the program, Mr. Cuomo is simply modifying a longstanding social services policy that made a distinction between people who showed symptoms and those who did not, Mr. David said. “The governor took a very creative and important approach to provide services to all people who are living with H.I.V.,” he said.

The governor’s office said that the new policy would take effect in 60 days. But city officials are still awaiting the language, said Steven Banks, the city’s Social Services commissioner. “We added money to our budget a number of months ago to extend HASA to all clients with H.I.V., and we look forward to seeing the details of this new program so that we can make sure that it covers all the New York City residents with H.I.V. we have identified in need, and also provides the necessary resources,” Mr. Banks said in an interview.

Mr. Banks said the city had estimated that it would spend about $52 million in the first year of the program’s expansion and $89 million a year after that. Mr. David said the state had estimated its contribution would be about $31 million a year.

Under the program, the city’s Human Resources Administration helps participants who spend more than 30 percent of their income on housing by reimbursing them the difference. They also get money for transportation and food.

Advocates say that housing assistance is an effective way to help keep people with H.I.V. or AIDS from becoming homeless and from spreading the virus. “When people have a home, they are taking their medicine,” Mr. Saunders said.

Corey Johnson, a City Council member who is H.I.V.-positive, said that thousands of New Yorkers had not been getting help because “they weren’t sick enough.” “This is going to help a lot of poor people,” Mr. Johnson, a Manhattan Democrat, said. He added that wealthy, white men often received better services than low-income, black women. “H.I.V. has really become a disease about poverty.”
Mr. Johnson praised Mr. Cuomo, though he said there had been disappointment when there was little obvious action after the governor announced his plans for the expansion, among other initiatives, on November 30, in recognition of World AIDS Day. “My understanding is that there wasn’t much appetite,” Mr. Johnson said, referring to the State Legislature. “The governor’s office was working hard.”

Kelsey Louie, chief executive of the Gay Men’s Health Crisis, said in a statement that his group was looking forward to helping the governor expand the HASA program. “The country and the world are watching what we are doing in New York,” he said, “and gratefully they see action on the part of our executive when our legislature falls short.”

The governor is likely to continue to feel pressure as advocates seek to bolster services outside New York City. “Advocates are always going to push the governor, but we view him as a friend,” said Anthony Hayes, vice president of public affairs and policy for the Gay Men’s Health Crisis. “There can always be more money and it can always happen faster.”

Correction: June 28, 2016

Because of an editing error, an article on Saturday about the extension of a state program for low-income H.I.V. patients paraphrased incorrectly from comments by Alphonso David, Gov. Andrew M. Cuomo’s counsel, about what the governor had to do in order to expand services in New York City. Mr. David said Mr. Cuomo had to find a way to work around a reluctant State Legislature, not find a way to work with it.

END ARTICLE

The Role of Social Movements

One key reason why there has been such a shift in how we think about and understand HIV/AIDS and people living with HIV/AIDS is because of the social movement that arose out of AIDS. The movement around HIV/AIDS was extremely diverse and aimed to be all-encompassing. It incorporated not just people living with HIV/AIDS and their loved ones, but also “grassroots activists and advocacy organizations...health educators, journalists, writers, and service providers” (Epstein 1996:8). Moreover, the movement successfully integrated a number of communities and constituencies who may not have worked together previously, but all were greatly affected by the disease in some way – the gay and lesbian community, people with hemophilia, injection drug users, and many African-American and Latino communities. This turned out to be a key component of the success of the movement – the all-inclusive nature of the participants allowed the AIDS movement to essentially build on groundwork laid by previous movements. In addition, the AIDS movement was exceptionally strategic in identifying strengths and weaknesses of these past movements (Epstein 1996). All this was done in an effort by the movement to normalize the disease and those living with it. Activists staged numerous events to offer a counter narrative to understanding how the disease spread. The HIV/AIDS movement also made sure to incorporate other issues into their activism so as to ensure maximum participation (Gamson 1989).

Another important component of this movement’s success was that the key groups involved employed varied strategies aimed at popular and institutional change through education, policy change, and research. One key group, AIDS Coalition to Unleash Power (ACT UP), engaged in numerous publicly visible actions, such as a public kiss-in condemning gay and lesbian violence, civil disobedience to push policies, and marches to bring awareness to issues (Anon 2012; Gamson 1989). Perhaps one of the most well-known actions of civil disobedience of this social movement was the organization of a conference, rally, and teach-in in protest of the U.S. Food and Drug Administration (FDA) led by ACT UP and other groups. Patients and activists believed that the FDA was dragging its feet with making new therapies
available for HIV/AIDS patients. While many agreed that medications need to be tested for safety and efficacy, many others maintained that AIDS sufferers had little to lose and maintained an individual should have a right to choose about when and what sorts of medications to take (Epstein 1996; Anon 2012).

This points to an important component of the AIDS social movement – the “expertification” of various participants. In order to successfully challenge medical and political authority, activists needed to learn pertinent information for themselves. While numerous HIV/AIDS experts certainly partook in the movement and were key in allowing others to gain the knowledge necessary, many more participants taught themselves the biological, epidemiological, and immunological details behind the disease. This allowed participants to have the ability to effectively counter and criticize “scientific research” predicated on homophobia or racism and push for redefining public health to include safe sex education for all. In addition, as “expertification” and credibility of movement participants grew (particularly as more and more individuals spoke “in the language of medical science”), the movement was able to push for new drug trials and criticize various clinical research methodologies. All this helped to legitimize the movement and its participants. This relationship between the movement and research community is one thing that makes AIDS movement so distinct (Epstein 1996).

More than anything, the AIDS movement successfully employed numerous tactics – theatrics, grassroots activism, consciousness raising, research, and education – to shift the notion of responsibility. Initially, individuals were viewed as having brought the disease onto themselves. Now, people living with HIV/AIDS are understood to live within frameworks which make them more or less likely to engage in behavior that will lead to infection.

Despite all the changes in how we understand and depict HIV/AIDS, one thing has not changed. The narrative of personal responsibility continues. This should come as no surprise given that we are still living in the throes of neoliberal policies and ideology. No doubt, education campaigns have increased as have services for those living with HIV/AIDS. But many of these services are run by private, non-profit organizations. Moreover, we have completely failed in devising a comprehensive strategy that takes into account social structural factors and that aims to address the primary drivers of HIV vulnerability – neoliberal policies that have created poverty, increasing inequality, and gutted social protection programs. The focus can no longer solely remain on biomedical and behavioral interventions, but instead must also institute policies that promote health and well-being – guaranteed healthcare, equal access to education, good housing, and protection from hunger (Auerbach, Parkhurst, and Caceres 2011). We must shift our focus away from viral infection and the person who contracts the infection, and instead concentrate on our societal framework.

**Conclusion: Rethinking how We Understand Disease and Illness**

This home study has discussed the notion of social construction and how illness is socially constructed. Illness cannot truly be understood outside of our social and economic policies and contexts. To truly combat any disease, we must recognize the vital role these factors play in the spread of diseases. That means you, as patient advocates must bring greater awareness to the role policies and policy-making plays in your patients’ lives. It is not enough to treat the pathology on its own, we must also address the underlying and root causes that bring about our current social problems and human suffering. Until social, political, and economic inequalities are addressed and individuals are guaranteed quality, affordable healthcare, our understanding of disease and illness will continue to be skewed toward personal rather than societal responsibility.
References


