Why people with HIV are let to die

Analysing medical ethics, drug patents and activism

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Human Rights studies

Spring 2012

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Abstract

In this essay it will be analysed why people in need of HIV-medicine do not get access to them, which has so far resulted in millions of seemingly unnecessary deaths. It will be discussed what responsibilities scientists have and what people can or should do to claim rights to medicine. It is found that the main reason is the patent system, which allocates power from states to companies. To a high degree rich states are however ultimately accountable and also the citizens in those countries.

Economic theory is used to analyse the economic effects of the system. This leads, among other things, to the conclusion that the patent system is dangerous according to economic principles and that those principles can explain why people have not had access to medicine. From the conclusions it seems like a good idea is to distinguish life-saving treatments from the medical industry and increase state intervention.

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Abbreviations

ACT UP	AIDS Coalition To Unleash Power
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral [drug]
AZT	Azidothymidine (or Zidovudine)
CEO	Chief Executive Officer
CSR	Corporate Social Responsibility
FDA	Food and Drug Administration (USA)
GPO	Government Pharmaceutical Organization (Thailand)
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MoPH	Ministry of Public Health (Thailand)
NGO	Non-Governmental Organization
PR	Public Relations
R&D	Research & Development
TRIPS	Agreement on Trade Related Aspects of Intellectual Property Rights
UDHR	Universal Declaration of Human Rights
UN	United Nations
WIPO	World International Patent Organization
WTO	World Trade Organization

1. Introduction

The issue dealt with in this essay is that of access to life-saving treatments, specifically HIV medicine. Far from everyone with HIV can afford existing medicine that would keep them alive. Lowering the prices on medicine, or handing them out for free, would of course solve the problem right away but as one might expect, it is more complicated than that. First of all, we do not even know who is responsible. It could be the companies, the states as well as scientists, for example. In this introduction the dilemma is acquainted with from different angels in order to find the right one to analysing it from. The main question will be formulated and the history of HIV summarized. It will be decided that the analysis will be made around some central concepts such as “power” and “stakeholders” and it will be made from a normative background defined by understandings of human rights. A mixed macro analysis will be presented, with narrative analysis to examine power relationships and then normative analysis to evaluate some arguments using economic theories. It is also displayed how material has been chosen.

1.1 Question formulation

In one end are the millions of people who have died from AIDS. In the other end are drugs that substantially would have prolonged their lives. What obstacles have there been in between that has prevented the drugs from finding their way into the hands of those in need of them?

1. 2 Main narrative

Around seventy years ago HIV is transmitted to a human from a chimpanzee in Cameroon. It

starts spreading throughout Africa without being identified as a new disease. In the developed countries scientific progress is made in many fields. In the fifties and sixties many great scientific dicoveries were made and there was a sense that all diseases could be cured. In this spirit the american scientist Jerome Horwitz funded by the government tries to find a cure for cancer, and creates some synthesis that he saw as failures then, but that quietly layed the foundations for future HIV-drugs.

In the sixties and seventies HIV spreads across Africa and to North America via Haiti, where white gay men went to buy sex. It also came to Europe through Belgium and other former colonies in french-speaking Africa. Being a immunodeficiency virus, it was hard to identify as a new disease, technically it was other diseases that killed patients, following from the damaged immune system.

In the 1980s the pharmaceutical markets in USA and Europe had become commercialized and many patents were granted, but not as many true innovations were made anymore. To strenghten patent protection internationally, WTO created the TRIPS agreement, which extended patents to all its member countries. Meanwhile scientists speculates on the cause of the unknown blood disease that had hit young gay men in urban areas of USA. It took until the middle of the 1980s before the scientific community stood united behind some basic ideas on its characteristics. A major reason that it took so long was the small existing knowledge of retroviral viruses, which had to be built up from scratch.

Jerome Horwitz' synthesis, the AZT, had given interesting results when a German team had tried it on mice. The pharmaceutical company BurroughsWellcome thought it might work against HIV and successfully let it be tested on the virus. Clinical studies showed remarkable effect and after pressure from activists the drug was patented soon after. The company set a price that was high and that they were critizised for, and protests made them lower the price several times. AZT was the only antiretroviral drug against HIV on the market for five years until two new drugs were approved. The team that BurroughsWellcome had consulted to try the AZT on the living HIV virus, lead by Samuel Broder, soon also found that the effect of taking two drugs on half dose was better than to take one on full dose. It was called HAART, or a “cocktail”, and this base formula with varying ingredients was to become the standard HIV-medicine, because it had least side-effects and the lowered the risk of resistance.

The virus spread unimaginably fast and soon more than twenty million people had died and just as many were infected. Some countries admitted and confronted the problem, for example

by promoting condoms, and managed to control the spread. In the rich countries people with HIV afforded medicines and could therefor start hoping to live long and normal lives while in other countries the spread had merely begun and there was no way to afford treatment to everyone.

Some countries, such as India and Thailand, did not have the same patent law system enabling them to legally make generic copies of HIV medicine that was patented in USA or Europe. Eventually thought, most countries and even India became part of the TRIPS agreement prohibitting generic copying. In 2005 the AZT patent expired. Now however, the virus has in millions of cases become resistant and next-generation drugs are needed, which are patented and very expensive.

1.3 Key concepts

Power is the "capacity or ability to direct or influence the behaviour of others or the course of events", according to Oxford dictionaries.[1] In this essay, it will be seen as the capacity to change the outcome of a narrative. The aim is to find out why power has been used to change the outcome in the way that it has, and first it has to be examined where the power is. The original hypothesis was that power is in one or more of three places: 1) The scientist who has the specific exclusive right over a substance. 2) The company that is given that right in order to produce a drug from the substance to distribute. 3) States that ultimately have legal authority over patents, and chooses which international laws to sign.

Responsibility is according to Oxford dictionaries: "having a duty to deal with something or controlling someone".[2] If one has power over something else, it is responsible over the other. This indicates how someone can have indirect power over the course of events, namely if it do not possess the power itself to change it but has power to affect the other in order to make the change. For example, laws makes states indirectly influential over the actions of people, even though the people themselves are directly responsible for the actions they make.

Accountability, of which satisfying definitions are not found in dictionaries, will in this

1 Oxford dictionaries, August 2012, viewed 6 August 2012, ‹http://oxforddictionaries.com/definition/power›.

2 Oxford dictionaries, August 2012, viewed 6 August 2012, ‹http://oxforddictionaries.com/definition/responsibility›.

essay mean to define in hindsight of who had power and was responsible for something that has happened.

This essay will focus mainly on finding out were the power is, because that is were it is constructive to look. Responsibility and accountability is more of interest when one is trying to find something to blame or judge, while the aim in this essay is to see what has changed the outcome of a narrative so that it can be discussed why. Still, they are concepts that will recur many times.

If a company has come up with a medicine against a life-threatening disease, it has power over a lot of people. The question is if they also have responsibility and are accountable if a person dies because he cannot afford the medicine or if it is only the state that is responsible for not having made laws preventing this from happening. Even as it is not formulated in laws, it is difficult to find voices arguing that companies have no responsibility at all. There seems to be few people who believe that. But there is debates on just how the responsibility should be allocated. Theories on this is called **stakeholder**-theories, which refers to the people who have something on stake, such as their lives. Many see it as a democracy problem in the global interconnected world that those who are affected by policies or companies' actions do not have a say in decision-makings. Politicians, CEOs or researchers, according to stakeholder-theories, are sometimes unable to understand how important some decisions are to those who have something very important, as their lives, on stake. Most people agree that people should be able to change the outcome of their own narratives, so that if a person for example dies, this is not because of some distant reason but because of their own shortcomings. That seems fair. But to adopt a stakeholder-theory in practice would be a huge step. For example geographical boundaries would not matter. Thirty million people living with HIV, spread over the world, should then be given power to change companies' decisions and state policies. This seems very unrealistic, but the stakeholder concept is nevertheless useful and inspiring.[3]

1.4 Perspective

[3] Macdonald, Terry., *Global stakeholder democracy [Elektronisk resurs] : power and representation beyond liberal states*, Oxford University Press, Oxford, 2008, chapter 5.

What right feels intuitively more natural than the right for a dying person to get existing medicine? Still, this intuitive right it is systematically violated. But to end up in a legal discussion about something that everyone agrees on is not fruitful. But we must not forget that, for example, UDHR is not only legally but also morally august. Human rights originates from moral ideas that states have agreed on. In this chapter human rights' legal boundaries will be examined which will form a base from which some departure points are established.

The main problem is the following: In a scenario where there are no patents, there would be competition. Then companies would not be able to set prices much higher than the cost to produce pills, put them in packages and distribute to stores. It would not matter how much sick people needed the drug or how much they were willing to pay, they would still buy the cheapest brand. In that scenario little money would be left for research securing future medicines. The basic problem is that it seems impossible to get both healthy competition and at the same time innovations. Today, patents are standard because it is considered more important to guarantee innovations. Sometimes patents are even seen as synonymous with article 27 in UDHR, for example WIPO has this point of view.[4] If this is true, it is a human right violation for states not to protect patents. Is that way of interpreting the article correct?

Other articles are concrete, the right to life is one example. Normally, rights can mean that states should either actively fulfil people's rights by various measures or passively restrain from acting in ways that violate them. But to apply the latter interpretation on the right to life means that states do not need to act when people are killed by other individuals or institutions. Of course, the right to life in itself demands that states do more than that. Most states have laws, health care, police force and so on, whose functions are to act. States not only respect the human right to life but prevent violations and protect people when there are threats of violations. Sometimes it sounds like the HIV-epidemic is no ones fault, because it is a disease. No one spread the disease by purpose. But if a tsunami would hit New York, the police would not stop working, the laws would not become invalid and medical professionals would not refuse to treat people because there is no perpetrator. Even under such circumstances, the state must do all in its power to not only respect the human right but act and prevent further problems. Accordingly, it cannot be considered a bonus for someone with HIV to get medicine. There is no doubt about it, when people with HIV do not get access to existing

4 Castelo, Roberto, '*Opening address by Mr. Roberto Castelo, Deputy Director General, World International Property Organisation, WIPO', May* 2012, viewed 25 May 2012, ‹http://www.wipo.int/tk/en/hr/paneldiscussion/papers/opening-wipo.html›.

medicine it must be considered a violation of the very clear right to life.

Other articles are more abstract and difficult to interpret, like article 27. The ”right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author”[5] can be read in many possible ways. Firstly, it is difficult to define moral and material interests. Secondly, there are many alternative ways of protecting interests resulting from scientific production than patents. Royalties and rewards are two examples. Furthermore, patents are preconceived to suit as copyright for all kinds of products even though there is no reason to believe that all products should be met with the same treatment. With all this uncertainties, does that mean that there is no correct way of interpreting the article?

> “Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein”[6]

It is important to interpret articles in UDHR in a way so that they do not violate other articles. If two human rights seems to contradict each other, at least one of them is therefore not read correctly. If one of them is very concrete, like the right to life, it is probably the other one that has been interpreted wrongly. If patent protection leads to the violation of the human right to life, article 27 is probably not interpreted correctly. And conversely, if there is a way to unify the article with other articles, a correct way has been found. To read it the way WIPO does, as if patent protection is an undoubted interpretation of it, is therefore not meaningful knowing that it might lead to the violations of the human right to life.[7] It depends on the practical and contextual consequences of having them. From this background, the essay will examine the practical consequences of having patents in the context of HIV-drugs to see if it fulfills the conditions for being a human right.

1.5 Methods

5 Universal Declaration on Human Rights, December 1948, Article 27 (2).
6 Universal Declaration on Human Rights, Article 30.
7 Castelo.

The first phase in the essay is an important one, especially according to many feminist scholars who are critical to the idea of objectivity and value-free research. Even the choice of subject and research questions cannot come from nowhere, they believe, and scientists choose them in one way or another, thereby making the study biased. In the choice of a subject one should therefore act so that one is at least "answerable" to it and take responsibility for it.[8]

That being a very important point, at the same time the solution seems unsatisfactory. An explanation to the choice of subject is good but not sufficient. The choice of subject should not only be honest and explained but also a considered conscientiously as a part of the whole scientific method. In this case, the subject was decided accidentally following a persons advice. The person said that this was an interesting topic and having neither much prior knowledge nor interest in the subject I chose it – simply because it was somebody else's advice. Early on in the process this method continued, always following the advice of the supervisor who led the work to unexpected places and gave research questions to study. This way, research questions were chosen rather accidentally as well.

Of course, neither the friend nor the supervisor are arbitrary sources, but the main purpose was to lay aside my own personal values since I was the one that was going to write the essay and therefore probable to be the biggest threat to a scientific method. Sooner or later, the personal values would appear anyway, which did not have to mean that subjectivity had to be embraced more than absolutely necessary. It was going to be interesting to see what effects those initial choices had on the work process and the results. What happens when you study something that you know little of and have little prior interest in? Soon the writing had to begin and by doing this it was impossible not to involve highly personal influences. At least with choice of words and emphasis shifting the approach to some direction.

What seemed to bring forth personal influence the most was the choice of material, sometimes simply advised by the supervisor but in many cases inevitable. By then, clear methods and strategies were necessary. One method that was used was a thematic narrative analysis, a method of analysing "sequences and consequences" in stories. The aim was to find out what had changed the outcome in history, because that was believed to correlate with the location of power, which was important to find in order to find out why a certain thing had happened, which was the main question. With this method, typically "events are selected,

[8] Haraway, Donna, *Feminist Studies*, Vol. 14, No. 3. (Autumn, 1988), pp. 575-599.

organised, connected, and evaluated as meaningful".[9]

A problem with using thematic narrative analysis on a macro level, according to Riessman, is that clarity is lost along with the "unspoken".[10] This problem was considered but in the end the accuracy was sacrificed to the benefit of being able to make a more general macro analysis. A micro analysis on for example the pricing of the AZT would also have been interesting, examining the BurroughsWellcome's exact numbers which would give us a clear view of this particular event. But I chose this subject without prior knowledge and it was therefore impossible to know that the pricing of AZT would be an interesting subject to examine until the process was already well under way. In stead of ignoring the work that had already been done from a more general perspective, it was acknowledged and expanded.

Narrative analysis is a step away from positivism and emphasises the usefulness in not only the norms, official information and famous stories, but also for example stakeholders' stories.[11] This lead the essay to averse itself from official statements but preferably examine facts on a more personal level, by for example not looking so much at companies' public statements but rather at stories of the individuals working for them. Activists were studied as people rather than as representatives of an organisation and the same went for politicians. This worked well with the human rights perspective, which postulates that all people are equal and all violations of human rights should weigh equally.

The narrative analysis had the time span of the pandemic in range, but the ambition was to additionally be aware of parallel narratives during the same time, for example the recent history of medical ethics and especially economic theory, so that they could later be compared to the main narrative, which could lead to findings.

When general knowledge on the subject had been processed, the work was specified into sub-groups. In each of the areas of subject analysed, arguments in today's debates were sought after alongside the narrative analysis. What was supposed to solve the issue? The arguments found were not analysed in detail but simply compared with the conclusions from the narrative analysis, deciding what will later be subject to more scrutiny.

First out was medical ethics. Existing codes were read and then compared with the real world of medical professionals. What were scientists or bio technicians impact on the

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9 Riessman, Catherine Kohler (2005) Narrative Analysis. In: Narrative, Memory & Everyday Life. University of Huddersfield, Huddersfield, page 1.

10 Riessman, page 3.

11 Riessman, page 1.

outcome on people's access to drugs? It was soon concluded that the connection was very weak and that companies played much more important roles in the drama. So the work went on to examine the patent system. Here a stronger connection was found between patents and peoples access to drugs, why this area were to be analysed deeper in a discussion of normative economics. The only people who openly defended high prices of HIV drugs namely seemed to be economists, and they were supported by organizations that were otherwise against regulations. The interesting thing was that for example WTO was working to open markets and at the same time to strengthen patent protection, which technically is a state intervention that disables competition. This tension was found interesting and it was decided that classic economic laws were going to be applied on the patent system to evaluate the patent system normatively. This analysis became the deepest dive in the essay. Is patent protection good from an economic perspective? And with the human rights perspective of this essay: what happens if we at the same time look at it not utilitarian but normative, considering the right to life as universal and not able to bargain with? Is there a contradiction between economy and human rights? From the Perspective chapter the conditions for the patent system to be a human right in it self was defined, namely that the patent system is a human right if there is no better alternative that satisfies article 27 in UDHR and a long as it does not violate the clear right to life. Human rights also functions sort of as the essay's frames, making sure discussions of utilitarian kind or ones that do not regard universal human rights are not wasted time on.

Originally the hypothesis was that the responsibility and power lain at either scientists, patent holders or states. However, the questions involved with medical ethics were answered in a satisfactory way surprisingly quickly why scientists were more or less ruled out. On the contrary, the part on the patent system grew and gave rise to new questions as it was examined. The initial idea was to examine it from a juridical perspective but very quickly it became obvious that international laws were intertwined with economic and political issues. After having analysed the patent system, and it had been found that activism had affected the outcome of history, it too, had to be analysed. They obviously had had some power, but how much? Historical examples were brought up to measure this. Another question came up: if ordinary people, that is, potential activists had significant power, why was it used so rarely? It could not be ruled out that there were multiple answers to the main question, why it was not seen as a problem to analyse activism and social factors with the risk of new findings.

The three parts in the analysis in themselves aimed to answer questions subordinate to the main question. And when one was answered there were to be no problems moving on to the next, without having questions hanging in the previous domain. They are put in an the order that represents the one in which they were worked on during the process.

1.6 Material

The main narrative explored was that of HIV, ranging from the human discovery of the disease to the creation of the first medicine against it, on to AIDS activism and today's debates on patents. For an overview on the main narrative *AIDS at 30* was used, which with neutral words told a story with high degree of detail. For more personal narratives, with more drama, less facts but many interesting interviews, *28: stories of AIDS in Africa* was read. In this book, voices of people who otherwise are hard to find opinions on were heard, such as stakeholders. It is no surprise that *Pharmageddon* gives a pessimistic view of our time. Being mostly engaged in the developed world, it suggests that the medical business is getting more and more shallow and removed from reality which is a theory that is partly adopted in this essay due to its convincing arguments.

Examining the patent system in particular, it was found to be an advantage having chosen the subject purposely accidental, because for a long time both sides in the debate seemed right and were examined with equal interest. Critics to patent protection were easily found, in everything from NGOs reports to scientific essays. It was soon noticed, however, that there was very little material emphasizing positive effects of patent rights in relation to HIV-drug access or comparable issues. There were a lot of voices defending strong patent protection but only in general terms or in areas where it was not controversial. This lead to the conclusion that possibly there was actually consensus that patents are good in general but not in this particular case. The follow-up question emerged: if there were consensus that patents were bad when it came to life-important medicine, why were they still a reality?

In the specific subject of HIV drug prices, the defenders of them that were eventually found had a utilitarian approach and they highlighted not the dilemma itself but that the alternative could mean that there would be no medicines at all. The documentary film *I Am Still Alive* contains interviews with many of the people involved or affected by the pricing of the AZT

and has been a great source to arguments of that kind, since it contains an interview with an official at BurroughsWellcome, speaking openly about the pricing of AZT. Otherwise it was very difficult to find interviews or articles citing company official's, except for some former officials who have criticised their old employees. Another important source was Wikileaks, from which it was possible to learn not only what US officials say publicly but what they express more unofficially, which had been the kind of information sought first but without result. Here defenders of patent protection speak not only in general terms but even regarding HIV drugs specifically. Furthermore, Wikileaks cables give generous descriptions on the dilemma for USA and their reactions on activists, how they handle other governments and fight for strong patent protection. Rather intimate information was needed in order to answer satisfactory the main question “why” people with HIV were left to die, instead of just “how”, or “who” or “what”.

1.7 Macroeconomic theory

On what grounds are states deciding their policies and laws concerning HIV medicine? And on what grounds do companies make their decisions? Economic theory has historically had an effect on both. It is the way states find economic policies that will lead to a desired result and also what companies use to calculate outcomes on different decisions. This means that the economical historical narrative also have an indirect effect on the outcome on the main narrative. For this reason economic theory will be used, firstly to evaluate the patent system and secondly to evaluate the theories themselves as powerful actors.

In the fifties and sixties the radical ideas of Keynes' economic theories were adopted in most countries of the developed world. Before, there was only classical economy with high belief in consumer rationality and pure free markets. Since the seventies the debate circulated much around how rational people are in their consumption and how much states should invest and when this should be seen as an intrusion on the markets' freedom. The iconic defender of the classical approach has been Milton Friedman. Keynes did not propose the opposite, but made the classical theories more complicated by saying that *mostly* free markets are preferable but *sometimes* external intervention is necessary. Friedman on the other hand claimed to be able to show that the idea of rational consumers were always true, Keynes had

just not been able to calculate on it. Thanks to contributions such as Friedman's, the classical approach regained most of it's power and today we are almost back in the pre-Keynesian era, with consensus that governments are a vice and markets are a virtue.[12]

Bernanke's and Frank's book *Principles on Macroeconomics* is representative of today's view. With some humbleness but still great belief in them, classical theories are presented. As opposed to a Keynesian approach, it focuses on examples when the principles work rather than on the exceptions. It furthermore takes up not just what happens inside markets but what happens between them, issues which are a key interests of economists today and which is relevant to this global subject. Four key economic principles will be used especially: The supply and demand-curve, the idea of opportunity costs, the idea of open contra closed markets and the one of rational consumers.

12 Krugman, Paul, 'The Case of Milton Friedman', *The New York Review of Books*, February 15 2007, viewed 30 July 2012, <http://www.nybooks.com/articles/archives/2007/feb/15/who-was-milton-friedman/?pagination=false>.

2. Analysis

Here it will be analysed in three steps why people with HIV do not get access to them. First however it is the scientists who lacks ethics or possibly they are too naïve to demand from companies some conditions for selling a drug. Then it will be examined however it is the patent system that blocks the way, a part that will be more thoroughly examined with its perplexity of states, companies, international laws, politics and economic ideas. Then activism and individual's power to demand drug access will be evaluated.

2.1 Ethical scientists

In this chapter scientists' power to change the outcome of the plot by acting ethically will be analysed. Firstly, their working conditions will be examined. Secondly, relevant medical ethics will be brought up. Thirdly, suggestions aimed at improving scientists' good impact will be evaluated. This will lead to conclusions on how much power scientists have and what should be done to make them use the power for a good cause.

2.1.1 A demanding profession

> "In this complex, demanding, commercialized and yet, values-laden, world of health care it is an understatement to say that there are fundamental challenges to what it means to be a medical professional in today's society."[13]

Already in the early 20th century some scholars complained that a change was under way that was not for the good. They claimed that doctors had become obsessed with curing instead of

[13] Nuala Kenny, Wayne Shelton, (2006),"Introduction: Lost Virtue: Professional Character Development and Medical Education", Nuala Kenny, Wayne Shelton, in (ed.) *Advances in Bioethics*, Volume 10, Emerald Group Publishing Limited, page XI.

caring, only studying diseases, not medical practice.[14] If that concern was relevant at that time, it is probably even more relevant today. In their educations, doctors today need to learn so much more theory than before. The work is much more knowledge-based and physicists can hardly focus on everything, like they could a long time ago. Most medical professionals today therefore become experts on a specific subject. For the same reasons, general practicioners who are supposed to make diagnosis on patients have a particularly demanding job, with so much knowledge demanded of them to have on so many areas. There are more known diseases and treatments than ever that doctors should know of.

If doctors, because of the high expectations on their knowledge, do have a lack of empathy, however, this is mostly a problem to patients in the developed world, which is a subject for another essay. But for HIV-patients, which is in focus here, the problem is never that doctors care too little. The highest priority for them is to get medicine at all. But doctors in the developed world do in fact affect a global development in the world that can be seen as a continuation of that dilemma. Medical companies namely directs huge resources at the doctors through ads and sponsorships to persuade them to prescript their drug. And in this complex business it is difficult for doctors to tell the difference between the effects of a drug from that of a generic one or to know which ones that gives the highest value for the money.[15] And regardless of how difficultly persuaded doctors are, the amount of money companies spend on this show that drugs are turning more and more into pr-products and the reason is that companies at least believe that they can persuade doctors. The pharmaceutical giants that produces HIV-medicine spend much more money on marketing than on research.[16]

At the same time scientists or bio technicians, compared to a general practionioning doctors who usually has one patient at a time, seems to have power over potentially millions of people. For those working at commercial companies this power is limited to the possibility of making discoveries that people can hopefully take part in. For scientists, mostly government funded, they themselves own the patent rights of their invention. But for it to turn into a drug that can benefit a lot of people, an investor is necessary and therefore a company will have to be given the patent rights anyway. The choices for the inventor to make are: what company and under what conditions it should use the patent.

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14 Healy, page 16.

15 Healy, page 23.

16 Annual report are found on companies websites, such as: GlaxoSmithKline, 'Investors', May 2012, viewed 26 May 2012, <http://www.gsk.com/investors/index.htm>

2.1.2 Ethical codes today

After the Second World War the world community decided that doctors' power should be regulated in some conventions. A modern version of the old Hippocratic Oath was the International Code of Medical Ethics and it was addressed to everyone in the medical profession and was written in 1949 by the World Medical Association. According to this document, medical staff should for example ”practice his profession uninfluenced by motives of profit”.[17] If doctors do not have access to treatment needed to cure his patient, this is also a violation against the code, saying that ”whenever an examination or treatment is beyond his capacity he should summon another doctor who has the necessary ability.”[18]

The Geneva declaration, upon which the International Code of Medical Ethics was based, was written with Nazi Germany in mind. After the scientists' misuse of their knowledge and the disastrous results this meant in the holocaust, a regulation seemed necessary. It, too, is an oath to everyone within the medical profession but it uses a more abstract language, similar to UN conventions. It urges for example not to use ”medical knowledge contrary to the laws of humanity”, to consider the health of the patient foremost and not permit considerations such as nationality to intervene.[19]

From this reading it is clear that the issue of HIV medicines not reaching everyone is covered by medical ethics in a broad sense. But is the Geneva Declaration, the Code of Medical Ethics or the Hippocratic oath of any help to 1) the doctors who should not contribute to a development in which the drug industry become more shallow or 2) to the inventors of drugs who has no choice but to depend on commercial companies to distribute the products?

2.1.3 Suggestions

Recently, the lack of ethics among scientists has been pointed out and aroused debate. Documents such as the ones put forth earlier are by many considered inapplicable on today's conditions. Nobel Price laureate Sir Joseph Rotbat was one of the first and most prominent supporters of a new oath, specifically for scientists.[20] He states that it is needed because the

[17] World Medical Association. International code of medical ethics. *World Medical Association Bulletin* 1949;1(3), pages 109-111.

[18] World Medical Association.

[19] Declaration of Geneva, General Assembly of World Medical Association, Geneva, Switzerland, Adopted September 1948.

[20] MaclLeod, Donald, 'Ethics code seeks to regulate science*', The Guardian*, January 2006, viewed 26 May 2012, ‹http://www.guardian.co.uk/education/2006/jan/05/highereducation.uk›.

public holds scientists responsible for any misuse of science.[21] It is true that no matter what obstacle that really obstructs access of drugs, scientists will ultimately be accused as long as they initially own exclusive rights. And even if they are tricked by international company, because its inherent logic, people will use the argument that if scientists make drugs over which they have exclusive power they are also accountable when the drug do not reach the sufferers.

But even if a new oath might make sure scientists are not seen as responsible and accountable in the eyes of the people, it is unclear if scientists have so much power that a new ethical oath would have any positive impact on the HIV issue. Bio technicians have, as was already noted, no relevant power at all as it is limited to the involvement with making inventions while the issue examined in this essay regards the distribution of existing inventions. Scientists have the exclusive power of their inventions until they decide to give it away. This, as was noted before, generally leads them to do the same thing as bio technicians, namely give their rights to a company. But are they naive and do this too easily? Samuel Broder at the National Cancer Institute, whose team definitely had a possibility to claim conditions for the agreement with BurroughsWellcome on the AZT patent, admitted in hindsight that he had been "somewhat naive".[22] Could the exclusive power, if they scientists not naive, be used to secure more people getting access to drugs?

Voices inside the medical profession suggests that medical professionals are taught patent laws so that their ethics are not trampled on.[23] Awareness of laws would probably counteract companies' exploiting of them and taking credit of their work, as BurroughsWellcome did with Samuel Broder. After they on behalf of BurroughsWellcome had tried the AZT with HIV in a test tube - which is more complicated than it sounds – the company got the sole right to the product. Broders team could only watch as the consequences of the high prices and no competition became more obvious. But when he and his collegues made their second contribution to HIV science by presenting the basis for what became HAART treatment, they did not want to repeat their former mistake. This time, they included a clause in the contract with the pharmaceutical company Bristol-Myers-Squibb saying they had to sell it at a "reasonable price". This shows that sadly enough, it might help in individual cases with

21 Rotblat, Joseph Sir, 'A hippocratic oath for scientists', *Science*, November 1999, viewed 26 May 2012, ‹http://www.sciencemag.org/content/286/5444/1475.full›.

22 Harden, page 137.

23 Gupta, Himanshu; Kumar, Suresh; Kumar Roy, Saroj; Gaud, RS, 'Patent Protection Strategies', *Journal of Pharmacy And Bioallied Sciences*, Year 2010, Volume 2, Issue 1, pages 2-7.

scientists knowing patent law.[24] Many books have been written aiming to introduce researchers to patent laws. From this reading one can sense that the image of the researcher as a nerd in white coat who is an expert on his subject but cares little of the world outside of the laboratory is not up-to-date.[25] Before, according to one book, patent strategies were important after discoveries had been made and filled the purpose of protecting it from being sponged off.[26] But now, during the making of the discovery, scientists are supposed to do "researching with property in mind".[27] This to maximize chances of making discoveries in the first place. In the book researchers are taught "how to research to obtain stronger patents and more of them".[28]

The risk is that government scientists, by thinking like commercial companies they will become equally focused on profits. It seems like a solution to teach scientists law so that they can learn to demand certain conditions for companies like Broder did. But it is unclear how much that clause actually made sure that the price of the drug enabled people access to it. And should we expect scientists to think about other things than what they are good at? The expectations on scientists are already very high as was concluded earlier, they have millions of potential lives in their power and we blame them as soon as something goes wrong. They are also presupposed to have higher ethical sense than companies. Should their work not be made less demanding?

More importantly, there is something wrong with a system that allows one individual's mistakes or lack of knowledge in law to grow out of proportion. It is not negative with individual scientists knowing law, but it is rather the companies they work at that seem to have the real power to change the outcome in the narrative.

2.2 The patent system

24 Harden, page 139.

25 Knight, H. Jackson, *Patent strategy for researchers and research managers*, 2. ed., Wiley, Chichester, 2001, page 117.

26 Knight, page 11.

27 Knight, page 117.

28 Knight, ibid.

This chapter deals with the complicated issue of the patent system today and how it affects access to life-saving drugs. Firstly, power relationships will be analysed using a narrative analysis of the history of patents. Why do patents exist and who benefits from them? Secondly, the structure of the global medical market today will be analysed using the same method, mostly to define the people who needs drugs and how they are affected by patents. Thirdly, the companies on the market will be analysed. This is because they are the link to the consumer and because it has already been consluded how much power they have. Forthly, the economic idea of rationality will be discussed with reference to HIV-medicine. Throughout the chapter, several economic theories will be used. This will lead not only to conclusions on power relationships between states and companies but also to an evaluation of patent protection regarding life-saving treatment, from an economical point of view but with a human rights perspective.

2.2.1 Consensus on patents

Patents and the protection of them were not seen as the standard until the last decades. Since they appeared in Europe five hundred years ago patent protection has been considered merely a strategy for countries to lure innovators to them.[29] Some periods, such as after the French revolution, medical patents were prohibitted tottaly, and even when they were allowed they were weak in practice compared to today. For example in Germany, which was the world leader in the medical field, only a chemical process was possible to patent. The product was not, leading many companies to find different ways of producing the same compound. Even in anglosaxian countries, which had the strongest patent protections, it was very difficult even to make it through the administrative process why many groundbreaking ideas remained unprotected.[30] This changed however, and it became easier to get a patent, especially in the USA.

After the Second World War, Germany lost its leading position to USA that started to build a dominance. Voices accused US patent offices of licensed drugs originating in Europe with only small configurations and work done on marketing and exploiting, saying that the americans had become experts on modifying existing drugs just enough to make them patentable. The debate resulted in a new bill restricting the patent offices slightly, but USA

29 Healy, page 27.

30 Healy, page 28.

has nevertheless remained the most generous patent licenser internationally.[31] Soon the European former patent opposing countries followed, by introducing strong patent protection policies. With similar laws covering most lucrative areas of the world, companies could now patent simultaneously in all countries, making way for global enterprises and blockbuster drugs.[32] Today, immaterial rights are definitely the standard. According to a U.S. Report issued 2007, this is due to a general recognition of the property laws' compatibility with innovation and consumer protection, and the opposition's relegation to the past:

> "Over the past several decades, antitrust enforcers and the courts have come to recognize that intellectual property laws and antitrust laws share the same fundamental goals of enhancing consumer welfare and promoting innovation."[33]

This conclusion is a simplification, since the link between property laws and especially consumer welfare but also innovation is widely discussed and seen as problematic in many ways, by many people. Maybe because the critics are ignored, it is as if their questions do not need to be answered. But it is necessary to answer the questions that NGOs and other critics asks: Why it is good for people in poor countries with HIV to have patent protection? And why are monopolies in this context not bad for the consumers when competition is considered the best on all other markets? The report's only answers to those essential questions is two shallow and general ones: That patent protection is necessary to encourage innovation. And that intellectual property rights do not create a monopoly problem since the consumers in most cases can substitute the product in some other way. The cases when no substitution to the product exists, as for life-saving drugs, are ignored.[34]

The US report slightly overestimates the consensus on patents but the main message is true. There is little doubt about patent protection in its broader sense - especially among politicians. It is obvious that ever since the financial potential of the strategy for a country to have strong patent protection was recognized, the general opinion about strong patent protection has rapidly changed in its favour.

The change in the general opinion is interesting, since only some countries clearly benefits

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31 Healy, pages 40-41.

32 Healy, page 29.

33 U.S. Department of Justice & Federal Trade Commission, 'Antitrust enforcement and intellectual property rights: Promoting innovation and competition', April 2007, page 1.

34 U.S. Department of Justice & Federal Trade Commission, page 2.

from it. How is it possible to reach consensus on an issue that should be more controversial? The WIPO is an organization with nearly 200 member states, regulating 22 conventions "to encourage creative activity [and] to promote the protection of intellectual property throughout the world".[35] How can an organization that only represents the interests of a few countries can have so many member states? The answer to this is that there are strong forces that do more than encourages.

WTO has 155 member states that apart from encouraging and supporting international trade also pressures countries to implement patent protection. To become a member of the WTO it is namely a condition to sign the TRIPS agreement that prohibits generic drug manufacturing of internationally patented drugs, among other things. WTO is an asset to member-countries in many other ways, primarily because it is a meeting place for discussions on economy that it is not wise to be left outside of, why the TRIPS agreement may seem like a necessary evil.

USA have another even stronger method of convincing countries to enhance patent protection whose mechanisms becomes clear from reading a Wikileaks cable by an american ambasador. In Thailand GPO, a state-owned company producing generic drugs, is among the international giants on the list of top selling companies on the domestic market. The ambasador reports that the GPO is subject to preferential treatment and that it is not rare that high-level officials refuses to sign patent grant certificates from international companies.[36] That Thailand do not protect patents has obvious reasons. For a country that does not have much innovative bio-tech companies and where it is legal to make generic copies, which GPO manufactures, it is not beneficial to strengthen patent protection. The generic industry is, after all, legal in the country and it has positive impact on the public health. But countries that do not satisfy USA gets monitored or watched and risk being subject to sanctions, depending on their status on the annual 301 Report. The report is based on the Trade Act of 1974, which aims to give the President autority to sanction countries, in pursuit of making American companies more competitive.[37] Thailand's main reason to comply with the Americans is to get a better status on the report.[38]

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35 Convention Establishing the World Intellectual Property Organization, July 1967, preamble.

36 Wikileaks, 'Pharmaceutical Costs and the FTA', December 2005, viewed 26 May 2012, <http://wikileaks.org/cable/2005/12/05BANGKOK7526.html>.

37 Obama, Barrack, 'Presidential Memoranda – Trade Act of 1974 Argentina', March 2012, viewed 28 May 2012, <http://www.whitehouse.gov/the-press-office/2012/03/26/presidential-memoranda-trade-act-1974-argentina>.

38 Wikileaks, 'American IPR owners discuss concerns with ambassador', December 2012, viewed 26 May 2012, <http://wikileaks.org/cable/2005/12/05BANGKOK7526.html>.

For countries like Thailand this is a difficult balance act. Stronger patent protection on the one hand risk eliminating their own generic industry and hit HIV-positives hard. Sanctions from the USA on the other hand risk expelling Thailand from the international political arena and loose a share of it's total and long-term economical interchange with the surrounding world. Judging from the international development, countries consider the risks associated with not enhancing patent protection to weigh more heavily. Because of above stated reasons, it seems that sooner or later most countries will have agreed to the TRIPS.

And then there is only one opening for people in poor countries to get cheap medicine. In most legal systems there is namely a "state of emergency" clause when most any laws becomes void. And the TRIPS is no exception, it's requirements "may be waived by a Member in the case of a national emergency or other circumstances of extreme urgency".[39] In practice, however, no country has successfully claimed a HIV-epidemic as a national emergency. After the 9/11 attacks, however, when Americans were in panic and some cases of bioterrorism using anthrax was detected, the americans found themselves in the same position as the poor countries. The drug against anthrax was namely patented by a german company. The company said they would be able to meet the demands, producing hundreds of millions of pills if necessary, but this did not calm the Bush Administration who, after three deaths, decided to override the patent, invoking the "state of emergency" clause.[40] This meant that the clause had been defined in practice, a success for the countries that had wanted to invoke it on their HIV-epidemics. But not much changed after this, except that it had become evident how little USA care about HIV victims in poor countries. Millions of people can die elsewhere, but it takes only three deaths on american soil to find the TRIPS agreement undesirable. Still today, South Africans, Brazilians and other sufferers of HIV still cannot afford the medicine they need because of patent protection. In countries like India, HIV is now considered a permanent emergency.[41]

2.2.2 Prices on a polarized market

The drug industry today is divided into two markets with different consumer profiles. One

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39 Agreement on Trade-Related Aspects of Intellectual Property Rights, signed April 1994, article 31 (b).

40 Clark, Emma, 'America's Anthrax Patent Dilemma', *BBC Online News*, October 2001, viewed May 2012, <http://news.bbc.co.uk/2/hi/business/1613410.stm>.

41 Hamied, Yusuf, 'Cipla Pharmaceuticals' Yusuf Hamied: 'I Am Not Against Patents ... I Am Against Monopolies', *India Knowledge@Wharton*, May 2009, viewed May 2012, <http://knowledge.wharton.upenn.edu/india/article.cfm?articleid=4374>.

market is shallow and lucrative and the other is concerned with life-and-death issues for poor people. Two hundred years ago, all countries belonged to the latter category, but when some countries became richer, the medical companies slowly adjusted their goal from making functioning medicine to making profitable products. It was in 19th century Germany that the outside of the package of drugs started to become a key feature. Because it was only possible to patent chemical processes, many similar products launched that the consumers could not tell the difference between. In this fierce competition companies tried different ways of distinguishing their drug from other ones. One company tried giving their product a name that related neither to the chemical substance or the disease. With the catchy brand name sales boosted and in this direction the medical industry moved. Companies started spending more money on branding and marketing and by the 1980s those elements had become major parts of the costs of a manufacturing drugs.[42]

Once a company had a patent, it became less relevant what ailment the patent originally was meant to cure. If a company could prove that a drug fulfilled the conditions to be patentable for some disease, they then manipulated the definition of the disease to make it sound as if the drug could cure much more.[43] Today, blockbuster drugs from big companies take up a bigger and bigger share of the market. Life-saving treatments take up a smaller part of the market to the benefit of disease management such as against high cholesterole, which there are alternative ways of lowering.[44] This reflects the rich American and European markets. It is those markets that the companies rely on and serve. This explaines why they are not eager to preoccupy themselves with medicines for diseases that are common in poor countries. It is not profitable in a world where some countries have superior consuming possibilities.

But even though some markets are more profitable than others because the consumer possibilities (or demand, on a supply and demand-curve) are higher, companies have to set the same price everywhere since the world is interconnected. Adapting the price to the comsuming possibilities would have been better both for the companies and the poor consumers. But the rich ones would not allow it in an open world market. For what message does the company send to consumers if their medicine is available elsewhere for a tenth of the price? It becomes much more obvious if the company "overcharges" the brand and people

42 Healy, page 21.

43 Healy, page 35.

44 Healy, page 10.

living in countries with strong patent protection would become frustrated from seeing that their expensive medication is available cheaper elsewhere. Today generic drugs are still legal in a few countries which leads Doctors Without Borders and other organizations to buy these and hand them out to people in need in other places. This is not good for companies' PR. Therefore, if companies' patents are to function in a globalized world, the TRIPS agreement have to be signed by all countries.

And the mission is almost accomplished. The world's biggest generic drug producer India was one of the last countries to join the TRIPS agreement in 2005. Before, India has constantly rejected patents for blockbuster drugs and companies have tried the patent office in many law-suits.[45] This means that drugs patented after 1995 will hereafter not be legal to replicate in India.[46]

2.2.3 Companies' costs

What normally keeps companies from spending too much money is that since all costs are included in the products' price they need to keep costs down or the high price will make the product unattractive on a competitive market. Under perfect competition this is regulated automatically so that the big spenders are eliminated which forces companies to carefully balance what expenses that are needed. But in a monopoly market companies do not have any reasons to watch their outgoings.

In a lawsuit against Pfizer with the former executive Peter Rost as a witness, it emerged that the company had spent large sums on for bribing doctors, for example by organizing meetings in "exotic locations" and additionally paying them up to $1,500 to attend.[47] All in the hope that this would increase the number of prescriptions the doctors wrote but of no benefit to consumers or stakeholders. In the pharmaceutical industry, the critical factor determining who gets market shares is companies' ability to create patentable drugs and also protecting the patents in lawsuits.

Another example of what consumers can pay for are companies' bad cost calculations. When BurroughsWellcome initially set the price on AZT they set it high because they thought

45 NDTV, 'India rejects US company's patent for HIV drugs' January 2011, viewed 26 May 2012, <http://www.ndtv.com/article/india/india-rejects-us-companys-patent-for-anti-hiv-drugs-78219>.

46 Hamied.

47 Chitale, Radha, 'Pfizer Pays $2.3B, but Will It Change the Pharmaceutical Industry?', *ABC News*, September 2009, viewed 25 May 2012, <http://abcnews.go.com/Health/PainManagement/pfizers-23-billion-settlement-change-practices/story?id=8476391>.

that there would soon come competitors. They calculated that they would get a certain amount annualy until a hypothetical year but grossly overestimated the competition. They had a complete monopoly for six years when two other drugs were approved and those were primarily used in combination with AZT which meant that they continued to earn money for five more years, when the HAART-cocktail launched. This means that the company had gotten higher profits than they had calculated on, which means that the medicine was priced higher than necessary.[48]

2.2.4 Rationality

According to economic theory the basic condition for making economic calculations is rationality. To be rational means to an economist having well-defined goals that one tries to fulfill.[49] Without jumping to conclusions it can be said that the primary goals for companies that are well-defined are the financial ones.

Still, CSR has become apparently increasingly important to them. Their motive for this can be that they want "to avoid negative publicity that may influence customers to take their business elsewhere"[50] or that they hope to seem like a more honest and therefor attractive partner for other companies to do business with.[51] It can also depend on individual employees who, contrary to companies, probably take more things into account than financials when they consider costs and benefits. But the company itself has to be rational and an employee who weights moral considerations too heavily is likely to be disposed of or will quit himself when faced with a certain amount of resistance.

The limit where employees decide that they have to turn against their own company and prioritize something else more than profits vary. In the USA a greater loyalty to the company is shown as compared to Europe, where companies agree with governments and NGOs sooner and to a larger extent.[52] The new CEO of the British newly merged GlaxoSmithKline in his first speech reflected this attitude among European companies, saying: "The pharmaceutical industry today sells 80 per cent of its products to 20 per cent of the world's population. I don't want to be the CEO of a company that only caters to the rich". This statement is irrational

48 Harden, page 136.

49 Frank, Bernanke, page 5.

50 Doh; Guay, page 54.

51 Doh; Guay, page 57.

52 Doh; Guay, page 62.

according to classical theory, since it shows that the company is concerned with issue of no direct relevance to the profits.

David Barry, the american vice president for research at BurroughsWellcome, to answer the critique on the high price on AZT pointed out that his company on contrary to other companies were courageous to invest in the area of antiretrovirals. Saying that, he reveals that companies typically do not care how serious a disease is but only how big the financial potential is.[53] What this means is that it is generally irrational to invest in life-science, like BurroughsWellcome did. The mystery then is why the company invested in AZT. Was it pure luck, a miscalculation that happened to be very fortunate? Or was the decision rational, like Milton Friedman would have said, only that other companies had done miscalculations when they did not invest? There are many examples of companies that respect human rights and when "greed" is a force that leads to good things. There are for example situations when prices on drugs are sold to the same price as the cheapest generic versions:

> "Merck representatives said that they sold efavirenz in Thailand at a no-profit price in recognition of Thailands AIDS situation and developing nation status (though MoPH complains it is chronically in short supply). As well, a survey on ARV pricing by Medecins Sans Frontieres showed that the 600 mg tablet of efavirenz was already being sold in Thailand at the same price as the cheapest generic version in India."[54]

The problem is that one never has to search long to find proof of the opposite, as in the same cable when, a little further down, a problem is acknowledged:

> Drug resistance to GPO-vir has increased over the past two years and an additional 10,000 patients in the MoPH program require second-line ARVs to continue treatment. The few second-line ARV cocktails available include drugs patented in Thailand by multinational pharmaceutical companies, and are available only at up to ten times the cost of first-line regimens.[55]

The conclusion is that companies sometimes are trustworthy and other times they are not. Even if Friedmans theory that there is always rationality is true, it does not matter in the case

53 Barry, David, *I am alive today: History of an AIDS drug*, Detours, Vincent; Henry, Dominique, 2002.
54 Wikileaks, 'Pharmaceutical Costs and the FTA'.
55 Wikileaks, 'Pharmaceutical Costs and the FTA'.

of HIV-medicine as long as they sometimes make miscalculations. The right to life is inviolable and if companies are trusted to calculate what decisions that are rational then there will always be violations of that human right.

Some commentators argue that the reason behind all medical care problems in our societies is that we have not fully embraced the market.[56] That it is regulations that give rise to irrational behaviour. But even if we did free markets, the human right to life would still be violated, because economic principles of opportunity cost teach us that it is impossible to reach all sufferers of HIV.

To every desicion made by a company there is an opportunity cost, which is the "value of the next-best alternative that must be forgone in order to undertake the activity".[57] For producers of HIV-medicine this results in a trade-off between two very different consumer groups. Every pill cost little to produce so they would make a profit on every pill they sold even at a low price. This way they would reach many more consumers than they do with a higher price. But with the low price, they would miss out on the rich individuals who are able to pay many times more than those in poor countries. In fact, if you look at a classic demand curve, it is obvious that no matter where you set the price, you will always lose either some money that rich people could have payed or a quantity of consumers that cannot afford the product. Basically, to reconnect with the HIV context, either you set a very low price or some people will not afford the medicine.

2.3 Activism

From the research on the patent system, activism showed to be more important to the outcome in the narrative than what had been expected. In this chapter it will be examined what power stakeholders and other arbitrary individuals without official power in a company or state has. Firstly, activism will be analysed narratively. Secondly, it will be discussed why most people do not act. Thirdly, the basic means of the little guy to influence the outcome will be analysed.

56 Healy, page 8.

57 Frank; Bernanke, page 6.

2.3.1 Activism is working

There are not many ways in which people with HIV can claim that they have a right to drugs. It depends on which country they live in, some being wealthy enough to provide their citizens with drugs while others' sole means is to via spokespersons try claiming their citizens' right to medicine to the companies or on the political arena. The most direct way for individuals to communicate to companies and states is through activism and the HIV pandemic is often named as an example of successful activism.[58] And there are some examples of this, such as when protestors the year 2000 made the Clinton Administration change its policies on South Africa,[59] but for most such examples there is at least one other example showing to the opposite. In this case, the reason for the protests was that the Clinton Administration before had preassured South Africa to revise their patent laws. The result was not an improvement but merely a correction.

In the early phase of the disease there was in USA, however, a constructive dialog between protesters and FDA and rules were bended in order to meet protesters demands. There were for safety reasons many stages to complete before a drug could launch, but as soon as it had become obvious that AZT had positive effects, clinical testings turned into mass distribution.[60] People with HIV felt that they would die anyway, so they had more to win than lose from trying the unapproved drug. The testings also meant that the thousands of enrollees got the drug for free. Normally the process takes up to ten years but within a year the AZT was an approved drug. This was a great success for activists. But then BurroughsWellcome presented the drug's price tag and activists had this to protest about. Having been given the medicine for free during the testings and considering the urgency, they did not consider a price tag at around $10.000 annualy reasonable. So they protested and BurroughsWellcome lowered the price with twenty percent. Later nine members of the activist group ACT UP barricaded themselves in BurrougsWellcomes headquarters demanding an even lower price. The company agreed to drop the price. Later the same year the group did a similar protest in the New York Stock Exchange, which made BurrougsWellcome drop the price further.[61]

Outside USA and Europe there is not as many examples of, especially successful, protests,

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58 Doh, Jonathan P.; Guay, Terrence R., 'Corporate Social Responsibility, Public Policy, and NGO Activism in Europe and the United States: An Institutional-Stakeholder Perspective', *Journal of Management Studies* 43:1 January 2006, page 61.

59 Doh; Guay, page 62.

60 Harden, page 135.

61 Harden, page 136.

even though that is were most infected people lives. There are several reasons why they are not as loud as protesters in Europe and USA, first of all they do not have the same level of civil rights such as freedom of expression.

But there are some examples, like Zackie Achmat, who from the nineties was the most prominent HIV-activist in South Africa. He became famous for refusing to take medicines that he afforded until they were cheap enough even for the poor people in his country. Apart from this, his group made other protests such as buying generic copies of drugs in Thailand that they "tried" to ship home.[62] When his group, with help of publicity from Nelson Mandela, finally made the US government allow South Africa to have softer patent laws, the own government got "mad" and refused to allow the drugs.[63] From then on Zackie Achmat unsuccessfully faught his own government and eventually he gave in to his friends pleas and started taking the medicine.[64]

To make themselves heard, activists often strategically focus on some aspects of a problem, in this case they focus on some victims more than other despite their basic argument is that everyone has equal rights. They avoided controversial aspects like drug addicts and homosexuals and emphasized definitely innocent victims like women and especially their contaminated babies. The most hard-hearted patent defenders or medicine deniers listen to these arguments. And confrontation with those who think that it is homosexuals or drug addicts own fault is avoided. Nelson Mandela, who had avoided talking about AIDS because he had felt that he as a Xhosa elder could not talk about sex,[65] when he finally got involved with the issue used babies an alternative entrance to discussions about ARVs with the government.[66] And because it worked, it was also a good strategy. On the other hand it is sad if activists give in to discriminatory treatment against homosexuals and drug addicts.

2.3.2 Not acting

Why are bystanders not acting? The problem is that the whole situation puts stakeholders furthest away from power and those with power, living in the part of the world that has most of it but few of the HIV-positives, do not have the immediate reasons to act. David Healy

62 Nolen, Stephanie., *28: stories of AIDS in Africa*, 1st U.S. ed., Walker & Co., New York, 2007, page 176.

63 Nolen, page 173.

64 Nolen, page 182.

65 Nolen, page 320.

66 Nolen, page 324.

likens that the polarised market with people in rich countries over-consuming drugs and people in the poor world not affording life-saving treatment with a gated community. Only rich people are allowed inside and regarding the patent system only "some of those inside the gates may regret this policy, but provided their children and families are not the ones dying from diphteria or AIDS these regrets are unlikely to lead to action".[67]

The same behaviour is even visible in the poor world, among those who are not infected. Graca Machel, Nelson Mandelas wife, explains this laziness or ignorance by saying that it is simply "human nature". After having beat the apartheid South Africans were so eager to build their society that they did not want to see a new catastrophe. Accordning to Graca Machel, they had "taken freedom for granted" and "forgot how difficult it was". Machel and Mandela did not get involved until the disease had penetrated their families and killed their relatives. Why they did not activate themselves before was partly because diseases were not their area of work, being not public health activists but freedom fighters. It was also because of social shame and sexual taboo.[68]

2.3.3 The little guy's means

It is startling that the two foremost examples of HIV-activism has been made by groups that had just won a civil rights fight against their countries: Gay people in USA and the native africans in South Africa. The feeling that they could claim their rights was probably fresh in mind, and they had learned how to effectively communicate their message to their states. Their newly found civil rights had given them tools that made it possible to express frustration and anger in a legal way, for example via the right to protest, freedom of expression and a right to organize in groups. Those tools are important for people in claiming their universal human rights because there are no boundaries of what can be expressed in, for example, a protest. It does not even matter that you are a stakeholder. Only that you use your human right to express youself.

It has been showed that in some cases, even when there is no apparent economic benefit, executives show some social efforts because NGOs pressure has become an integrated part of their thinking.[69] CSR is built on the idea that companies might as well regard public opinion before they do things, if not because of goodness then at least because the public opinion

67 Healy, page 62.

68 Nolen, page 321.

69 Doh; Guay, pages 62 and 58.

should be part of good cost calculation. This is in line with classical economic theory on rationality and Friedman, who think that it is not a question of weather there are rational decisions to make, only how to calculate them. In BurroughsWellcomes' case, they made a bad calculation when they set the price on the AZT based on their expectations on how much they could make people pay for the product. They had not expected the public to start to demand lower prices, at least not as militant as they did. If they had foreseen the reaction, maybe they had not made the initial investment. So in this case it was fortunate that the company did not regard the public opinion in their expectations. The downside with CSR is that if companies are expected to take responsibility, they may not find it worth their while to invest in areas where strong public reactions are to be expected, such as in the area of life-saving treatments.

3. Conclusions

Now it is time to summarize what conclusions that can be drawn from the analysis. First, the outcome of the narrative analysis on power relationships will be presented, showing which actors that has power to affect the outcome on drug access. Then, a detailed answer to the main question of the essay will be given, mixing all the relevant knowledge that has been found from the analysis and also reconnecting with the assumptions from the introduction. Then, even though it is not necessary to answer the question, an idea on what can be done will shortly be introduced.

3.1 Where power is

Scientists are often claimed as responsible for ethical problems such as people not affording life-saving drugs. Suggestions have therefore been brought up to fix this. One is to update the medical ethics by writing an oath specifically aimed at scientists. This may solve the problem that scientists are blamed, but it falls short of being able to solve the real problem, because scientists (especially commercial ones) have little power and because oaths are weak and cannot guarantee that people follow them the way that laws can. Another suggestion is that scientists are taught law so that they are not pushed around by companies. This presupposes that scientists are ethically superior to companies, which cannot be guaranteed either. Working conditions for medical professionals are tough and the least thing they need is another thing to learn. Companies are also not as dependant on scientists as one might think and with too many legal demands from the inventor they would simply not go through with a deal. For medical companies there are options - other profitable areas – to invest in.

It is a problem that there is consensus that companies have responsibilities towards stakeholders but that there are no corresponding laws to supports this view. There are no laws preventing companies from ducking from their responsibilities. Therefore, it is also difficult to claim them accountable, despite their great power, which has only been loanded to them by

the states that in turn are responsible for them. They do what they are allowed to do. States are more responsible since they have the indirect but sole power to decide patent laws. On the other hand, small states are pressured by stronger ones with harsh means, why they are juridically responsible, but hardly accountable. It is hard to blame them for giving in to US sanctions, for example. The strong states are both responsible and accountable, but their power is indirect. The companies have the direct power.

Activism has affected the outcome of history more than what was expected when the research begun. This power is not unproblematic though. Many times activists' first priority is result and this can sometimes lead them to not respecting human rights themselves. As when some issues are emphazised because others are controversial, which might lead to discriminatory treatment of the other groups. How much power activists have also vary greatly, depending mostly on their basic civil rights. But again, activism plays an important role. Wikileaks cables show that even USA in their lobbying for strong patent protection in Thailand mentions NGOs many times and seems concerned with their agendas. In the pricing of HIV drugs activists also showed strength by several times convincing companies to lower their prices or even change laws. Thereby companies are both directly and indirectly affected by human rights.

3.2 Why people with HIV are let to die

Since they are in a monopoly-position, companies do not have to be careful with their costs. Companies are allowed to and choose to have higher prices than what is necessary to cover costs and they have large marginals on their profits. They spend little money on research, compared to what is put on administration and marketing, and former officials have witnessed in court describing how companies spend a lot of money on bribing doctors to make them prescript their drugs. This careless spending magnifies the polarisation of the world medical market, with one market becoming more shallow and the other concerning life-and-death issues. Because of the polarization and because prices have to be the same everywhere, prices are set for the rich part of the market because that is most profitable. People in the poor world therefore cannot afford medicine.

Since the sixties economic theory has shifted from a belief in state regulations back to a

more classical economic theory based on the idea of free markets. It is interesting that this has not affected the consensus on patent protection, which has at the same time become stronger, although patent protection is technically a state regulation that builds monopolies and knocks out competition. According to economic theory patents are also an enemy to the opening of markets. Compared to in the sixties, regarding medicines specifically, the situation today is quite the reverse, with patent regulations seen as the standard. At the same time the stubborn aim to apply classical economic theories on everything except patents has persisted. This is furthermore done regardless of it being patents on furniture design, HIV-medicine, movies or cholesterol pills. In the case of life-threatening diseases, there are no rational reasons to let markets be closed. Discoveries are clearly not encouraged through incentives for commercial companies, whose priorities are other than to make ground breaking findings. In the case of federal spending on base science however, states have indeed followed the pattern of economic theory and minimized intervention. Since it's peak in the sixties federal funding in science as a percentage of GDP has decreased steadily.[70] The answer to the question how patent protection could become the standard even though regulations of other sorts are historically unpopular, is because it benefits the individual countries housing many patent owners. This since the companies in their countries escapes global competition in a lawful way making the companies stronger, in return benefiting the state on the whole. With free and globally open markets, companies have potential competitors everywhere, but a global monopoly cannot have competition under any circumstances. So far, there has always been some countries that has permitted generic copies of drugs which has resulted in some sort of competition pressuring prices down but soon it seems that the monopoly will be global. Countries such as the USA are strong enough to convince or threaten smaller countries to strengthen patent laws.

With life-saving treatments, rationality is incalculable as prices do not reflect demand but only consumer possibilities. The supply and demand-curve is therefore not applicable to life-saving treatments. This specific market is the most extreme example of a monopoly that can be found. In most situations were patents enable competition, the consumer still have the alternatives to resign or find a substitute of some kind but in this case consumers are dependant on the companies to a much higher rate. As of today, we have a situation with

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[70] LiveScience, 'Science R&D Spending in the Federal Budget', January 2011, viewed 30 July 2012, <http://www.livescience.com/11233-science-spending-federal-budget.html>.

many losers and few winners. The losers being potential competition on the market, people with HIV as well as most countries in the world. The winners being only the pharmaceutical giants and a few countries. Economic theories are meant to point out directions in which we should go to achieve the opposite situation, one that everyone is benefiting from. The problem is that no consideration is taken to the fact that human lives are on stake, which makes theories on rationality void. With a classical approach, human lives, like everything, has a price, but that is not compatible with a human rights perspective. Contradictory teamed with belief in patent regulations the economical theories are even acutely dangerous to human rights. Calculating on situations were human lives are on stake, firstly it is important to acknowledge a Keynesian approach so that situations can be evaluated specifically. Getting rid of patents would not help since a free market could not handle a situation where human lives are on stake anyway. Also, since there is a positive connection between government spending on research and innovations made, more regulations are necessary to secure future medical innovations. This is because states, as opposed to companies, can afford to loose money and therefore dare to invest large amounts of money in base science in areas where there are little profits to expect.

The idea of rationality that Friedman defended is still a good one and it is one of the key principles that also Keynesian theories are built upon. With help from human rights the theory might be read in a way that works even when human lives are on stake. Human rights are not only international laws but also moral ideas that many people have together decided upon. This should be seen as an asset to economists rather than as a problem. Here we have documents showing what moral beliefs most people value. Adapt those values into economic theories and we could find one that benefits all and that can be used even in complicated issues such as the one examined in this essay. To human rights, it matters not how prices are set or if markets are free or regulated, but only if the result is respect of or violation of human rights. In the introduction it was settled that article 27 in UDHR could be interpreted as a human right, but that there was two conditions. That there was no better alternatives and that the right to life was not violated because of it. It has been found that the patent system violates the right to life. Therefore it was unnecessary to examine the other condition but indications show that there are many different alternatives. Deciding upon which alternative is preferable is a matter for politicians since it presumably differs with the place and time.

Even though companies are affected by human rights both through activism and civil rights

they are rarely part of the economic calculus, which however can be both good or bad. On the one hand it is bad that companies do not care more for human rights. On the other hand it is good that activism is underestimated so that it does not deter companies from investing in controversial domains of science. There is a delicate balance-act between wanting to encourage investments in life-science and at the same time the need to protest when companies do not respect human rights. It shows that companies have an advantage over the stakeholders and it is unclear if activism directed at companies is good in the long run. This is another reason why states are are better alternatives than companies to handle life-saving medicine. They do not have obvious reasons why they would want to take advantage of a situation where they are in power over individuals, but reversely (in democratic states) states are dependant of their support. Protesting against strong states is therefore safer than to protest against companies. It should be noted that companies are dependant on laws that gives them their monopoly-positions, and since laws are made by representatives of the people in democracies, it is mostly up to the citizens in strong, democratic countries to pressure their states to weaken patent laws. This would affect companies to act with respect of human rights in a lasting way. The distance between those responsible and the stakeholders is very difficult to bridge and that is a key problem. Citizens in a rich country have too few reasons to act, and maybe they do not understand what power they possess by being in position to affect the law making in their countries. But it is at the moment not very easy for critics to urge changed patent laws, even as a citizen in, say, USA. With classic economic theory now being the standard, it is namely difficult to argue against free markets. Some markets are still regulated, but the regulation of a market that for the moment is free seems very distant. We need some Keynesian pragmatism and start to address cases individually, not with free market-mantra as a standard respons.

3.3 Distinguishing life-saving treatments

To revolutionize the industry by abolishing patent rights is not an option. First of all universal distribution of drugs can still not be guaranteed on any free market. It is also a complicated solution with so many for all companies that uses patents and already own patents. The best would be to remove life-saving drugs from the uncertain medical market.

Today, there is already a separation made between real medicine and alternative. But during the last century real medicines have, in turn, been divided into two sub-groups. One of them is more similar to alternative medicine, were the consumer gets low value for the price, because most of the profits go to other things than research. The other one is life-saving treatments. The sub-groups generally represent two kinds of consumers and some of them are clearly more in need of medicine. A conslusion from this essay is that it is destructive how life-saving drugs are bundled with all kinds of medicines, since they are a human rights issue and not a simple economical calculation.

That no distincion is made leads to concerns not least to many companies. In Thailand for example, counterfeit medicines sold by street vendors are a concern shared both by patients and companies. Companies are afraid HIV-patients will actually believe that they are real and buy them but suffer continue to suffer from the disease. This is not very likely, but could of course happen, especially in a situation where many people cannot afford the real medication and in their desperation belive a vendor. But the concern is most eagerly expressed by companies, and their solution is, of course, strengthened patent protection in the Thailand. The problem is that NGO activists do not like this idea, as expressed by the american ambasador in the country:

> "When the pharmaceutical industry attempted to train officials on anti-counterfeiting, health activist NGOs protested, claiming that industry exaggerates the scope of counterfeiting in Thailand and is trying to block generics rather than actual counterfeit medicines."[71]

The main reason why NGOs protests is the risk that patent protection policies would hit people living with HIV in the country. For all companies that are not related to this issue it must be a thorn in their side. And the Thai government prioritate the same way as the NGOs and do not want to cooperate with patent enforcers at all "because of its position on generic rugs".[72] Are media distributors, cultural professionals, video game producers and IT firms aware of this? Do they like that this issue – to which they are not related whatsoever – aggravate their struggle to enhance patents? Even the international pharmaceutical companies, that make the most profits from other treatments, is being weighed down by this single issue.

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71 Wikileaks, 'American IPR owners discuss concerns with ambassador', December 2012, viewed 26 May 2012, <http://wikileaks.org/cable/2005/12/05BANGKOK7526.html>.

72 Wikileaks, 'American IPR owners discuss concerns with ambassador'.

So it seems that there are good reasons make sure that life-threatening diseases are treated more seriously than baldness or high cholesterole.

3.4 Summary

The main conclusion in this essay is that, both from an economic point of view and from a human rights perspective, the patent system that we have today is unpreferable. It does not follow economic theories in a logical sense and the result is that we have a lot of losers but few winners. From a human rights perspective, the losses are also invaluable as compared to the the small gains that are made.

A market can never treat human lives the way that people have agreed that they should according to moral consensus – which is what human rights are. Therefore, the market for life-saving medicine should be regulated. State investments in base science should also be increased so that future innovations can be secured. The rich states are the ones who has the power to change this, and the people living in those countries have a responsibility to encourage such a development.

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