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MAY

Year

2015

Diploma Programme subject in which this extended essay is registered: SOCIAL + CULTURAL ANTHROPOLOGY

(For an extended essay in the area of languages, state the language and whether it is group 1 or group 2.)

Title of the extended essay: NAMING A PLAGUE : LINGUISTIC RELATIVITY AND THE INITIAL RECEPTION AND TREATMENT OF HIV/AIDS BY SOCIETY AND GOVERNMENT IN THE UNITED STATES

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I have acknowledged each use of the words, graphics or ideas of another person, whether written, oral or visual.

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had some difficulty finding sources on the topic but overcame this difficulty by consulting a broad range of secondary sources and selectively choosing data. Her advantage was having a clear, focused research question to narrow her research.

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Assessment form (for examiner use only)

Candidate session number		
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Achievement level

Criteria	Examiner 1	maximum	Examiner 2	maximum	Examiner 3
A research question	2	2		2	
B introduction	2	2		2	
C investigation	3	4		4	
D knowledge and understanding	4	4		4	
E reasoned argument	4	4		4	
F analysis and evaluation	3	4		4	
G use of subject language	4	4		4	
H conclusion	1	2		2	
I formal presentation	4	4		4	
J abstract	2	2		2	
K holistic judgment	4	4		4	
Total out of 36	33				

Name of examiner 1: _____ Examiner number: _____
(CAPITAL letters)

Name of examiner 2: _____ Examiner number: _____
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Name of examiner 3: _____ Examiner number: _____
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Naming a Plague: Linguistic Relativity and the Initial Reception and Treatment of HIV/AIDS by
Society and Government in the United States

Extended Essay

May 2015

Social and Cultural Anthropology

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Abstract

In this essay, I will explore the hypothesis that the terms initially used to describe the virus now known as the Human Immunodeficiency Virus shaped the way it was first viewed and treated by the society and government in the United States. In order to analyze this topic in depth, I will first examine concepts in linguistic anthropology, such as linguistic determinism, linguistic relativity, and taboo. These concepts will aid in the comprehension of the societal effects of the primary names of HIV, such as "gay cancer" or "Gay-Related Immune Deficiency".

The primary text used are *And the Band Played On* by Randy Shilts and *How to Have a Theory in an Epidemic* by Paula A. Treichler. I will discuss their heuristic perspectives and then the ethical considerations of both reading ethnographies and writing an anthropological paper before exploring the affects of language in terms of taboo, power, determinism, relativity, roundabout speech and language neutrality.

I found that although difficult to determine the precise effects of language on the initial perception of HIV/AIDS in the United States, there are undeniable correlations between the language used to speak about the virus, infections rates, and statements made by persons with AIDS. It was heavily indicated that this effect was negative, and that the preliminary names for HIV engendered fear, hatred, and further ignorance of the virus amongst the unaffected American majority.

Word Count: 229

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Introduction

The Acquired Immune Deficiency Syndrome (AIDS) epidemic was and continues to be one of the most serious yet most ignored health crises in the United States. The language used surrounding the Human Immunodeficiency Virus (HIV) and its ensuing syndrome, AIDS, is one of the major sources of this neglect. Language is the symbolic source of human information. However, for only being a symbol of actual reality, language holds great power. Language has connotation created in the mind of the speaker, because language has the capacity of determinism, meaning language and the way we use it may determine worldview (according to the Sapir-Whorf hypothesis). This capacity of language means that the words we choose to use have a direct impact on the way we view the thing they symbolize. Likewise, the Sapir-Whorf hypothesis also sets forward another idea of linguistic relativity, in which linguistic differences will also reflect difference in worldview¹. Granted, the Sapir-Whorf hypothesis is generally used to describe the differences in worldview between groups who speak different languages. However, in this case, it will be used to examine differing worldviews in a nation that speaks the same language, albeit with many different speech genres.

When HIV first began to spread at increased rates in the United States, the Gay Liberation movement was in full swing. Homosexuals, mostly men, were finally receiving recognition and small tastes of equality on the national level, yet the gay community was still somewhat of a taboo in American culture. The term "taboo" refers to "persons, activities (including speech), or things under prohibition"². In this case, homosexual behavior (along with other connected behaviors like prostitution and drug use) associated with HIV fell under this category. Homosexual behavior was considered taboo for mainly religious reasons – an issue far too complicated to delve into in this paper. When doctors and scientists began discovering the patterns of HIV, they struggled with addressing the virus, as it dealt mainly in this taboo world of homosexuality. For the heterosexual American, the taboo of a virus first publicized as "gay cancer" or the "Gay Related Immune Deficiency" caused immediate disengagement. The taboo of the term "gay" as well as the experiential negativity of the word "cancer" had created a predetermined viewpoint of both of these topics, forcing this new epidemic to the sidelines of the American viewpoint. Taboo, roundabout speech, and primarily linguistic relativity attempt to describe the way in which the terms initially

¹ Zdzienek Salzmänn, *Language, Culture, and Society: An Introduction to Linguistic Anthropology, Second Edition*, (Boulder: Westview Press, 1998), 42.

² Salzmänn, *Language, Culture, and Society*, 194.

used to describe the virus now known as HIV shaped the way it was first viewed by the society and government in the United States.

Groups Studied, Ethical Considerations, and Ethnographer Bias

The group analyzed in this paper is large – the affected minority, the moral minority of scientists and government officials, and the unaffected American majority in the United States from 1980 until 1988, the year in which United States Surgeon General, C. Everett Koop distributed the first comprehensive material on the virus to the American public. The affected minority was for the most part, a hugely marginalized group in the United States at the time. Initially consisting of mainly homosexual men, intravenous drug users, and sex workers, this group lacked sociopolitical power and authority. Another portion of the group, the moral minority of scientists and government officials, held a large amount of sociopolitical power and authority stemming from their general higher education, higher economic status, as well as the fact that many of them were straight white males. This inequality existed to the point in which the involved scientists and officials held the majority of power over the lives of those infected. This power dynamic left the majority hanging between the information being presented by the two groups, generating the situation discussed in this text.

Just as many groups discussed in this paper held a disproportionate amount of power, ethnographers also have a great amount of power in portraying the lives of others. *And the Band Played On* by Randy Shilts and *How to Have a Theory in an Epidemic* by Paula A. Treichler were the two most-considered texts in this paper. Neither is solely ethnographic, but both authors were college graduates who had extensive prestige in the writing world. While Treichler and Shilts effectively had ability as less-marginalized people to write as they wished about those affected by HIV/AIDS, they also had the responsibility to share the story of those who could not share it themselves. Both Shilts' and Treichler's heuristic perspectives are structure-centered, as they both focus on how the hegemonic heterosexual-centric structure of the U.S. Government and powerful moral minority impacted the lives of those living with HIV/AIDS. Their texts are also highly conflict-centered, focusing on the effect of the push and pull of these groups. It is difficult to determine if they have diachronic or synchronic perspectives, as they both touch on the complicated history of the power dynamics of homosexuality in the United States, but ultimately their foci are on the issue as it stood in the 1980s and 1990s. Likewise, they both have a particularistic heuristic theory as both texts are focused in on a very particular group at a particular time. Both authors also have an

idealistic heuristic theory, as they focus on how beliefs and values of mainly authoritative groups shaped the reality of those affected by HIV/AIDS. Both texts are highly postmodern, as they focus on issues of local narratives and a previously repressed homosexual history in the American culture.

It may seem difficult to believe that both authors share heuristic perspectives through and through, but this ties in with yet another ethical consideration. Because the general knowledge and awareness of the topic was so low until the late 1980s, many of the anthropologists and scientists who initially reported on the topic were very close to the patients and affected groups themselves. Even if the authors were not in the same physical environment, emotional connections concerning this topic run deep, so a pure, unbiased opinion is difficult to find.

Evolution of a Name: The Creation and Effects of GRID, Gay Cancer, and WOGS

Although HIV began to seriously affect people in the late 1970s, there was no common name for the virus or its associated symptoms until the mid 1980s. Many complexities were associated in the naming of the virus, and these complexities generated misinformation, fear, and ignorance amongst the American public.

Some Basics

The name of any thing contains high value to humans. Humans live in a symbolic world generated by language that represents the physical and imagined world around them. Human language possesses many qualities that distinguish it from animal communication. Edward Sapir and Benjamin Whorf examined one of these qualities in the early-to-mid 1900s. The Sapir-Whorf Hypothesis discusses the double principle of linguistic determinism and relativity. Determinism is the idea that one's thoughts are shaped by the language that one speaks while relativity is the idea that language differences are the reason behind the differences in worldview perceived between different linguistic groups³. In this case, all members of the groups studied speak the same language (American English), however their speech genres are very different. Speaking on the same topic, there are not only regional differences, but differences in education and perspective that intensively impact the terminology used.

The case of naming this particular virus presented many ethical problems that, from an anthropological viewpoint, are particularly familiar. Initially, scientists and doctors were faced with the struggle of naming this syndrome, solely so they could publish and conduct research on it in a

³ Salzmann, *Language, Culture, and Society*, 42.

more organized manner. In this case, due to possession of cultural capital of higher education, the language used by these scientists and doctors was considered authoritative. At the time, the majority believed that HIV only affected homosexual men. This was a widely misunderstood group and so the situation was similar to an anthropologist attempting to find an ethical way to observe and report on a cultural group from an etic perspective without trivializing the group itself. The scientists' lack of knowledge on this cultural group led to a more ethnocentric perspective. There were two groups, "us" (being the authoritative moral minority of scientists and government officials) and "them" (being the marginalized affected minority), and the majority of unaffected, unconcerned people were caught in the middle. Linguistic relativity was prompted by a name created by the authoritative minority. Even when a preliminary name was agreed upon, neither scientists nor patients were content. However, by the time "HIV" and "AIDS" were finalized, the preliminary names had done irreversible damage.

Determinism and Relativity

When the virus now known as HIV and its associated syndrome (AIDS) first began affecting people in the United States, scientists and patients alike had no way of analyzing what had hit them. Within this small group, members began to call the unknown killer by what made sense. The illness affected primarily gay men, and it affected their immune systems aggressively. Thus emerged the first name: the Gay-Related Immune Deficiency, or GRID. Kaposi's sarcoma, a rare form of skin cancer, was also associated with the illness, leading to another of the preliminary names: gay cancer. More conservative physicians (most of which were not in direct contact with HIV-infected patients) began calling the illness "Wrath of God Syndrome" or WOGS, a feeble attempt to describe the horrors of the illness while also suggesting that the "unholy" lives of those primarily affected had led to their infection (to some extent, this was actually true). All of these names were descriptive of what patients, scientists, and doctors alike believed to be the situation. However, their unawareness combined with specific language did become a problem when it reached the greater community who had not yet been greatly affected by the virus.

Often, when the Sapir-Whorf Hypothesis is discussed, examples of language comparison are brought up – the Hopi grammatical structure concerning time, for example, its comparison to that of modern English. However, the ideas of determinism and relativity are applicable within a single language when looking at singular word choice in specific speech genres.

GRID, gay cancer, and WOGS were all detrimental misnomers. As the virus became more prevalent and these terms began to seep into the life of the American public, they rapidly shaped the worldview of the virus. Words like "gay", "God", "wrath" and even "cancer" evoked negativity –

the first three from religious connotation and taboo, and the last because of harmful experience. Because of the public's reaction to these terms and their general reluctance to deal with those ideas, the virus was shifted out of the American worldview, when it should have been at the center.

Taboo

As stated before, homosexuality was often seen as taboo for mostly complicated religious reasons. However, this avoidance engendered poor education on the topic. Rumors of strange sexual practices, outrageous promiscuity, emotional detachment from sexuality, and abounding sexually transmitted infections. Some of it was true, but some of it was fear-fueled ignorance. There were so many taboo topics associated with one group of people. When the full scope of HIV patients and risk groups was uncovered, more taboo topics popped up. Intravenous drug users, prostitutes, and certain groups of immigrants were all at high risk. All of these groups, which had been nearly invisible to the American public for so many years due to low status, were now targets of this new virus. Again, the idea of "them" and "us" was perpetuated. The virus became attached to "them", and the power of the "us" (the moral minority) convinced the American public majority that they were near immune. The media, scientists and doctors all perpetuated this myth, avoiding the most taboo topic of all: that the unaffected majority occasionally partakes in activities that only "they" do.

Roundabout Speech

When scientists first reported on the virus (then seen only as a recurrence of *Pneumocystis carinii*), no one dared use any term associated with homosexuality, not only to avoid offending homophobes, but also to avoid offending the homosexuals themselves. The article was placed on page two of the CDC's weekly *Morbidity and Mortality Report*, and was titled "Pneumocystis carinii-Los Angeles" (as that is where the majority of reported cases were occurring⁴). Avoidance was a major component of the formation of the term AIDS as well. An attempt to create a term that would create a more positive worldview led scientists to name a rather horrible syndrome something comparatively tame. Salzmann states in *Language, Culture and Society*, "Some cultures value directness ('Would you please close the door?'); others prefer roundabout speech ('It seems to be getting a but cold in here, don't you think?')"⁵. Roundabout speech is more consistent in the American culture, if one can generalize on such a large nation. Terms like "gay cancer" are very direct, and therefore did not settle well in a digressive nation.

⁴ Shilts, *And the Band Played On*, 68.

⁵ Zdznek Salzmann, *Language, Culture, and Society: An Introduction to Linguistic Anthropology, Second Edition*, (Boulder: Westview Press, 1998), 194.

Language Neutrality

In order to seek out a term that would hopefully shift the American worldview on the virus and those it affected in particular, it was necessary for doctors and scientists to take an approach of language neutrality. Language neutrality, discussed by Salzmann, is the idea of selecting a means of communication to generate a more neutral worldview⁶. While most commonly manifested as explicitly choosing a national language, in this case it was the selection of a speech genre and even specific words to generate worldview. This is a form of language planning, in which language is used to reinforce and generate ideas concerning a cultural group or nation. By creating a new word to describe the virus, scientists were able to begin to take ownership of the way in which Americans perceived and treated it.

Categorization

Another aspect of the naming of the virus was the categorization of those it affected. Before the virus itself was isolated, it was called GRID or gay cancer. Regardless, both of these names referred strictly to homosexuals as those contracting the syndrome. As research proved that there were more and more risk groups, scientists and doctors continued to refer to these risk groups in their reports and studies, rather than the effects of the syndrome or creating a more neutral name. Reports read "*Pneumocystis carinii* Found in Intravenous Drug Users" or "GRID Expanded to IV Drug Users and Female Prostitutes". Soon, the categories listed as risk groups were nearly greater than the non-affected population: homosexuals, prostitutes, IV drug abusers, people in poverty, third world women, hemophiliacs, Haitian immigrants. It wasn't until C. Everett Koop's report on the virus in 1986 that the public finally recognized the possibility of and HIV infection in anyone, no matter their sexual orientation, sexual practice, income status, citizenship, or existing health. This report echoed the demand of a neutrality of language when it came to discussing the virus. When scientists finally settled on AIDS as opposed to the now-irrelevant GRID, James Curran commented that the name was "reasonably descriptive without being pejorative"⁷ (Black 60).

Ownership

An entirely related setback to creating a neutral name for the virus was the authority over the virus itself. Two laboratories, one in the United States and one in France, had isolated the virus almost simultaneously, and a battle over the legal name ensued. Luc Montagnier, at the Pasteur Institute, had named it the lymphadenopathy-associated virus (LAV), while Robert Gallo at the National Cancer Institute had identified it as the human T-cell lymphotropic virus type III (HTLV-

⁶ Salzmann. *Language, Culture, and Society*, 285-286.

⁷ David Black, *The Plague Years: A Chronicle of AIDS, the Epidemic of Our Times*, (New York: Simon and Schuster, 1995), 60.

III). In 1987, the two scientists agreed to a settlement over HIV as the official name of the virus. While this settlement provided a universal name that allowed scientists and everyday citizens alike to finally begin a unified discussion on the topic, with the original names died an alternate interpretation of the virus as cancer-like, for the time being marring a more truthful understanding.

Action and Reaction in the United States

While HIV is one of the most complicated viruses, and the initial epidemic in the United States was hard-hitting and difficult to manage, it received little attention in its first ten years in the nation. Actions taken against the virus were greatly influenced by the persons affected by it, as well as the language used in concordance with it. As previously stated, the use of the word “gay” in reference to the virus both deterred and inspired people in relation to the cause.

Societal

There were four main societal responses to the virus once it became prevalent in the United States. Two of these responses occurred within the male homosexual community, another was the response of the “general public” – those not deemed “at risk” by the CDC or Department of Health. The last was the opinion of persons with AIDS.

One part of the male homosexual community was vastly concerned both by the virus and the fact that no one with any political power seemed to be doing anything about it. One such group, the Gay Men’s Health Crisis, was formed in this time in order to raise money for what they referred to as “gay cancer”. Headed by Paul Popham, the group of men had all been affected by the virus and wanted to do anything to stop it⁸. They held events to raise awareness and funds, and although they were eventually successful, they were initially met by opposition in the homosexual community. This community was the one that, although originally referring to it by the homophobic names, routinely fought for neutral medical terminology⁹.

The Gay Liberation movement was in full swing at the time of the HIV outbreak in the US (this most likely contributed greatly to the rapid spread of the virus). Homosexual men finally felt free to express themselves and their sexuality, and the last thing most of them wanted was to be told what to do in their personal, sexual lives. The Gay Men’s Health Crisis pushed safer sexual practices and abstinence as a means of preventing the virus, and they were often met by a cold

⁸ Randy Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic*, (New York: Saint Martin’s Press, 1987).

⁹ Treichler, *How to Have a Theory in an Epidemic*, 18.

shoulder. Most men believed that they were invincible or, if nothing less, were having so much fun that even HIV could not slow them down. Only increased numbers of cases and nationwide campaigns would warrant a significant lifestyle change.

The third societal reaction was that of the American majority: indifference. The use of the word “gay” or “homosexual” placed the virus into another category, that which concerned “them” and not “us”. Most Americans did not know what AIDS was until a publication entitled *Understanding AIDS* was deposited in every American mailbox courtesy of the Surgeon General. Ignorance breeds fear, and in this case, disease. By the time information on the virus and its syndrome was readily available, the myths associated with HIV and AIDS had already perpetuated the minds of many Americans.

Persons with AIDS (PWAs) had minor voices in the AIDS movement, at least on the national stage. Most PWAs were already a part of at least one minority group, and their illness further decreased their political and societal power. However, at the first meeting of People with AIDS/ARC, a document was created called “The Denver Principles”, outlining the opinions, wishes, and desired rights for PWAs¹⁰.

Governmental

The reaction of the government to the AIDS epidemic was dismal. Faced with a rising epidemic, many concerned scientists, and thousands of dying Americans, the government effectively did nothing for ten years. In *AIDS Crisis in America*, a book written by Mary Ellen Hombs, she writes, “There has been a failure to commit the necessary fiscal resources to prevention and education, in large part because those groups perceived to be at-risk are not at the center of U.S. society”¹¹.

When the health sector of the government did become involved, it did attempt to finally quiet the prejudice and fear that came with the term “AIDS”. In his report on the syndrome in 1986, Surgeon General C. Everett Koop wrote, “At the beginning of the AIDS epidemic many Americans had little sympathy for people with AIDS. The feeling was that somehow people from certain groups “deserved” their illness. Let us put those feelings behind us. We are fighting a disease, not a people”¹². Koop went on to dispel many of the rumors that had been generated about AIDS and PWAs, but as we now know, the effectiveness of his efforts was slim.

¹⁰ Mary Ellen Hombs, *AIDS Crisis in America: A Reference Handbook*, (Santa Barbara: ABC-CLIO, 1992), 13.

¹¹ Hombs, *AIDS Crisis in America*, 17.

¹² Hombs, *AIDS Crisis in America*, 128.

Related Data and Analysis

While no data was found directly comparing language use and infection rates, one look at a chart depicting the composition of AIDS cases in the US in its early years shows a decrease of percentile representation of heavily publicized risk groups. As one can see in Fig. 1 (see appendix) depicting the composition of AIDS cases in men from 1981-1997, the percentage of AIDS cases transmitted through homosexual sex in both whites and minorities decreased over this span of fifteen years, percentages of cases due to intravenous drug use, heterosexual sex, and other means of transmission all increased over this same time span. Likewise, in Fig. 2 (see appendix), one can see that in women, the transmission of AIDS through intravenous drug use decreased between 1981 and 1997, while transmission through heterosexual sex and other means increased (or in the case of "other/unknown", decreased and then increased).

While this data is not a direct result of a survey conducted specifically about language, one can easily see that the target groups of HIV/AIDS awareness as well as the only group depicted in early names for the virus and syndrome (homosexual men) is the only group which saw a decrease in new infection rates over time in terms of male PWAs. Furthermore, one can see that heterosexual infection rates in both males and females in this time period increased. Whether or not this is a direct result of language has not been determined, but the two pieces of information seem to show correlation.

Conclusion

Rarely do we recognize the consequences of small language choices that we make. For the most part, this is not detrimental to hegemonic group or even the moral minority, but in cases like this one it can fuel marginalization, fear, ignorance, and facilitate the unchecked growth of an epidemic. It is difficult to determine precisely the effect of linguistic determinism and relativity in this case, but statistics on infection rates, media portrayals of the virus and PWAs, societal statements, and records made by PWAs all point towards a highly negative result. No one intended for the first few names of HIV and AIDS to be misnomers, let alone detrimental to its cause, yet that was the product. Language generates worldview and vice versa, and worldview directly impacts the way in which we assess and react to major issues such as the AIDS epidemic. Because of the power of language in shaping worldview, it is necessary to occasionally stop and think of its effect on marginalized minorities and even uninvolved majorities, and consider the possible

consequences. The deterministic properties of language, linguistic relativity, and the use of roundabout language and the many complications and misunderstandings that accompanied naming the virus now known as HIV greatly impacted the way in which American society and government responded to and treated the epidemic.

interesting essay, well argued. Analytical approaches, concepts and theories from linguistic anthropology are applied, in a critical way, to a well contextualized research question.

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Appendix

Figure 1: Changing composition of AIDS cases among men by risk of transmission and period of diagnosis (Data used in this figure have been adjusted for delays in reporting after 1993).

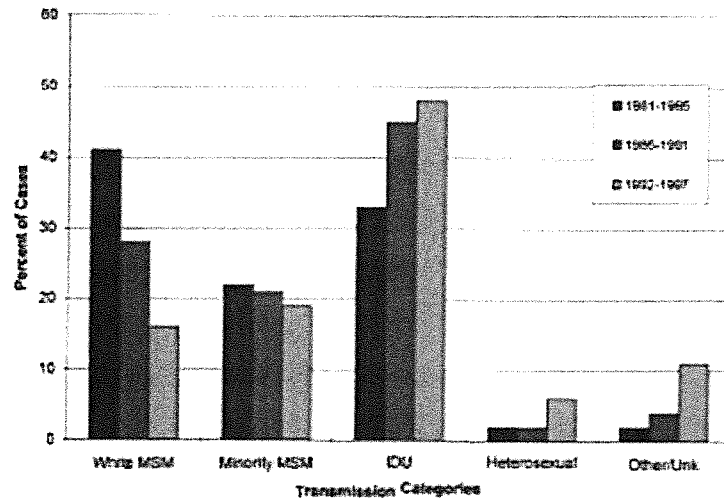
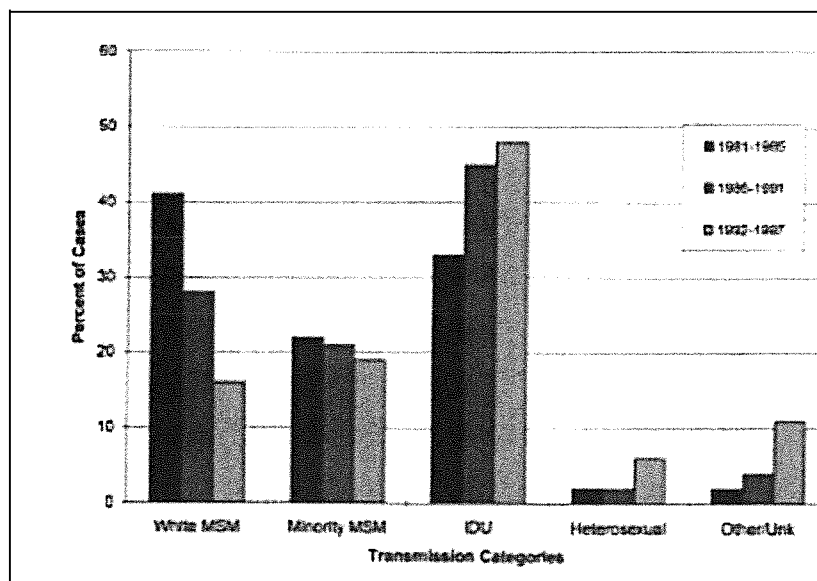


Figure 2: Changing composition of AIDS cases among women by risk of transmission and period of diagnosis (Data used in this figure have been adjusted for delays in reporting after 1993).



Both figures are from p. 538 of *Evolution of an Urban Epidemic: The First 100,000 AIDS Cases in New York City* by E. J. Fordyce, T. P. Singh, F. M. Vazquez, J. McFarland, P. Thomas, S. Forlenza and M. A. Chiasson